Experiences of menorrhagia and hysterectomy:

An exploratory study

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Rebecca Crook BSc (hons)

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ABSTRACT
Abstract

Hysterectomy is the second most commonly performed women's operation today, and yet still 'the psychological implications remain obscure' (Meikle, 1977; p128). Previous research focused on whether hysterectomy 'caused' psychological distress, but was methodologically flawed. Despite lack of evidence, researchers assumed that post-operative distress, not explicable by pre-operative distress, must be due to changes in self-concept.

This study advocates a first-principles approach, returning to those who are most important – the patients. Two main aims were fulfilled during the study – to capture the experience of hysterectomy and menorrhagia, and to carry out trustworthy research in accordance with preset criteria.

Qualitative interviews were used to draw themes & discourses from women's accounts. Comparison was made between those awaiting endometrial ablation/ hysterectomy, and those post-hysterectomy (N=16 in total).

Main themes included effects of menorrhagia on women's lives, fighting but failing, searching for meaning, reducing cognitive dissonance, unfulfilled hopes, stepping into the void, operative fears, removing the womb - endings, switching roles, assumptions and misunderstandings, needing to trust the surgeon, lack of information, and resolution. Issues of choice and control permeated women's accounts and gave rise to the core theme of disempowerment.

Attribution theory and a formulation are used to account for the processes described by participants. Implications for gynaecology practice and future research are discussed; the researcher concludes that self-view may be altered prior to hysterectomy as a result of menorrhagia. Fears of hysterectomy relate to the symbolism of endings, and the relative importance of functions of the womb to the individual.
INTRODUCTION

CHAPTER 1

GYNAECOLOGY AND PSYCHOLOGY
1.1 Introducing the area

Gynaecology has long held a reputation as an area where physical disease and psychological distress may meet and merge, and yet the reasons for this are not fully understood. At the most basic level, it is apparent that as with any medical problem, experiencing of symptoms and consequent beliefs and actions will be determined by psychological factors (e.g. Marshall, 1998), but the common belief that this is particularly so for gynaecological disorders remains open to debate.

Historically, the uterus itself, as well as female hormones, have been perceived (by professionals and lay persons alike) as significant determinants of female behaviour, and even causative in mental illness (Unger, 1979b from Brown-Travis 1988). Roeske (1978) notes that since the time of the Greeks till the present day, there have been only two extreme views on the uterus; ‘one position equates the presence of the uterus with womanhood, motherhood, and sexuality, and another equates the uterus with intractable hysteria’ (p11).

Therefore, since the time of the first successful hysterectomy in 1853, hysterectomy has earned a reputation as a ‘cure-all’ (for physical, sexual and psychological illness), and a release for women ‘at the mercy’ of their biology (Sefcovic, 1996; p370). Whilst we may believe that this evangelical view has been replaced by sound science, it may be surprising to learn that hysterectomy is commonly prescribed for conditions the surgeon views as psychogenic, rather than organic in origin (Beard, 1984; Ross, 1996). This seems to echo the ‘hysteria’ viewpoint, neatly captured by Mandy et al. (1955) who concluded that ‘many women seeking aid for female troubles are, instead, troubled females’ (quoted in Francis, 1971, p472).

Beginning with a backlash in the 1970’s by women’s pressure groups (Sefcovic, 1996), there has been opposition to the denigratory belief that women are ruled by their biology, and therefore
emotionally labile. Many feminist theorists regard the medicalisation of menstrual phenomena leading to hysterectomy, as the ultimate in oppressive practice, whilst others celebrate it as a release from the constraints of social roles (Scambler & Scambler, 1993). This is undoubtedly therefore an area characterised by controversy and polarised opinions.

Today, concerns regarding menstrual loss are one of the most common reasons for a woman to visit her GP (Killick & Maguiness, 1997; Scambler & Scambler, 1993), and some 228 per 100,000 women will undergo the operation in the UK (Mc Pherson et al, 1981). It is generally accepted that in around half of these women, there will be no obvious organic pathology (Richards 1973; Scambler & Scambler, 1993). This is generally taken to imply a psychogenic cause, although this is by no means proven (Scambler & Scambler, 1993).

Extending the psychogenic theme, it is often reported that gynaecology clinic attendees have higher rates of psychological distress than expected, generally taken to mean that psychological distress ‘causes’ somatisation as menstrual problems (Greenberg, 1983). Studies have also shown that in menorrhagia (a common reason for hysterectomy), there may be little correspondence between objective measures and subjective reports of blood loss, again taken to imply psychogenic influences (e.g. Chimbira et al, 1980; Fraser et al, 1984). It is perhaps surprising therefore that hysterectomy is usually undertaken on the basis of a woman’s (subjective) symptom reports (Kincey & McFarlane, 1984), and ‘formal psychological assessment does not usually feature in the decision...’ (Broome & Wallace, 1984, p156).

Hysterectomy itself is an operation which has been variously hypothesised to result in improved quality of life, depression, improvements or problems in sexual functioning, physical problems, regret and loss of femininity or changes to self-concept. Estimates vary, but between 8 and 37% of hysterectomy patients may experience a deterioration in one or more aspects of their life as listed
above (Galyer et al., 1999; Kjerulff et al., 2000). This area of gynaecology is therefore seen as ripe for ‘co-operative approaches between gynaecologists and psychologists to identify patients for whose problems hysterectomy may not be the best solution’ (Broome & Wallace, 1984, p.156).

It will be demonstrated in the following literature review that there are many aspects of the gynaecological forum from the experience of symptoms, presentation at clinic, through to treatment decisions and surgery outcome, where psychological processes come into play. Particular attention will be paid to hysterectomy for benign origin menorrhagia, as the most common and yet perhaps least well understood aspects. As the review will also demonstrate, given the methodological problems of previous studies and the lack of a ‘female-friendly’ research culture, it is perhaps unsurprising that the ‘psychological implications [of hysterectomy] remain obscure’ (Meikle, 1977; p.128).

The main aim of this thesis therefore is to untangle some of the issues confounded by previous research, and present a firm foundation for future development of frameworks for assessment and identification of patients who may be at risk of psychological distress post-operatively. This is achieved through a thorough review of the literature, identifying themes, flaws and unanswered questions in previous research. A ‘first principles’ approach is then advocated; the study itself returns to those most important in hysterectomy, the (female) patients. It is hoped that the research forms a non-oppressive project by using qualitative methodology, exploring the effects of menorrhagia on women’s lives, their experiences of the consultation and decision making processes, their hopes and fears surrounding hysterectomy, and the after effects of this major operation. This is then utilised as a stepping stone for suggesting future research, and as information for improving gynaecological practice.
1.2 Menorrhagia and the meaning of menstrual distress

Menorrhagia – heavy periods – is the most common reason for hysterectomy, and may have elusive specific causes in 60% of cases (Beazley, 1972; Scambler & Scambler, 1993). The clinical definition is more than 80ml of blood loss over the course of a period (Coulter, 1997), representing loss above the 90th percentile of the normal distribution. In reality however, objective measurement is difficult and hence rarely carried out, so diagnosis is usually based upon subjective reports. As already mentioned, these are only partially related to objective measures of amount of blood loss (Fraser et al., 1984). Nevertheless, emphasising ‘objective’ measures may obscure the manner in which blood is lost, with ‘gushing’ leading to soiling being more problematic than steady heavy flow (Wood, 1997).

Cultural changes have resulted in a huge increase in the number of periods for women. Changes in nutrition, contraception and pregnancy rates mean that women today average 400 menstrual cycles, as opposed to the 30-40 of the first half of the twentieth century. The increased role demands of work and family for women may also contribute to increased demand for effective treatment (Coulter, 1997).

Heavy periods are reported by some 31% of women aged 16-45 (it is most common in women aged 30-40), but only 36% of those reporting problems consult their GP for advice or treatment (Corrado, 1990). Like many health concerns, there is obviously a variation in the extent to which people symptom-report, but reasons for women deciding to consult may include concerns about impact on health, changes in quality of life, perceived effects on mood and sexual functioning (Coulter et al., 1994). Aspects of the consultation process are considered in more detail in section 1.3.
Few medically based studies take account of the significance and effects of menorrhagia on the patient, for possibly a number of reasons. Firstly, it may be because this is considered subjective, and hence outside the confines of 'good research' (see later). Secondly, most medical researchers and gynaecologists are male, and there may not be a full understanding of the implications of the condition. Thirdly, as feminist writers suggest, a patriarchal medical and research culture may tend to concentrate on life threatening, rather than quality of life threatening, conditions (Scambler & Scambler, 1993; see chapter 4). Research therefore has tended to ask rather limited questions, such as, are these women depressed/ anxious/ neurotic etc, and the obsessive comparisons of objective and subjective reports of blood loss implies that women may be exaggerating, making their complaints up, or somatising (Marshall, 1998). Little research has paid attention to why these women may be depressed etc., or tried to undertake research from a female perspective in order to understand rather than merely diagnose.

A typical study in this vein was conducted by Greenberg (1983) (N=50), who investigated the association between menorrhagia and depression, using a semi-structured interview, the General Health Questionnaire (GHQ), and measures of haemoglobin and iron levels. They concluded that women with positive GHQ screening who showed signs of depression in interview, had evidence of less severe bleeding, and suggest that either menorrhagia is a symptom of depression, or that a depressed woman may choose to present with menstrual problems since this is 'a socially accepted explanation' (p212). The study can be criticised on a number of counts however; firstly, these were women who were attending for the first time to see a gynaecologist, and hence may have been anxious about the consultation and what the outcomes may be. Secondly, levels of haemoglobin and iron may not be the best indicators of blood loss, since menstrual blood can consist of fluid as well as actual blood, and this does not account for the manner of menstrual flow, which can cause considerable social embarrassment (Fraser, 1997; p17). Greenberg did not at any point suggest that menorrhagia may leads to depression, and the differences between the groups on blood loss measures
were actually small and statistically insignificant. The conclusions of the study therefore appear somewhat erroneous.

Similarly, Byrne (1984) screened patients using the GHQ, and interviewed a further sub-sample using the Present State Examination (PSE). Subjects were compared to a matched population sample. 46% of those referred to the clinic scored as 'psychiatric cases' on the GHQ, with high scores being associated with being divorced, separated or widowed, and with complaints of pelvic pain. The smaller sub-sample also contained a higher rate of cases, as measured by the PSE, than in the general population (29% as compared to 17%). There was no attempt to distinguish between those attending for malignancy and those with more benign pathology. Arguments regarding the validity of the concept of psychiatric diagnosis aside, the PSE is generally recognised as providing good reliability and validity (Casey, 1990). The issue is therefore whether severe menorrhagia leads to psychological distress, or women attend gynaecology clinics because of negative attitudes towards mental illness which result in somatisation, reinforced by the medical system. The latter view is most often implied by studies in this area of interest.

Marshall (1998) provides a less reductionist study, with a qualitative project (N=23) exploring women's reason for presenting at a gynaecology clinic, their worries and concerns, and the desired outcome after consultation. Themes identified through thematic analysis within a constructionist and feminist framework were:

1. physical symptoms associated with menstrual cycle
2. consequences of cycle on daily life
3. ideas about what is normal blood loss
4. the role of doctors
5. hopes and expectations of the consultation
Using detailed quotes to illustrate these themes, Marshall notes that the woman, the referring GP, and gynaecologist, as well as the woman's sociocultural background, will all influence symptom perception, communication during consultation, and the treatment choices offered and taken. She suggests that in order to maximise congruence between patient and physician beliefs about the consultation and condition, medics should take care to elicit the woman's concerns and expectations so that '...anxiety...and unresolved trauma...is not translated into offers of unnecessary surgery' (p259-). The themes drawn from this study will be utilised later as a comparison for the present research.

1.3 Dynamics of the consultation process

The decision to perform a hysterectomy, is usually made by the gynaecologist on clinical grounds (as opposed to sterilisation, which is usually requested by the patient). It is clear that within the process of experiencing symptoms, attending clinic, and receiving treatment, two main interacting dimensions are important in determining the outcome of the process. Firstly, the woman herself, her attitudes and beliefs, will determine whether she reports symptoms, the manner in which she reports them, and whether or not she complies with doctor's advice. A study by Kleinman (1985) suggests that on average, women tend to consult social networks eleven times as frequently as consulting their GP, with the cultural reference group providing a yardstick against which to measure the necessity of a professional consultation. There is also therefore a wider dimension to the consultation process, which may impact upon treatment choices.

The second dimension is that of the medical professional. Their attitudes and beliefs have a role to play in eliciting symptoms, decision making for treatment, and communicating with the patient, which
may impact on compliance with advice. As already noted, disparity exists in the rates of hysterectomies across the UK/USA/Australia, and these differences are apparently based more on gynaecologists’ backgrounds and beliefs and the local medical culture, than patient characteristics (Bickell et al., 1994; Kleinman, 1985). Bickell et al.'s study, carried out in North Carolina with a random sample of 77 female and 154 male gynaecologists aged 31-75, surveyed clinical beliefs regarding attitudes to hysterectomy, practice characteristics, and demographics. Clinical scenarios were also presented, which included presentations such as fear of cancer, and bleeding or painful fibroids, and doctors rated the appropriateness of surgery for each scenario. The method of surveying attitudes to surgery was not specified. The authors discovered that male gynaecologists performed 60% more hysterectomies than female gynaecologists, and that those who performed more hysterectomies were typically further from training (and hence more likely to be male), practiced in areas with fewer gynecologists, and had more patients with abnormal bleeding or cancer. Doctors' ratings of the appropriateness of hysterectomy were affected by attitudes toward surgery, recency of training, and practice case mix, and by patients' expressed desire to avoid surgery; however, appropriateness ratings did not predict hysterectomy rates.

The study emphasised two main points – firstly, that perhaps the decision to perform a hysterectomy is undertaken less lightly in those doctors who are more recently qualified, which may reflect changing cultural attitudes. Secondly, in most cases patient preference will have a bearing on the decision making process. However, as mentioned earlier, obtaining patient preferences may not be as simple as it first sounds, and much depends upon the individual, the doctor and the degree of collaboration within the encounter.

Charles & Barry (2000) in a qualitative study of unvoiced discourse, investigated patients' voiced and unvoiced agendas in GP consultations, finding that all of their 35 respondents had more than one item on their agenda, but only 4 voiced their full agendas. The effects of not voicing concerns were often
specific difficulties, such as adherence or misunderstandings of advice. Commonly unvoiced items were worries about diagnosis and the future, patients’ own hypotheses regarding conditions, side effects, not wanting a prescription, and information relating to the social context. They note that GP’s were unaware of these hidden agendas, saying ‘doctors may overestimate the extent to which patients are primarily concerned with medical treatment rather than gaining information and support’ (p1246). They suggest that outside the consultation and within the research interview, patients are more autonomous and can present their own ideas, but this autonomy is often partially lost on entering the surgery. The consultation process may therefore be improved by simulating aspects of the research interview, such as being person-focused, using open-ended questions, and taking more time over the interview, which may result in greater congruence between physician and patient beliefs about the interview and hence better outcome.

Investigating aspects of consultations between female patients and doctors, Waller (1988) identified 3 key dimensions governing the doctor-patient relationship. These were;

1. communication style, affecting symptom reporting, questions and answers by both patient and doctor, and information and instructions by the doctor
2. affective tone of the relationship, which links to empathy, trust and rapport, which in turn affects information flow
3. the negotiative quality of the interaction – is the patient allowed to participate in the decision making process, and how are conflicts resolved when differences of opinion arise? (p132)

She states that there may be actual or perceived gender differences between doctors, with female doctors typically perceived as taking more time, being more caring, sympathetic and easier to talk to, such that they are more likely to be seen as having understood patients’ problems. Indeed, Weisman
& Teitelbaum (1985)'s literature review identified that a number of studies found male physicians more likely to view female illnesses as psychogenic, whatever information is provided - a belief which will undoubtedly affect physician empathy. Likewise, male doctors may also be less willing to give full answers to questions, or spontaneously offer information to female patients. They conclude that 'the communication process in same-sex dyads will be better suited to sorting out 'true' symptoms and negotiating treatment based on these symptoms' (p1125).

This may be particularly so for gynaecological problems, where men in general are typically perceived as unable to fully understand by virtue of their gender (Scambler & Scambler, 1993; p93). This comes on top of anxieties about the gynaecological examination itself, which involves breaking social taboos regarding privacy of the genitals, and so on. The gynaecology patient may therefore be seriously disadvantaged with regards to communicating her needs and wishes.

1.4 Treatment options

In terms of treatment for menorrhagia, Coulter (1997) notes that 'improvement in quality of life is a key goal of therapy' (p11), and Fraser (1997) suggests that the surgeon must take into account the following consequences of the symptoms in assessment for treatment:

1. excessive blood loss sufficient to cause iron deficiency and anaemia
2. menstrual loss escaping in gushes sufficient to cause soiling or saturation of clothes, and social embarrassment
3. perceived increase in menstrual loss leading to a fear of possible underlying cancer (often unstated) (p 17)
Whilst the above represents the surgeon’s priorities, the author of this study could not find literature which addresses whether these also represent the patients’ priorities.

There do exist a number of options for treatment, with an inverse relationship between certainty of controlling blood loss, and invasiveness and side effects of treatment, as illustrated in figure 1:

Figure 1: from Killick & Maguiness, 1997, p3; ‘The relationship between the invasiveness of treatment, unwanted side effects and the certainty of controlling menstrual symptoms’

A number of treatment options do exist therefore for women with heavy periods, but many women still go on to have a hysterectomy. Killick & Maguiness (1997) note that despite the fact that most women will have no pathology behind their bleeding, ‘many will not accept reassurance and will request treatment to lighten their menstrual loss….or to stop menstrual loss altogether’ (p 3). The implication is that some gynaecologists believe menstruation is troublesome for women, and if the
side effects of drug treatments are unacceptable, then complete cessation of bleeding by hysterectomy is the only option.

Research also suggests that some women may not be offered an alternative to hysterectomy, with both women and GP’s being unaware of all treatment options (Fender, 1999; Henderson, 2000). However, Henderson’s (2000) reporting of a US survey draws attention to the fact that whilst doctors recommend hysterectomies to one in four women, and 82% accept their recommendation, one third do not discuss alternatives, even though most doctors are happy to help them consider other options. A large scale study (N=14072) by Byles et al(2000) in Australia found that the probability of hysterectomy was greatest for those with less years in education, married with more than two children, and having more visits to the GP in general. These women may perhaps be disadvantaged in obtaining information about alternatives or by aspects of the consultation process.

1.5 About hysterectomy

Hysterectomy is a common major gynaecological procedure, second only to caesarean sections (Ross, 1996), and is a ‘catch-all’ term used for a variety of procedures. These include removal of the uterus, and/or the ovaries and fallopian tubes (bilateral salpingo-oopherectomy), and/or the cervix (so-called total hysterectomy). The organs can be removed via the abdomen or vagina, the latter obviously being less intrusive (and hence requiring shorter recovery time) and without visible scarring, but more complex to perform and involving greater surgical skill. The typical hysterectomy candidate is aged less than 50 years, and may have one of the following conditions (in order of incidence):
a. dysfunctional uterine bleeding, including menorrhagia (heavy bleeding) and intermenstrual bleeding
b. fibroids
c. malignant disease of the uterus
d. dysmenorrhoea (painful menstruation)
e. malignant disease of the ovaries
f. endometriosis
g. Pelvic inflammatory disease (PID)
h. Prolapse of the uterus
i. Chronic pelvic pain

(Hunter, 1995; Kincey & McFarlane, 1984).

Hysterectomy is frequently a ‘discretionary’ operation (Savage, 1983, p839) which has disparate rates across areas of the UK, a picture also mirrored in Australia and the USA, despite differences in the health care systems. According to Savage’s (1983) reporting of the Hospital Activity Analysis and the Hospital Inpatient Enquiry

Although there are some conditions for which most surgeons would agree hysterectomy was indicated - for example endometrial and ovarian cancer and large submucous fibroids giving rise to menorrhagia and anaemia - the majority of operations are performed for less clear-cut indications (p840-841).

This is important when one considers the controversy surrounding menstrual disorders and psychological distress – hysterectomy seems a major operation to perform when surgeons are not even sure if the underlying condition is psychogenic or organic, or even if this is the desired treatment option. Medical professionals are in a privileged position of power and knowledge, and often their
advice is taken unquestioningly (Scambler & Scambler, 1993). The implications of all the aspects discussed are huge for gynaecology. It has been demonstrated that the decision making process is not as clear-cut as one might imagine; the process of eliciting patient symptoms and preferences, and marrying these with medical knowledge via clinical judgement, is fraught with unacknowledged and hidden agendas on both sides. It is not such as leap therefore to begin to imagine that for some women, a hysterectomy may not be the 'cure-all' it appears.
INTRODUCTION

CHAPTER 2

THE PSYCHOLOGY OF HYSTERECTOMY
2.1 Theoretical standpoints

The purpose of this section is to briefly outline useful frameworks to understand hysterectomy outcome literature. Meikle (1977) suggests that research on hysterectomy can be conveniently divided into studies taking psychological factors as independent variables, and those which take them as dependent variables. In relation to psychological factors as independent variables, and as previously mentioned, some authors suggest that there is an overrepresentation of women with psychological/psychiatric disturbance amongst gynaecology clinic attenders (Greenberg, 1983). Research teasing out what may be cause and effect is limited, but the usual (unfounded) conclusion is that women with psychological distress are using gynaecological problems as a 'calling card'. Further research is required to determine whether or not this conclusion is correct, and if so, to help predict which women will use this route to express distress. Meikle (1977) provides an excellent review of the extremely meager research in this field, and rightly concludes that the lack of sound, prospective, longitudinal, well-controlled studies in this area makes such predictions impossible. Interested readers are referred to Meikle’s review for an analysis of this area, since it does not relate to the research goals. Instead, an analysis of literature pertaining to psychological effects as dependent variables is presented below.

There are many studies which measure rates of depression, anxiety or sexual problems in the hysterectomy population, but few attempt to explain these rates. Hypotheses offered tend to rest upon the assumption (which has little evidence to commend it as yet), that the uterus and reproductive ability have a central role in a women's self concept and gender identity. This then provides the initial seed for the present study, which seeks to look beyond incidence of psychiatric diagnoses post-hysterectomy, and instead take a more normative view of examining the range of reactions pre and post-hysterectomy. In order to do this, it is first necessary to distinguish between
Theoretical frameworks which may be useful for interpretation of depression and sexual problems are numerous. Psychodynamic and feminist theorists tend to view hysterectomy as a psychological trauma which induces changes in self-concept and feminine identity. Without becoming prematurely embroiled in psychodynamic and feminist literature, it is apparent that such formulations have suffered from a lack of supporting clinical evidence in the past, and sound research in the future is required in order to address the question of whether womanhood equals full reproductive function equals self-worth. Consideration of gender development, sexuality and self-concept literature may be however important, and will be addressed briefly in chapter 3. The idea of hysterectomy as a crisis means that consideration of adjustment literature may be also be of relevance.

Traditional models of depression conceptualise it as a response to loss, OR as a reaction to circumstances/events over which there is little control/escape (Beck, 1967). These models may be useful if indeed hysterectomy is considered a loss or if the process itself is perceived to be out of women’s control. Losses induced by hysterectomy include the loss of childbearing potential, the loss of menstruation, and the loss of a body part, albeit an invisible one. Hospitalisation has also been found to produce feelings of dependency and loss of control. Theoretically therefore, hysterectomy may be a process which contains elements known to contribute to depression in predisposed individuals.

2.2 Evaluating the literature

Lindemann’s suggestion, some fifty years ago, that pelvic surgery may be associated with higher rates of post-operative psychiatric morbidity, has evolved more latterly into a generally accepted
notion that there is an increased rate of depression following hysterectomy. However, as noted by Gitlin & Pasnau (1989) in a review of hysterectomy research, 5 separate dimensions interact to obscure research findings in the area of psychiatric syndromes linked to reproductive function in women;

a. psychodynamic aspects of sexuality and reproduction  
b. substantial hormonal fluctuations  
c. imprecise syndrome definition  
d. culturally biased attitudes towards women  
e. failure to identify pre-existing psychiatric illness (p1419-1420)

Likewise, as observed by Meikle (1977), the picture has been further clouded by flawed methodology. Methodological failings include inadequate matching of controls in terms of demographics, parity and medical status, or a lack of surgical controls, non-homogenous groups in terms of reasons for and method of surgery. However, the latter may not be so important when one considers Strauss et al.'s finding (1996) that in a longitudinal study of 83 patients, no differences in terms of psychological and sexual outcomes dependent on surgical method for hysterectomy. The authors concluded instead that outcome was more likely to be dependent on pre-operative characteristics.

Many studies however can be criticised for poor assessment and analysis techniques, which have failed to take standardised, quantifiable measures of psychological functioning. Literature for the present study was evaluated using Coombs' (1964) model of the research process, which identifies 5 main phases where mistakes can be made, and the relative importance of mistakes at each of these phases. This model is illustrated in figure 2.
According to the model, analysis of the current literature should allow appropriate research questions to be derived. Mistakes at this level (Phase 1), where the questions do not logically derive from the literature reviewed, render the entire study invalid. Phase 2 mistakes occur in development of the so-called 'procedural model', which specifies the subjects, settings and observations required to answer the research questions. Of particular note as mistakes are; non-random samples, lack of control group, small subject numbers in a large and diverse population, measurement of variables or in settings which do not answer the research questions, and so on. These mistakes mean that the research cannot answer the research questions. At phase 3, mistakes can be made in summarising measurements or categories. An example of this would be the use of a Likert scale to quantify answers on a questionnaire, when some answers are clearly of greater clinical significance than others. In this case, mistakes result in the data being inadequately represented, and so the results may not be a true reflection of what actually occurs. Phase 4, the choice of analysis, should be guided again by the research questions as well as the type of data. Mistakes here are not so serious as in earlier phases, as the data can be re-analysed, but the conclusions may differ according to the analysis. Finally, translation of analysis into answers to the research questions/conclusions may also be subject to error (phase 5). This is the least serious of mistakes, as alternative conclusions may be readily apparent.
Figure 2: Adapted from Coombs, C (1964); A theory of data; p4
2.3 Reported post-operative complications

What then are the important areas of outcome which require consideration following hysterectomy? Cooper et al. (1982) identifies 3 main areas of outcome which are considered important: psychiatric/psychological symptoms, sexual outcome, and feelings of regret. However, this neglects the nature of surgery itself, as well as potential physical complications of the surgery, all of which may also impact on psychological functioning. Physical problems/effects of major surgery, psychological and sexual outcome are considered in this section, since they are assumed to impact on women's fears regarding hysterectomy and perhaps account for feelings of regret. A literature search revealed over 1000 articles related in some way to hysterectomy outcome, hence given the confines of the thesis, the decision was made to focus on a few key articles only.

2.3.1 Physical complications and effects of major surgery

A number of physical complications may occur during or after hysterectomy, such as damage to the bladder (risk 1 in 5000) or bowel (less common), and of course mortality (rated at 15 in 10000 for abdominal hysterectomy and 4 per 10000 for vaginal hysterectomies) (Brown Travis, 1988; Dennerstein et al., 1982). Whilst damage to the bladder or bowel is rare, bruising causing discomfort or pain, and changes in functioning are more common. Wound infections or haemorrhage may prolong hospitalisation and complicate recovery, and may affect the appearance of the scar. Thromboembolism may be a further complication with potentially fatal consequences.

In a discussion of the psychological response to surgery, Pitts (1991) suggests that surgery may be one of the most stressful experiences encountered by many, for 3 reasons. Firstly, the experience of anaesthesia may be terrifying, with its loss of consciousness and hence control, worries regarding being awake and in pain, but unable to communicate, and fears about not waking up. Secondly, the
anticipated of post-operative pain may cause significant anxiety. Finally, the invasiveness of surgery may be distressing, given the implements used, the incisions and opening of the body (p67).

Physical recovery from a major operation will depend on a number of individual factors, including perhaps physical fitness as well as psychological variables. Wilson-Barnett & Fordham (1982) provide a diagrammatic summary of all factors potentially affecting recovery, including:

1. previous health status & risk factors
2. patients' support system
3. gender (greater risk in males)
4. personality, anxiety, self-concept
5. expectations, ideas & understanding about health care
6. illness/surgical experience
7. complications or further hospitalisation
8. other life events
9. financial situation
10. pre-morbid occupation/occupational attitudes
11. flexibility of roles
12. doctor/nurses expectations and advice (p44)

They also mention coping skills and the meaning of the illness, quoting Cohen & Lazarus (1979). In a classic article, Norris (1969/2000) notes that convalescence provides an opportunity for reviewing one's life and the meaning of the illness, given that the nature of recovery forces dislocation from normal, everyday life. She continues by stressing that during recovery, patients confront their own vulnerability, and the illness is experienced as a developmental crisis or transition.
Thus a number of dimensions relating to the actual operation and recovery in hysterectomy may result in psychological distress, such as low levels of social support, pre-morbid psychopathology, complications which prolong hospitalisation or convalescence, those for whom the operation has a significant meaning, and those with unrealistic expectations of the length of recovery.

2.3.2 Psychological/psychiatric symptoms

As previously mentioned, a number of studies indicate levels of distress are high amongst obstetrics and gynaecology attendees, making evaluation of pre-operative psychological status imperative. Barker (1968) carried out one of the earliest studies which used a surgical control group and evaluated preoperative psychiatric status. 729 hysterectomy patients were compared with a control group of 280 cholecystectomy patients, and the hysterectomy group was divided into those with and those without major pathological changes (although unfortunately no distinction was made between those with benign and those with malignant pathology). Those without major pathology suffered more pre and postoperative referrals to psychiatric services. Divorce and marital disruption was greater in those referred for hysterectomy than cholecystectomy, although perhaps this is not surprising, given that the hysterectomy group suffered greater psychological disturbance than the cholecystectomy group. Depression accounted for 85% of those referred to psychiatrist and 28% were admitted after an overdose. The peak for psychiatric referrals was in the second year after hysterectomy, and no such peak was observed in the cholecystectomy group. Three factors were linked to referral to psychiatric services—absence of pelvic disease, previous referral and history of marital disruption.

The study, which represented a sophisticated design for its time, falls down on the fact that no psychometric measures of psychological status were used, particularly as psychiatric referral represents a relatively blunt instrument. Barker concludes that...
It is suggested therefore that there are certain patients on whom a hysterectomy should be performed only after much thought and perhaps only after a psychiatric assessment. This would be the case where the patient complained of menorrhagia or pelvic pain, and where there was no anaemia or significant findings on pelvic examination (p64).

Richards (1973) in a retrospective study reviewed the records of an urban GP practice and selected 200 patients who had undergone a hysterectomy, matching them with 200 randomly selected age-matched controls. The most common reason for the operation was fibroids and endometriosis, followed by prolapse and dysfunctional uterine bleeding. Post-operative depression, as defined by diagnosis and treatment with antidepressants by any of the four practice partners, was found in 53% of those with dysfunctional uterine bleeding, 42% of those with fibroids/endometriosis, 40% of those with malignancy. There were no significant differences in post-operative depression between those with and without uterine pathology. Depression occurred in 36.5% of the hysterectomy group and in 15.5% of controls. Preoperatively, 4% of the control group showed evidence of depression and 19% of the operative group, but these rates did not account for postoperative levels of depression. Concurrent oopherectomy had no effect on depression rates, which may suggest that perhaps hormonal fluctuations do not account for post-surgery depression, and the risk of postoperative depression appeared to decline with age.

Obviously this study is subject to differences in diagnostic criteria and rates between partners, reporting rates and the fact that some patients may refuse antidepressants. Neither did the author control for the effect of the GP's knowing which women had undergone hysterectomy, which may have affected prescription of antidepressants, and no surgical control group was used. It could be argued therefore that the likelihood of the control patients suffering from anything more than minor ailments would be reduced (Meikle, 1977). Postoperative depression rates did seem greater than expected however.
In a study which utilised psychiatric measures, Gath et al. (1982) interviewed 156 women with benign origin menorrhagia referred for hysterectomy, and re-interviewed at 6 months (N=147) and 18 months (N=148) post-operatively, such that patients acted as their own controls. Levels of psychiatric morbidity were significantly higher prior to surgery, as measured by the PSE. Similar results were obtained using the POMS (profile of mood states) and psychosexual and social functioning measures, with most improvements occurring 3-6 months after hysterectomy. The authors noted that both pre- and post-operative levels of psychiatric morbidity were higher in comparison to general population, but lower than in psychiatric patients. In addition, a strong association was found between preoperative mental state, neuroticism (as measured by the Eysenck Personality Inventory), previous family psychiatric history, and ‘caseness’ on the PSE. There were no associations between uterine pathology, bilateral oopherectomy, demographic variables, or younger age, and postoperative caseness, as had been suggested by earlier studies.

Again, as mentioned above, given that oopherectomy was not associated with postoperative psychiatric caseness, it may be that hormonal depletion has little role in explaining depression after surgery. This is in direct opposition to the common belief that a woman’s hormonal status may be held to account for a variety of negative psychological symptoms – examples include PMS, postnatal depression, and the menopause. This reflects feminist writings which condemn biological explanations of women’s distress, citing oppression and the difficulties of their social roles as more credible explanations.

Returning to Gath et al. (1982)'s study, those who did not report improvement after surgery were distinguished by higher neuroticism PSE scores pre-operatively. The authors note that ‘menorrhagia is a disagreeable and disabling symptom likely to induce distress particularly in predisposed personalities’ (p342). On self-report, 84% of patients described feeling better in themselves, 11% were unchanged and 5% felt worse in themselves. Psychosexual function improved in the whole...
group. The authors conclude that there is no support for the common assumption that those with no organic pathology underlying their bleeding are more distressed than others, and that hysterectomy does not seem to cause disturbance. Both conclusions seem well founded given this is perhaps one of the soundest studies methodologically.

Jenkins (1983) examined the GP records 3 years pre-and post-operatively, of 16 patients randomly selected out of 198 who had undergone hysterectomy. He noted that hysterectomy did not result in a significantly higher rate of consultation for minor ailments, major ailments or psychiatric referrals in either group, and in those who had previous referrals to psychiatric services, the number of consultations fell. Again however there was no attempt to distinguish between reasons behind hysterectomy, and no measures were taken – the results of this small sample of patients were dependant upon formal referrals rather than subjective measures of distress, which may a rather blunt instrument. The author believes that prior to surgery some symptoms of the underlying gynaecological condition were wrongly attributed to psychiatric problems; an important inference, relating again to Roeske’s ‘hysteria’ school of thought.

In summary it is difficult to conclude whether hysterectomy itself results in adverse psychological reactions, given that most of the studies contain some methodological flaws. However, there is evidence to suggest that pre-operative psychological distress may predict and explain most adverse post-surgery emotional reactions. In most women it appears that hysterectomy may have a neutral or even positive effect on psychological functioning, but in others, previous psychological difficulties can be exacerbated. Whilst there are some suggestions that changes in functioning are not explained by hormonal changes, age, parity, or presence/absence of uterine pathology, research which attempts to understand adverse reactions is missing.
Conflicting ideas exist over the effects of hysterectomy on sexual functioning. For some, freedom from risk of pregnancy, and/or from debilitating gynaecological conditions, provides a renewed sense of sexual vitality. For others, as mentioned in Drellich & Bieber (1958)'s study, hysterectomy may be associated with negative beliefs about ability to enjoy sex and sense of womanhood, for both male partners and women.

Darling & McKoy-Smith (1993) examined the quality of life (QOL) and other emotional wellbeing aspects of 97 women (mean age 43.5) post-hysterectomy, and 249 age-matched controls. Measurement instruments included the Index of Sexual Satisfaction, and Generalized Life Contentment Scale. There was no significant difference in the QOL between groups, but hysterectomy subjects perceived greater sexual satisfaction than non-hysterectomy subjects.

The study does have some weaknesses. No attempt was made to ensure the hysterectomy group was a homogenous one, and no surgical control group was included. Participants were asked to recount their experiences retrospectively, and no preoperative measures were available. All the women involved were members of a college associate group, and hence some doubts may be cast over the generalisability of the results to women of other socio-economic groups.

In a more recent study, Galyer et al. (1999) found no difference in sexual desire between gynaecological and non-gynaecological surgery patients, and none between different methods of hysterectomy. Women (aged 30-65 yrs) completed postal questionnaires, including the Sexual Desire Questionnaire, Hurlbert Index of Sexual Desire, and the Sexual Desire Inventory, in this retrospective study. Whilst no pre-surgery measures were taken, the study was thorough in that it included a surgical control group, and distinguished between surgical method, although not reasons
for surgery. Group sizes were extremely small. Differences in androgen levels did not predict sexual function.

The above finding is similar to that of Dennerstein et al. (1977)'s study, which found that neither oophorectomy nor oestrogen administration correlated with sexual function/dysfunction. Again this was a retrospective study, but one which excluded hysterectomy for malignancy. No comparison with other surgical groups was made, and results were obtained by semi-structured (non-standardised) interview, conducted by one of the authors - a possible source of bias. 37% of subjects felt their sexual relationships had deteriorated as a direct consequence of the operation. The authors conclude that 'an expectation that the operation will adversely affect sexual relations' (p96). This idea of a self-fulfilling prophecy, although making sound common sense, may or may not be a valid conclusion given the methodological problems outlined above.

Whilst hormonal changes may not be responsible for sexual problems post-hysterectomy, recent research suggests that the uterus itself and its nerve supply may be involved in the ability to achieve and experience orgasm (Guthrie, 2000). This may be particularly the case for women who reach orgasm through deep vaginal stimulation - around 39% of women - quite a large proportion. For these women, sex after hysterectomy may be at best different, and at worst unfulfilling. It is easy to imagine how this in itself may lead to decreased desire or sexual problems. DeMarquiegui & Huish (1999) suggest the same, saying

after hysterectomy women often have great difficulty becoming sexually aroused...However, in some women,...hysterectomy can be a relief from heavy bleeding, pain, and tiredness, allowing a freer sexual life (p179)

They go on to suggest that surgery may be perceived as disfigurement or mutilation, and
Disfiguring and mutilating operations, especially of the face, breasts, genitals, and reproductive organs, often have a deleterious effect on a woman's self image and sexuality (p178).

They suggest that changes in body image following such surgery may be responsible for changes in sexual functioning.

Given that these few studies rest on somewhat shaky ground methodologically speaking, further research in this area might clarify whether surgery in general, hysterectomy itself, or pre-morbid characteristics in conjunction with surgery give rise to changes in sexual functioning.

2.4 Predicting 'successes' and 'failures'

Most women who undergo hysterectomy are reported to be satisfied with the operation, but figures vary according to the study. Richards (1978) reports that 90.9% of women in a large scale study expressed satisfaction with the results, with 84.7% saying they would recommend the operation to others. 77.7% stated they felt better, 4.0% felt worse, 12.8% felt both, and 4.7% reported they felt the same as prior to the operation. The figure of 12.8% feeling both better and worse is interesting, and perhaps points to the resolution of menstrual problems but also generation of new difficulties. However, no effort was made to distinguish between those having hysterectomy for benign or malignant pathology, and the length of time since hysterectomy was not specified.

The percentage of women satisfied is similar to that in Gath et al's (1982) study, who found that 84% of women having hysterectomy for benign indications felt better, 11% felt unchanged, and 5% felt worse. Some 14.3% expressed dissatisfaction with the operation. The authors also asked if patients
had experienced any changes in feelings of femininity (and did not define this so as to leave it open to respondents) – 81% felt the same, 13% felt more feminine and 6% reported a decline in femininity.

In summarising the two studies, it would seem that roughly 5% of women may feel significantly worse after hysterectomy, and around 11-18% may feel unchanged. These figures are similar to those regretting sterilisation (5-10%, Lambers et al., 1984). This means that roughly three quarters of women can safely be expected to feel better after their operation, but for the others, hysterectomy may bring no appreciable benefits, or worse, new problems.

There has been some suggestion that women with more traditional sex role orientations may suffer more after hysterectomy, perhaps due to their increased investment in the role of childbearing. However, a prospective study by Tsoi (1982) found no such association, finding instead that mental health improved over the whole group.

Gath et al. (1982) provide the best study in terms of predicting who may or may not gain a new lease of life after hysterectomy. They suggest that pre-operative distress, previous or family history of psychiatric problems, and neuroticism (as measured by the EPI) correlate best with post-operative distress – in other words, those who may be generally at risk under conditions of stress. Stress research has emphasised that the severity of stress experienced by the individual will depend on the nature of the stressor, the individual's perception of threat, tolerance of stress, and external resources/social support (Carson & Butcher, 1992).

Surmising from the other literature reviewed, it appears that oopherectomy/loss of hormones does not pose a risk factor, but patient expectations/coping skills and social support or stability of relationship may also be important in determining outcome. Likewise, the meaning of the illness to the patient, and the sense of control or choice may also significantly affect mood post-operatively.
The meaning of hysterectomy is discussed in the next chapter, with reference to menstruation, fertility, femininity and self-concept, after suggestions made by previous authors.
INTRODUCTION

CHAPTER 3

THE 'MEANINGS' OF HYSTERECTOMY

Themes from the literature
3.1 The meanings of hysterectomy

The meaning of hysterectomy can perhaps be conceptualised in two main ways – the first relates to the actual losses which occur after hysterectomy, namely the loss of menstruation and the loss of childbearing ability, and the second relates to losses inferred from hysterectomy or the loss of uterine functions. Drellich & Bieber (1958) provide an attempt at explaining the ways in which these two meanings of hysterectomy may be understood;

The psychologic importance of the uterus can best be understood in terms of a conscious and unconscious idea which each woman has about her own uterine anatomy and physiology. Those beliefs are derived from a woman’s knowledge of the realistic functions of these organs as well as her personal and individual concepts...derived from her individual developmental experiences (p323)

This quote illustrates the personal and individual meaning for each woman, based on knowledge, experience, and ‘fantasies’, all presumably within the socio-cultural context.

Various authors have speculated on the meanings of removal of the uterus, but few have actually investigated their assumptions by systematically analysing women’s accounts. Fears and losses, as well as positive aspects of hysterectomy mentioned in a handful of studies include;

1. surgical fears – death, dependency & helplessness, destruction, anaesthesia, scarring, removal of a body part (Dell & Papagiannidou, 1999; Dennerstein et al., 1982; Notman, 1974; Pasquali, 1999; Wallace, 1984).
2. Loss of menstruation – as a function in its own right or for its symbolism with regard to femininity or fertility (Dell & Papagiannidou, 1999; Dennerstein et al., 1982; Drellich & Bieber, 1958; Notman, 1974; Roeske, 1978; Webb, 1982).

3. Loss of childbearing ability (Dell & Papagiannidou, 1999; Dennerstein et al., 1982; Drellich & Bieber, 1958; Notman, 1974; Raphael, 1974).

4. Guilt & Shame – hysterectomy as a punishment for sexual/ reproductive ‘sins’ such as abortion, masturbation, miscarriage etc. (Dennerstein et al., 1982; Drellich & Bieber, 1958).

5. Aging or loss of youth due to loss of child bearing ability (Dennerstein et al., 1982; Notman, 1974; Pasquali, 1999).

6. Loss of attractiveness or body image – linked with changes in femininity (Dennerstein et al., 1982; Notman, 1974; Pasquali, 1999).

7. Beliefs about changes in sexuality/ sexual problems linked with loss of child bearing ability or directly with loss of womb (Dell & Papagiannidou, 1999; Dennerstein et al., 1982; Drellich & Bieber, 1958; Lees et al., 2001; Pasquali, 1999; Raphael, 1974; Webb, 1982).


9. Concerns over partner’s reaction – loss of child bearing ability seen to mean loss of femininity (Drellich & Bieber, 1958; Webb, 1982).

10. Self-concept / ‘wholeness’ changes (Pasquali, 1999; Roeske, 1978; Webb, 1982).

Obviously this is an incomplete list of authors who have written on the subject, but around half the authors purely speculate on these meanings, and the rest are derived from qualitative studies, which means that it is impossible to gauge the relative importance of each ‘loss’/ ‘meaning’. Similarly, femininity, sexuality and self-concept may be used interchangeably by authors as well as subjects.
and all are concepts which are difficult to define, making it difficult to tease out what is meant and what meanings are contingent on the loss of which function.

3.2 Links to other areas

In trying to tease out the four main losses which are implied as important in hysterectomy, consideration of four linked areas may be of relevance – infertility & sterilisation, menopause, gender identity and self-concept. Of necessity, all are briefly considered in the next section, to provide comparison points for the themes of the current study only.

3.2.1 Infertility and reversal of sterilisation

A few studies consider the reasons given for requests for reversal of sterilisation, and it is thought that these may prove useful in discussing the importance (or otherwise) of the ability to bear children to women. Winston (1977) conducted a large-scale study of such requests, finding that the most oft-cited reasons for reversal were a new relationship (this was separated from the wish for another child) or feeling less feminine. Nearly half the sample also considered that their sex lives had deteriorated since the operation. It is interesting that these three reasons seem to go hand in hand – the implication is that childbearing ability seems important within a sexual relationship to both partners. This is in line with Raphael-Leff’s (1991) comment that ‘the wish for a baby is located in the context of cultural, social and personal motivations to reproduce’ (p3), and Humphrey’s (1984) comment that infertility is seen as a ‘social handicap’ (p77). Fertility or ability to bear children is still seen as an important attribute within our society, and hence important to self-image for women, despite the social changes in women’s roles and expectations (Raphael-Leff, 1991).
Given that social roles may have changed, but fertility is still seen as an important attribute for women, it is perhaps of value to consider Drellich & Bieber's (1958) qualitative study despite its age. They interviewed 23 women, randomly selected from those undergoing hysterectomy for benign and malignant disease – none had a previous psychiatric history. All received pre and postoperative interviews, the latter at 6 – 12 months. Most women expressed concern over the loss of their childbearing activity, which the authors found unsurprising saying ‘it is easy to demonstrate that most women have a wish to bear and raise children’ (p325). A high degree of regret was expressed in those women who were childless or who had not completed a family. Reasons expressed for wanting the ability to bear children included personal gratification and fulfillment, having an object to love, and to please others.

These studies indicate that a small percentage of women may experience regret of the termination of childbearing potential, possibly when other life changes occur concomitantly (Berkun, 1986). This may indicate that it is not the uterus per se, but rather the potential to bear children in women for whom this is important and integral to their self-concept, which may come under threat after hysterectomy.

3.2.2 Menopause

The menopause, and the range of somatic and psychological symptoms supposedly associated with it, is an area of great controversy, and will not be tackled here. Instead, articles which examine the meaning of the menopause to women will be discussed. Berkun (1986) provides such a view of the menopause which comes directly from interviews with 60 women at various stages of the climacteric, all within the expected age range for this transition. Women expressed two main themes relating to the menopause; firstly, signs of aging and a wish to control them were noted, although most agreed that sense of age was mostly in the mind; and secondly, women dismissed suggestions of regret at
loss of mothering roles or the ability to have children. Aging was more likely to be deemed problematic when marriages or jobs seemed unstable. The study can be criticised for its non-random sample, the mixture of natural and surgically induced menopause in subjects, and the over-representation of women of higher socio-economic status. However, it is interesting to note that the cessation of uterine and ovarian function was not viewed as problematic and indeed the whole event was viewed in positive terms by many, in opposition to much of the literature.

In contrast, Pasquali’s (1999) ethnographic study of premature menopause revealed negative views of the cessation of menstruation, feelings of difference and alienation to peers, feeling less feminine and less attractive for some (but not all), and feelings of loss and sadness, as well as searching for the meaning of the event. This was a small mixed sample (N=11) of women with chemical, surgical or natural but unexplained reasons for premature menopause, mostly occurring in their thirties. In terms of efforts to maintain reliability and validity using qualitative criteria, the author states she used a triangulation strategy, but this was only by the use of a literature review. Nevertheless, the provision of quotes within the text allows the reader to check themes and draw some conclusions from the study. In summary, it would seem that the stage in life at which the menopause occurs, as well as perhaps the reasons behind its occurrence is vital for determining reactions to it.

With regard to menstruation, Drellich & Bieber’s study (1958) provides some ideas regarding the functions attached to menstruation. They suggest that many women in their study viewed menstruation as having healthful and important functions, such as cleaning out the body, the rhythm of life, strength and energy, and maintaining sexual desire. Menstruation may also be regarded as a symbol of fertility or femininity (Sloan, 1978).
Coope (1983) notes that for many, the menopause is linked with old wives tales of mental illness and failing marriages, with the negative social stereotype perhaps accounting for negative attitudes held by women to the transition.

3.2.3 Changes in gender identity/ femininity

One of the first things we learn to say about ourselves is whether we are a girl or boy (Carlock, 1999). Gender identity (knowing one’s gender) develops in most children by age three, gender stability (knowing that one’s gender will stay the same throughout life) normally follows by age 4, and by age 5, most children have developed gender consistency (knowing that one’s gender cannot be altered by changes in clothing) (Vasta, Haith & Miller, 1992). Gender identity is however said to be assimilated into core self-concept very early on in life (Carlock, 1999).

A number of theories exist to explain gender development, but it is generally agreed that a biosocial model provides the best fit with research evidence and captures the complexity of the process. Both information-processing and social learning approaches emphasise the role of the behaviours of others and environmental cues to distinguishing gender, and little mention is made of internal physical differences in gender identity (Vasta et al., 1992). However, research into transgendered individuals does suggest that at the least the external appearance of the body is invaluable in expressing the type of woman (or man) one is. (King & Elkins, 1999). It may only be with menarche that girls become aware of their internal organs in relation to their gender role expectations, i.e. as future mothers (Raphael-Leff, 1991).

Holmud’s (1992) large scale Swedish study is interesting with respect to the perhaps the realised of gender roles by adolescent girls. The study of adolescents and young women suggests that adolescence is a time when girls become oriented towards more traditional female roles, i.e. feminine
roles. This is explained by the occurrence of the menarche, the move to more abstract thinking, and advances in social development/social influences. Menstruation may therefore be critical in the development of a feminine identity role, as just one aspect of self-concept. Femininity is also discussed by Polivy (1974), in her critical review of the hysterectomy literature. She suggests femininity is made up of physical attractiveness and the ability to bear children, concluding that ‘woman’s breasts, genitals, and reproductive organs are probably essential to her adaptation and self-evaluation as a woman’ (p317), thus linking femininity with self-concept as many other authors have (e.g. Drellich & Bieber 1958).

It would seem that femininity, gender identity and gender role are comprised of more than just physical attributes/functions, also including personal/socio-cultural attitudes, and may all be associated with self-concept. Roeske (1978) notes that the medical and societal attitudes which equate the uterus with ‘womanhood, motherhood and sexuality’ (p11) mean that ‘the hysterectomised woman is damaged goods’ (p11). Women who express fears regarding changes in femininity therefore may well be responding to societal or significant other views, rather than purely personal views.

3.2.4 Self-concept

The Self has been the subject of much speculation and study for some 2000 years (Hattie, 1992) and in many ways still remains as elusive today as it was in the time of Socrates. The self has been defined by theorists in many ways, and components of self-concept may be physical, social, emotional and intellectual, as well as real, ideal or perceived, and inter-dependent with self-esteem (Hamachek, 1992). During hysterectomy, physical self-concept must alter to incorporate the loss of menstrual function (and fitness post-surgery), emotional self-concept may alter perhaps due to unexpected reactions to the surgery, and social self-concept may change if attitudes towards the
woman alter or if she believes herself to be different to her peers. Self-esteem, and perhaps real and perceived self may move away from what the woman sees as her ideal self, if that ideal had incorporated ideas about childbearing ability. Thus changes or stability in self-concept after hysterectomy may vary from individual to individual, dependent on the relative importance of the functions of the womb to each.

Argyle (1969) discusses 4 factors which may influence development and maintenance of self-concept. These are, the reactions of others, particularly significant others, comparisons with other people which help us to define/measure our own attributes, our roles, and identification with similar others. Again, all aspects may potentially be affected during hysterectomy. For example, in relation to the reactions of others, an adverse reaction by a partner or trusted friend, perhaps echoing the societal attitude, may occur. Likewise, comparison with other women (childbearing ability being seen as the norm) or identification with other women may result in negative evaluations by the hysterectomised woman if she perceives that she is now different to them in some way. Finally, if her primary role has been that of a mother, the loss of the ability to bear children may adversely affect perceptions of her ability to fulfil that role. All may affect self-concept negatively. In relation to this latter point, Josephs et al.(1992) concluded that aspects of self-esteem may be contingent on the extent to which we fulfil the goals/role prescribed for our gender, given that this results in social approval.

Theoretically therefore, a number of aspects of self-concept may alter after hysterectomy, but this will vary according to the individual and her beliefs regarding uterine functions, as well as the immediate and broader socio-cultural context. It remains to be seen whether this can be supported by research evidence – the author could find no studies at the time of writing which attempted to directly measure this using sound methodology.
INTRODUCTION

CHAPTER 4

AN OVERVIEW OF FEMINIST WRITINGS
ON REPRODUCTION & MEDICINE
4.1 Introducing feminist writings

There are many different strands of feminism, emphasising different and even conflicting arguments. The term refers to a movement, rather than a single line of thought. However, what all have in common is 'characterising the world...as a patriarchal world and the culture...as a masculinist culture' which oppresses women (Crotty, 1998; p161). One line of thought is that patriarchal cultures subordinate women by seeing male experience as the norm ('Self'), and female as 'Other' or objects, with roles and rules needed to control the threat that Other poses to the Self (de Beauvoir, 1953, cited in Crotty, 1998).

In relation to the topic at hand, feminist criticisms of reproductive medicine rest on two main arguments. Firstly, that medicine's respectability has been gained through adherence to 'scientific' principles, but these principles are not wholly objective or indeed may be flawed (Crotty, 1998). Secondly, that medicine, as a social institution, is imbued with patriarchal values, since it exists within a patriarchal culture (Scambler & Scambler, 1993). A fuller discussion of the 'received' view of science is presented in chapter 6, but of necessity this will be but a brief overview of some of the writings by feminist authors which are pertinent to the topic in hand.

4.2 Historical background to women and medicine

Historically, healing was the domain of women. This is in contrast to today's medical system which is dominated by men. Many reasons have been postulated for this, but traditional healers as powerful women became decried as witches during the fourteenth to seventeenth centuries, and women remained excluded as medicine became professionalised in the nineteenth century (Scambler & Scambler, 1993; Ussher, 1989, 1991). It was only in the 1940's that recommendations were made to allow admission of women to single sex medical schools, and the 1970's when sex discrimination
legislation was passed (Scambler & Scambler, 1993). Women have therefore had little opportunity to contribute to the development of the profession or research until recently.

The fear of women giving rise to the witch trials and oppression in general, are seen as rooted in male perceptions of female reproductive biology. The menstrual taboo is one of the oldest and most pervasive myths, which occurs across cultures, even up to the present day. Milk was said to sour, fruit would rot and various other calamities would befall any living thing which came into contact with a menstruating woman (Ussher, 1991). The mystery of monthly, non-fatal bleeds attracted many religious explanations, from possession by evil spirits, punishment for Eve's sin, and so on, construing women as dangerous and contaminating. Explanations evolved in the nineteenth century, as religion was replaced by positivism, and witchcraft with insanity, to construe women's responses to oppression and menstruation itself as sickness, positioning women as weak and frail. The womb was said to compete with the brain for energy (blood), such that women were unable to match men's intellectual prowess (Ussher, 1989). These explanations posit women's different biology as inferior to men's, and therefore women as unable to assume equal rights and roles with men (Brown Travis, 1988; Ussher, 1991). The implications of this for women in general, and women's health care in particular, are clear — at best, women's interests are not as well represented as men's, and at worst, women are actively oppressed by the medical system (Nicholson, 1992).

4.3 Illness models of (normal) reproductive phenomena

The conviction that women's (reproductive) biology rendered them weak and hence vulnerable to sickness is at the root of the medicalisation of normal reproductive functions. This vulnerability is also seen to extend to mental illness, and women's biology is placed at the helm of explanations of differences in mental illness rates between men and women. However, this explanation does not take account of women's position in society or the pressures of their multiple roles.
Certain aspects of reproductive phenomena are also construed negatively. The language of medical textbooks, even today, privileges teleological accounts of women’s biology – for example, the first half of the menstrual cycle is described in terms of preparing for implantation of the embryo, but the second half is seen as relating to decay and destruction as the ‘purpose’ of the cycle is not fulfilled (Scambler & Scambler, 1993). Menopause is described in similar terms; indeed any reaction or function which does not fit with woman’s primary social role – that of the benevolent mother – is construed negatively and a product of awry hormones which must be treated. Thus we have premenstrual syndrome, post-natal depression, and menopausal ‘madness’, where women who do not fit the compliant, nurturing mothering role are construed as suffering from illness, emanating from their weak bodies – so-called biological essentialism (Hunt, 1994). The dual effect of this is that women are more likely to be seen as emotionally labile because of their fluctuating hormonal cycle, and hence complaints about their situation are more likely to be passed off as hormonal emotionality and treated in that vein (Scambler & Scambler, 1993).

4.4 Hysteria and hysterectomy

The Greeks’ concept of the ‘wandering womb’ provides an ancient example of the coupling of emotional lability and reproductive dysfunction (Ussher, 1991). The womb, particularly in childless women, was thought to wander around the body, causing all manner of disturbance and disease. The rise of biological essentialism and the medical model did not displace the belief that ‘all women’s madness, illness and deviant behaviour was ... located in the womb’ (Ussher, 1989, p3). Hysteria came to be the medical term for illness, distress or deviancy within women (Ussher, 1991), and is directly derived from the Greek word hustera which means womb (Foreman, 1966). Treatment for hysteria was therefore clear – surgery to the genitals or reproductive organs – hysterectomy.
Whilst we may believe that attitudes have moved on, and that such obvious methods of controlling
dissent are obsolete, negative cultural and medical attitudes towards menstruation and the uterus
do persist. The media is replete with negative imagery around menstruation, propagating the notions
that menstruating women are unclean and malodorous, and that menstruation should remain secret
(Brown-Travis, 1988). Likewise, as recently as 1969, medical textbooks reinforced teleological
doctrines of the uterus, e.g.

\[
\text{The uterus has but one function: reproduction. After the last planned pregnancy, the uterus becomes a useless, bleeding, symptom producing, potentially cancer-bearing organ, and therefore should be removed (Wright, 1969; p560, cited in Scambler & Scambler, 1993).}
\]

Since the uterus is not required for life, therefore it becomes dispensable (Sloan, 1978). The absurdity of such a position is apparent when Sloan (1978) discusses the hypothetical case of a man who elects to undergo a surgical resection of his prostate gland because he has suffered inconvenient symptoms, plans no more children, and won’t have to worry about developing prostate cancer in the future (quoted in Brown Travis, 1988; p179).

Feminist thought on menstrual phenomena has centred around trying to advance more positive views which celebrate it as a natural symbol of woman’s unique biological capabilities (Willmott, 2000). They have argued that women are not bound by their biology, but rather their roles within society. The dominance of the new religion of science encourages attribution of distress in these roles to hormones, further elevating the position of (male) physicians who have the power to ‘cure’ women’s distress. Whilst the feminist movement has been invaluable in advancing women’s rights and expectations, there are however some difficulties with certain aspects of theory in relation to menorrhagia and hysterectomy.
4.5 Gaps in relation to menorrhagia and hysterectomy

A number of gaps or difficulties within the feminist literature are of relevance to this study. Firstly, menorrhagia does not much feature in feminist writings, perhaps because it does not sit easily with current conceptualisations of menstruation as a phenomena to be celebrated (Willmott, 2000). Similarly, the statement that women are not bound by their biology denies the very real sense of loss some women may feel when they are unable to become mothers, or when they have a hysterectomy. Feminist discussion on motherhood appears to take two paradoxical positions; one sees motherhood as a social role which constrains women, and the other celebrates this unique ability (Willmott, 2000; p108). Hysterectomy likewise is seen as either as liberation or repression. Finally, some (but not all) feminist strands see women as a group, and/or menstruation as a unifying phenomena (Crotty, 1998; Willmott, 2000), yet this ignores individual differences in interpretation and meanings attached to menstruation. So whilst their critique of the social, medical and research systems is helpful in revealing hitherto hidden assumptions and prejudices, their explanations may leave many women alienated in their experiences. Research examining women's accounts of menorrhagia and hysterectomy therefore can only add to the literature.
INTRODUCTION

CHAPTER 5

THE SCOPE OF THE STUDY
5.1 Gaps in previous research

As outlined in previous sections, a number of questions remain with regards to the psychological impact of hysterectomy, and the field in general has suffered from a failure to pay due attention to methodology. Thus it is still unknown whether hysterectomy is associated with an increase or decrease in psychological distress, and what may underlie this distress. The author could find few studies which aimed for understanding from the women’s point of view, rather than purely diagnosis and incidence of depression. Major assumptions are made about the possible causes of such depression, and research from other related areas cannot be easily ‘slotted’ into understanding about hysterectomy. Research in this area is mostly more than 20 years old, and there have been significant cultural changes in this time, all of which have a bearing on attitudes. The popularisation of feminist writings means that previously hidden cultural, research and medical attitudes which devalue and disguise women’s own experiences enabling us to change practices, but feminism has not yet grappled decisively with menorrhagia and hysterectomy.

The need for a ‘bottom-up’ study in this area is clear if understanding is to progress further than assumptions and diagnoses. It is the researcher’s contention that, as endorsed by government initiatives to involve service users, there is a need to go back to the patients themselves and try to ‘walk in their moccasins’ (Indian proverb) to attempt to understand their experience (Lauver, 1999). There is a need to listen to these experiences and amplify the expression of health needs, so that action may be taken to improve services or undertake further research.
5.2 Research questions, ‘hunches’ and aims

A number of research questions were identified based on obvious gaps within the literature. These were;

1. What are women’s experiences of menorrhagia and hysterectomy (for non-cancerous conditions)?
2. What is important to women about this experience and about the treatment process?
3. What are the hopes and fears which surround hysterectomy? How accurate are these hopes and fears?
4. How and why do women decide to have/not have a hysterectomy? What influences their choice?
5. What aspects of hysterectomy are difficult?
6. Are changes in femininity or self-concept cited under fears or as reasons for post-operative distress?

Whilst the emphasis behind the study is to move away from pre-emptive testing of a narrow range of hypotheses, it is important to lay out the researcher’s ‘hunches’ to the above questions. Pre-held beliefs generated from the literature and thinking by the researcher were as follows:

1. Women’s individual experiences of their condition and treatment will differ, but there will be easily identifiable common themes.
2. Most women may wish to talk about aspects of the doctor-patient relationship, the effect of the condition on their lives and worries about the actual operation. Some women may talk about the impact of losing fertility and periods, and the views of their partner.
3. Women's hopes will centre around reversing the effects of the condition on their lives. Their fears may involve operative risks as well as worries relating to the symbolic nature of losing their womb for some.

4. The decision making process will involve the weighing up of pros and cons for hysterectomy. 'Fantasy processes' or unconscious beliefs (Allanson & Astbury, 1996) may play a role in the decision-making process.

5. The length of the recovery period will be difficult for most women. Adjusting to the loss of fertility and periods may be difficult for some but not all women.

6. Worries about changes in self-concept will only be relevant for some/ a minority of women. This may be more likely for those who place great importance on childbearing ability or valuing menstruation. Those who value keeping the womb may be more likely to opt for related but less radical techniques (such as endometrial ablation).

Questions for participants were based broadly on the research questions, but since the aim was to open up discussion rather than prematurely narrow the subject area, questions were kept as broad and as open as possible. The main aims for the research therefore were

1. to capture the experience of menorrhagia and hysterectomy and to enable women's voices to be heard

2. to carry out trustworthy research, in accordance with predefined criteria.

It was anticipated that questions would change slightly as data was gathered and analysed to incorporate new insights. The choice of methods and rationale are discussed further in chapters 6, 7 & 8.
METHOD

CHAPTER 6

EXPLORING DIFFERENT PERSPECTIVES ON RESEARCH
6.1 What is scientific research?

The Collins Westminster Dictionary defines research as 'scientific investigation and study to discover facts' (Foreman, 1966; p411), which underlines the assumption that the research process aims to uncover facts or 'truths'. This is the most common view of scientific endeavour, exemplified by experimental research and the natural sciences. A researcher develops, from an analysis of the literature, a hypothesis and null hypothesis regarding a certain phenomenon, which is then tested out through an experimental condition and statistical analysis, leading to disconfirmation or non-disconfirmation (but never confirmation despite appearances to the contrary) of the hypotheses. The researcher and other aspects such as measurement tools are viewed as fallible and hence potential sources of bias, and attempts are made to eliminate or control these sources of bias. The end result is seen as an objective account of what is 'truly' happening (Pidgeon & Henwood, 1997). This notion of truth and objectivity tends to inform both the professional and layperson's view of what is scientific research.

Woolgar (1996) identifies four main assumptions that are central to this 'received view' (p13) of science, noting they may vary according to the cultural emphasis of the time. These are

1. Objects in the natural world are objective and real, and enjoy an existence independent of human beings. Human agency is basically incidental to the objective character of the world 'out there'.

2. It follows from this that scientific knowledge is determined by the actual character of the physical world.

3. Science comprises a unitary set of methods and procedures, concerning which there is, by and large, a consensus.

4. Science is an activity that is individualistic and mentalistic. (Woolgar, 1996; p13)
This view of science is underpinned by an objectivist or positivist epistemological stance, where there is assumed to be a linear relationship between the phenomenon of interest and the knowledge of that phenomenon. That is to say, the ‘truth’ is seen as being ‘out there’, and only requiring suitable tools to capture it.

6.2 Criticisms of the ‘received view’ of science

Criticism of this ‘received view’ of research is not new, and debates surrounding ontology (the nature of reality), epistemology (how we know what we know), and axiology (the role of values), have fuelled philosophers, the founders of science, for many years (Cresswell, 1998). This is succinctly illustrated by a disciple of Socrates who said

But as for certain truth, no man has known it

Xenophone, c430-353BC

At first glance, the assumptions would appear to hold a certain logic for the natural/physical sciences. However, as Woolgar (1996) notes, science as a practice, and in particular acceptance of its findings, is cultural, political and historical context-bound. Hundreds of examples exist throughout history of scientists denounced as heretics, or their theories ignored, demonstrating that very often, the prevailing views of those in power influence what research is carried out and what is disseminated.

A second criticism arises from the assumption that scientists, as neutral beings using neutral instruments, merely describe what they see. Again, Woolgar (1996) suggests that instead, researchers actively formulate in a creative process which leads to new insights. The tools they use have only become seen as neutral as time progresses, but in fact are imbued with a history of
selections and decisions, since measurement criteria and the intervals of measurement are defined by researchers and do not exist in the natural world. The process of defining and testing hypotheses means that there is a tendency to seek out methods which will prove the researcher correct, rather than setting out to disprove the hypothesis; i.e. confirmation bias.

Finally, the epistemological debate argues that there may be no such thing as objective, knowable reality, where there is a direct connection between the object studied and its representation (positivism or objectivism). Instead there may be an imperfect relationship (mediative or constructionist view), or it may even be that objects themselves are created by representations (the emotionalist, constitutive or subjectivist view) (Silverman, 2001; Woolgar, 1996). Such differing stances, and the criticisms levelled at science's central tenets suggests that the four main received assumptions of science may be 'at best inaccurate and at worst positively misleading' (p19).

Woolgar argues for the adoption of alternatives in their stead, as summarised below:

1. Science comprises the constitution of objects, 'within the context of changing social relations, and the changing configurations of equipment and method'.

2. Scientific knowledge is therefore not determined by the actual characteristics of the physical world, 'but instead by social relations, beliefs and value systems that pertain within scientific communities'.

3. Science is not a unitary set of methods nor a universal practice. 'What counts as 'science' varies over time...and is elusive. It is more... an evaluative repertoire than a universal procedure'.

4. Science 'is a social process that takes place within a language community, and hence is responsive to the prevalent values, beliefs and expectations of that community'.

(Woolgar, 1996; p19)
6.3 Specific criticisms relating to psychological research in the scientific tradition

Psychology, as one of the newer scientific traditions, has battled to become respected generally, and (more recently) to gain equal status with medicine. It has therefore tended to uncritically adopt the tenets and values of the traditional sciences (Pidgeon & Henwood, 1997). However, thinking critically about the received view assumptions in relation to psychological research, and in what we know about human cognition, emotion and behaviour, reveals obvious flaws and inconsistencies. Very often in psychological research, the phenomena of interest are internal (unseen) processes. Most modern models of behaviour accept that there is rarely a linear relationship between thought, attitude or intention and observable behaviour or the reporting of those internal processes (Pidgeon & Henwood, 1997). Thus in the world of psychological research, a positivist or objectivist stance becomes incompatible with most theoretical models or research goals.

Secondly, in clinical practice, psychologists are often concerned with an individual’s viewpoint, which by its nature, is unique and subjective, and indeed the validity of this unique viewpoint is emphasised in the profession’s core values and philosophy. Research however tends to focus on group means rather than individual viewpoints, calling the mean the ‘true’ experience, and seeing any individual experience more than two standard deviations outside the mean as distorting that reality (Dorahy & Millar, 2000). However, it seems highly dubious both rationally and ethically to call the average experience the true experience and ignore all others, particularly as these ‘outliers’ typically present the greatest challenge in clinical practice (Gabriel, 1999; Rowan, 1999).

Finally, if (as the cognitive model suggests) each person’s perceptions in a certain situation are influenced by their previous experiences and assumptions (Beck, 1967, 1976), then it must follow that the researcher as a human being, and hence the research, will be equally influenced by previous interpretations of experiences. The whole process of research therefore, from choice of subject at
conception, through design, and to interpretation of results, is subject to the experiences and hence
biases of the researcher, disputing the idea that all possible sources of bias can be separated out and
derived. The research process itself therefore is a constructive or subjective one (dependent on
one’s viewpoint).

Whilst the epistemological debate is not one which can (or indeed should) be easily settled, its
relevance lies in bringing to light inconsistencies between assumptions, methodologies and methods,
preventing the unquestioning adoption of traditional values of research, and allowing the evolution of
practice into methods other than purely positivist and quantitative.

6.4. What makes good research?

Padgett (1998) suggests that whatever one’s position in relation to the ‘received view’ debate, a
researcher must first ask, what constitutes good research? They suggest that whatever the stance or
methodology, researcher reflexivity, reliability or repeatability, predictive ability, transparency and
accuracy, and revealing useful patterns in the data, are of paramount importance. Sherrard (1998),
Padgett (1998) and Cresswell (1998) all note that the goals of the research must drive decisions on
epistemological stance, methodology and methods, all of which must be consistent and compatible.
This consistency provides the first answer to the question, what makes good research, and also the
framework which was adopted in designing the current study (figure 3 overleaf):
Figure 3: Framework for design of research: taken from Crotty (1998), p4
CHAPTER 7

DESIGN OF THE STUDY
7.1 Epistemology

Given that the present study is concerned with the lived experience of menorrhagia and the decision making process in hysterectomy, an objectivist stance was deemed incompatible with the research questions. Instead, a position on the continuum between constructionism (where the participant and researcher co-create the phenomenon) and subjectivism (which acknowledges the uniqueness and equality of the participants’ perspectives) was deemed most appropriate (Burr, 1998). A decision was made to adopt evaluative criteria against which to judge the research, to ensure some degree of reliability and validity (see later).

7.2 Theoretical perspective

Based on the literature presented in the introduction, a number of theoretical perspectives which could provide frameworks for examining the data were deemed relevant. These include cognitive/phenomenological models of attitudes and behaviour, doctor-patient communication frameworks, and depression and loss models. All of these models are concerned with the internal experience, but all pay respect to the socio-cultural context. This search for meaning or identification of beliefs is said to call for ‘more than quantitative measures in research designs’ (Patterson, Behr & Blue-Banning, 1993; p296).

7.3 Methodology

The methodology of choice for an area which is relatively unexplored, where there are no appropriate measurement tools, and where there is a desire to capture the ‘lived experience’, seeking understanding rather than confirmation, is qualitative research (Padgett, 1998). As George Miller said;
A great scientist, Lord Kelvin, once said, 'When you cannot measure...your knowledge is of a meagre and unsatisfactory kind'...In truth, a good case could be made that if your knowledge is meagre and unsatisfactory, the last thing in the world you should do is take measurements. The chance is negligible that you will measure the right things accidentally. Nevertheless, many social and behavioural scientists....have rushed out to seek numbers before they knew what the numbers would mean. (George Miller, 1962; p95)

7.3.1 Qualitative Research

Loosely defined, qualitative research is a category of research designs or models, all of which elicit verbal, visual, tactile, olfactory, and gustatory data in the form of descriptive narratives like field notes, recordings, or other transcriptions from audio- and videotapes and other written records and pictures or films (Preissle, 2000)

There is no unitary qualitative method for analysing material, but most methods of analysis rely at some stage on the identification of common themes. The data may then be further processed, dependant on the method and the goals of the research.

Qualitative methodology is deemed particularly appropriate for exploring under-researched, sensitive or emotionally charged areas of interest, and where a subject group or previous research may be subject to 'institutional prejudice' (Padgett, 1998; Pidgeon & Henwood, 1997). This was felt to be particularly important in this case, given that feminist writers have identified gynaecology as an area where women typically have little involvement or control in the treatment process (Scambler & Scambler, 1993). Qualitative methodology was also chosen therefore for the possibility it affords of
carrying out more inclusive research, where participants have greater control over the process, analysis and outcome (Patterson et al., 1993).

The objective of qualitative research is to seek understanding rather than confirmation, and studies are often described as 'emic', which means they seek to understand from the participant's viewpoint, rather than taking a 'fly-on-the-wall', outsider-looking-in stance (Padgett, 1998). In many ways, it mirrors clinical practice in psychology, through the use of in-depth interviews where the researcher seeks to make a relationship with the participant which allows the participant to speak freely (Padgett, 1998; Silverman, 2001). The researcher is thus acknowledged and encouraged to play an active role in the research process, and also to make this role explicit.

For the present study, two main methods of analysis were used within a grounded theory framework; these were thematic analysis, and a sub-sample of the data were analysed using discourse analysis. The former was used to identify common themes of experience between groups of participants, and the latter to provide some insight into how decision-making arguments and participant's stories were constructed. Thematic analysis was a constant process carried out in parallel with interviewing, as new data brought new insights to the research problem, as advocated by Padgett (1998) and illustrated below in figure 4:
Throughout, the explicit aim was to connect directly

...with experience as it is ‘lived’ or ‘felt’ or ‘undergone’...Qualitative research, then, has the aim of understanding experience as nearly as possible as its participants feel it or live it.

(Sherman & Webb, 1988; p7).

7.3.2 Grounded Theory

Grounded Theory refers to ‘generating theory that is ‘grounded’ in interviews, field-work observations, case-study documentation or other forms of textual material’ (Pidgeon, 1996; p75), and refers to both a method of analysis and a framework for analysis (Pidgeon & Henwood, 1997).
Whilst it was first operationalised by Glaser & Strauss in 1967, its roots can be traced to the emphasis on 'Verstehen' or meaning as opposed to the pursuit of causal explanations (Dilthey, 1894/1977), and to the symbolic interactionist perspective of Blumer (e.g. 1969b). Symbolic interactionism sees an individual’s social world as being defined through gestures, symbols and meaning systems within a specific context. This means that grounded theory emphasises participants’ own accounts of events in their worlds, through flexible research which is conducted in those everyday contexts (Pidgeon, 1996, p76-77).

However, grounded theory has been criticised for its uneasy straddling of the realism-constructionism divide. That is to say, whilst the method emphasises the uniqueness of the participant’s perspective, it also suggests through its tenet of theory emerging from the data, that there exists an objective truth to be discovered after all (Pidgeon, 1996). However, its value lies more perhaps in its ultimate goal of theory generation, which should move the research beyond simple description of local events.

In the present study, some of the techniques of grounded theory were used to provide structure and pre-set guidelines for carrying out the research, although it is not primarily a grounded theory study. The techniques used included:

1. use of constant comparison of the data to coding categories
2. use of low-level codings which should fit the data well, as well as more abstract/higher level categories
3. looking for multiple facets of a coding category
4. theoretical sampling to search out participants most likely to provide the data required;
5. use of the literature to compare against the themes from analysis as part of the triangulation strategy
6. writing of memos and field notes to enhance the traceability of researcher’s own decision processes.

7. Collection of data until 'saturation'; i.e. when no new insights occur (Pidgeon & Henwood, 1996)

The framework was found to be useful in carrying out the main analyses, as detailed below.

7.3.3 Thematic Analysis

Themes refer to patterns within the data which describe, organise or interpret aspects of the data, according to Boyatzis (1998, p4) and may be at a ‘manifest level (directly observable in the information) or at the latent level (underlying the phenomenon)' (p4).

Like all qualitative methods, there is no one way to develop themes from raw data, and indeed there are likely to be as many ways as there are researchers. However, all have in common the following main principles:

1. A thorough reading of the data – at least 4 readings is recommended, till one is familiar with every aspect

2. Creativity and ‘free association’ in attempting to capture the essence of a line or paragraph, note interesting ideas or words which summarise the phrases

3. Trying to group together like-labels, looking for links, commonalties and differences between categories. Splitting or merging of categories

4. Returning to the data to check for ‘fit’

5. Documenting the decision making process (from McCormack Steinmetz, 1991; p87-88; also Padgett, 1998; p 76-84).
It is possible to analyse the data by manually cutting the data into segments and physically moving it, using cards to summarise the themes from passages, or spider diagrams, etc, but the aim is to allow meaning to emerge from the data, and not the other way round (Padgett, 1998). It is in this respect that thematic analysis differs from content analysis, in that content analysis fits the data to pre-existing categories derived from the literature, and then counts the number of instances of each category (Pidgeon & Henwood, 1997). In identifying and defining categories, it is possible either to start with general themes and move to specific, or vice versa, but either way, there should be some attempt to identify both the smallest meaning units, as well as over-arching or ‘umbrella’ categories (Garner, 1991).

The guiding principle behind thematic analysis is eloquently summed up by Garner (1991);

To analyse is to find some way or ways to tease out what we consider to be essential meaning in the raw data; to reduce and reorganise and combine so that the readers share the researcher’s findings in the most economical, interesting fashion. The product of analysis is a creation that speaks to the heart of what was learned. (p 140)

7.3.4 Discourse analysis

According to Harre (1997), a discourse ‘is a sequence of jointly produced acts’ (p27). Discourse analysis then refers to analysis which concentrates on the ways language is used in describing action sequences in human interactions (and self-talk) (Harre, 1997; Potter, 1997). It focuses on the social practices of talk and texts, and the resources which support these practices (p129). Generally speaking, this is a purely constructionist approach to analysing data, which aims to identify how particular attitudes or psychological processes are manifested within interactions. In particular, it is
concerned with 'interpretative repertoires', which are a related set of terms, often organised around
central metaphor(s), which are a resource used to support social practices (Potter, 1997; p 131).

The methods of discourse analysis again vary, but all are concerned with the importance of the
text/talk in its own right (as opposed to its use for revealing 'reality' behind the discourse), the
constructive and functional aspects of the language, and the rhetorical function of the account (Gill,
1997; p141-142). Gill goes on to suggest the following ways of carrying out the analysis,
summarised below;

1. Suspend current knowledge about how language is used
2. Focus interest on the function and purpose of the language
3. How you look at the text depends on what questions you want to answer
4. Read & reread till you know each transcript very well - immersion
5. Go through and highlight any instances that relate to your question
6. Coding should be as inclusive as possible to start with, use cards, piles, photocopies etc
7. Once coding is complete do the opposite of 'reading for gist'
8. Look at what is actually said and examine why you read it in a particular way, what makes it seem sarcastic, etc
9. Look at the purpose of what is said e.g. rhetorical persuasion and protection
10. Look for objects – often nouns, subjects – categories of persons
11. Choose terminology to label the discourses

Discourse analysis therefore requires a radical change of mind-set in relation to the way we read or
listen to interactions. Instead of summarising and distilling what is said, the researcher must engage
with the way the speaker’s meaning is portrayed, looking for the facets of the language which produce that meaning (Potter & Wetherell, 1987; p168).

7.4 Ensuring rigor in qualitative research

Whilst quantitative methods have guidelines for rigor which are well accepted by the research community, there are still many debates surrounding issues of rigor in qualitative research. Essentially, the debate centres around whether traditional methods of demonstrating reliability and validity in quantitative research should evolve to a parallel but separate set of criteria (as espoused by those taking a post-positivist epistemological stance), or whether new terms and criteria should be developed such that qualitative research is judged within its own framework (constructionist stances). A third way however, that of Post-modernist (subjectivist) stances, entirely reject the notion of evaluative criteria, based on the belief in the equality of all ‘truths’, which cannot therefore be judged against a unitary set of criteria (Padgett, 1998).

Psychology claims its place amongst the traditional sciences, with its history of ‘scientific endeavour’, whereby its research is judged against the values of traditional sciences (typically, reliability - replicability - and validity – credibility and generalisability) (Woolgar, 1996). At the very least therefore in order to be respected (and published!), psychological research at present must ensure that some criteria exist for its findings to be judged against. Indeed, as Padgett (1998) states, if we reject all evaluative criteria then ‘the door is open to intellectual guruism where judgements...are left to the whims of a self anointed academic elite’ (Padgett, 1998; p90).

For the purposes of this study, evaluative criteria were deemed necessary and indeed vital to ensure that the study was rigorous, and could span the needs of its prospective audiences (i.e. examiner, medics, peer-reviewed journals).
Typically, qualitative research concerns itself with the range and not the mean of experience, celebrating multiple participant perspectives as opposed to a single, unitary true experience (Padgett, 1998). Replication and generalisability in the original senses of the words therefore become moot concepts. Instead, Padgett suggests the concept of trustworthiness, i.e. 'fair, ethical research which represents as closely as possible the participants experience' (p92).

The threats to trustworthiness are identified as the same as those in quantitative research, but possibly magnified due to the greater involvement with fewer participants. These threats include reactivity — distortion of phenomena by the presence of the researcher; researcher/confirmation bias, and respondent bias — withholding or overflowing and hence distortion of their experience (Padgett, 1998).

Six strategies are identified to combat the three sources of threat — prolonged engagement, triangulation, peer debriefing, member checking, negative case analysis, and leaving an audit trail (p94). Triangulation and member checking provide ways of combating all three threats at once. For the study in hand, all but prolonged engagement (due to time constraints) were used to enhance rigor, and are detailed next.

7.5.1 Triangulation

Triangulation refers to the use of two or more sources to achieve a more comprehensive (but not necessarily 'the best') view of the subject matter (Silverman, 1997). Denzin (1978) identifies four types:
1. Theory triangulation – the use of multiple theoretical perspectives against which to examine the data

2. Methodological triangulation – the use of multiple methodologies, such as qualitative and quantitative, or analyses such as thematic and discourse analysis

3. Observer triangulation – the use of more than one observer or analyser

4. Data triangulation – the use of more than one data source, such as interviews, documents, observation

Triangulation itself does not mean that all sources must correspond; indeed discrepancies between sources often allow for insights. In this study, triangulation in all four areas was achieved, with results being discussed from a number of theoretical perspectives, the use of thematic analysis and discourse analysis of a random sample of data, the use of a second coder for a sub-section of the data, and the use of interviews, written material and self-observation data. Different groups of participants were also used, including a clinic and non-clinic sample.

7.5.2 Member checking - credibility

Member checking refers to returning periodically to participants to follow up ideas and hunches, to check out themes, to ensure that during abstraction of the data, the data still reflects the participants’ experience. As Lincoln & Guba (1985) note

Credibility is a trustworthiness criterion that is satisfied when source respondents…agree to honour the reconstructions; that fact should also satisfy the consumer. (p329)

After each interview, hunches and ideas, as well as broad themes were taken and checked out with the next participant. Some participants also checked their transcripts and the themes drawn out of them to determine if after analysis, the themes still reflected their experience.
7.5.3 Negative case analysis

Negative case analysis refers to the deliberate search for participants whose experience may not confirm one’s hunches, or more generally, taking opposite arguments or stances during data analysis (Padgett, 1998). In this case, participants who did not ‘fit’ the hypotheses were sought, including those without children, those previously sterilised, those undergoing endometrial ablation, and those of hysterectomy age but who had no problems with their periods or womb.

7.5.4 Leaving an audit trail

The research steps were documented, through a research diary, plus the inclusion of transcripts and fieldnotes, allowing the reader to make their own judgements as to trustworthiness, whilst also enhancing reproducibility. Examples of the transcripts and a summary of the research diary are included in the write up for this purpose.

7.6 Methods and data sources

Multiple methods were used to collect the data, and included analysis of themes from the literature, individual semi-structured interviews, and analysis of written information supplied by participants. Self-observation data were collected and used to supplement transcription and analysis, but were not analysed in a formal sense. The methods were chosen for their ability to answer the research questions, and also for practical considerations, such as the length of time to complete the study (i.e. methods of prolonged engagement such as case studies or ethnomethods would have been unfeasible). Justification for the use of these methods is provided below.
7.6.1 Literature and written material

Silverman (2001) notes that textual material is used in qualitative research to try to 'understand the participants' categories and to see how these are used in concrete activities' (p12). Thus, in the research literature, themes can be drawn out which relate to the psychological and medical viewpoints and how these are constructed in relation to women with menorrhagia. This can be contrasted to the written materials of women themselves. Analysis of textual material differs from transcribed interviews in that they are produced without the presence of the researcher and hence the perspective or data is not co-constructed. Thus the social context is removed from the production of data, providing a different type of data as part of a triangulation strategy. Written materials were deemed important in this study because of their role in accessing assumptions, decisions and meanings within the hysterectomy process from women's perspectives without interaction with the researcher. They are also extremely time-efficient, which is important in a doctoral study.

7.6.2 Interviews

An interview is a 'goal directed conversation' (Padgett, 1998; p59), where (according to the epistemological stance taken in this study) the participant's story is more important than rigidly adhering to the researcher's own agenda (Silverman, 2001). The aim should be to build rapport and 'try to formulate questions and provide an atmosphere conducive to open and undistorted communication' (Holstein & Gubrium, 1997; p116).

McCormack Steinmetz (1991) suggests that planning an interview should take account of the following.
1. What does the researcher know about the participant and what should they know?
2. Access, privacy, confidentiality and location of the interview
3. How to begin – each interview should begin with comfortable questions
4. Have a structure and questions/goals in mind but be prepared to be flexible
5. Checking equipment
6. Concluding the interview, how to make opportunities for follow-up etc (p 59).

She also suggests that the research interview should make use of the same skills as a counselling interview, i.e. open questions, following leads and probing, summarising and rephrasing, in order to deepen discussion. The researcher should see the participant as an equal but an expert in his or her own experience, and should be prepared to alter their goals accordingly (Silverman, 2001).

It should be noted however that no matter how open-ended the interview, the researcher is still influencing the process in some way or other, either by their activity or passivity (Silverman, 2001). The situation is still one which is open to social expectations, and the researcher may well be seen as or indeed is someone in a position of power, despite reassurances to the contrary. Like any social interaction, the interview will be subject to problems of self-presentation, little or over-commitment to the interaction, the context, and difficulties or otherwise in accessing private experience (Silverman, 2001). However, these are not seen as problems or distortions (as they would in a positivist stance), but as integral parts of the data set which need to be described as far as possible for use in the analysis.

Interviews were deemed valid as the main method of data collection in this study for a number of reasons. Firstly, observations of participants would not have provided answers to the research questions, as the researcher wanted to access mainly mental/cognitive and emotional processes. Secondly, they provide a time-efficient way of collecting in-depth material. Thirdly, the
acknowledgement of the researcher’s own thoughts, feelings and ideas (perhaps even transference) during the interview provides a way of checking out the validity of these hunches with the participant.

Fourthly, as illustrated by protocol analysis, and the phrase “I’ll know what I think when I hear what I say”, it is possible that the interview may provide a forum where “thinking aloud” was made possible, giving access to the participant’s experiences in more detail.

7.6.3 Self-observation/ research diary

The epistemological stance taken in this study means that the researcher is not viewed as an objective measurer of data, but rather as a person who brings their own experiences, beliefs and attitudes to all aspects of the process. The action of these attitudes will inevitably bring ‘bias’ or particular emphases to the whole encounter from choice of topic, through data collection, analysis, and the write-up. The research diary provides a way of documenting some of these influences, along with decisions, ideas and hunches, helping to place the researcher relative to the construction of the research (Banister et al., 1994; Smith, 1996). The research diary also provides a way of ‘laying a paper trail’ (Pidgeon & Henwood, 1997; p270) which may be audited by readers or used to evaluate the research.
METHOD

CHAPTER 8

PROCEDURES
8.1 Overview of Procedures

A thorough literature review was conducted to identify gaps and questions and to guide data collection. This was followed by the first main phase of data collection. Data was analysed as it came in, and a second literature review was conducted using questions and ideas from the analysis. The second data collection phase arose from the themes, questions or ideas from the analysis and literature. The whole data set was re-analysed, and a portion second-rated, and another portion examined from a discourse analysis point of view. The whole process is summarised below in figure 5:

Figure 5: Overview of review, data collection, and analysis procedures
8.2 Choice and recruitment of participants

In order to address the research questions, a number of groups of women were seen to be appropriate participants, and this was tempered with considerations of accessibility of these populations.

Women on the waiting list for hysterectomy for benign origin menorrhagia were an obvious choice for assessing the decision making process for hysterectomy. The researcher felt they would also be appropriate for accessing perceptions of the womb and its importance, since their minds may be concentrated on this due to their impending surgery. It was hypothesised that they would have reached a point where the effect of menorrhagia on their lives was highly apparent since they had decided to ask for treatment. They also formed an easily accessible participant population.

In order to determine the accuracy of hopes and fears, and access difficult aspects of hysterectomy, a post-operative group was needed. A shorter-term follow-up could be gained from re-interviewing some of the pre-operative group as far as possible after operation. It also seemed important to track down some women who were much further on with recovery, and for this reason a non-clinic and (hopefully fully) recovered sample was recruited through a beauty salon, as an example of a woman friendly and non-pathologising environment (see later for recruitment procedures).

In order to determine some of the general fears and ‘old wives tales’ surrounding hysterectomy, a non-surgical and non-clinic sample was deemed appropriate, who were of a similar age to those having hysterectomy. Finally, in order to capture possible links between the womb and self-concept without directly asking, a group opting for endometrial ablation was thought to provide a contrast to those having a hysterectomy. It was hypothesised that choosing this treatment may be due to wishing to keep the womb itself, or due to doctor’s advice, and this would form an interesting contrast.
Participants from a number of ‘groups’ were recruited in different ways. Participants included:

1. Women who had not had any surgical treatment for heavy periods who were of average hysterectomy age (30-50 years)
2. Women awaiting endometrial ablation for benign origin menorrhagia
3. Women awaiting hysterectomy for benign origin menorrhagia
4. Women who had undergone hysterectomy not more than five years ago for benign origin menorrhagia

These groups were chosen to represent different stages of the hysterectomy process — “pre-contemplation”, “contemplation” and post-treatment. Endometrial ablation patients were chosen as the procedure results in practically the same effects as hysterectomy but requires less recovery time and the uterus is kept. The rationale was in investigating why each group had chosen their particular treatment, which may have thrown light on the priorities for each group, and/or the question of sense of self and the uterus. A second contrast was between those who had not had to think about hysterectomy (women who had not had any treatment), and those who had, and to determine whether stage of thinking resulted in different priorities. A third contrast was between those who were awaiting hysterectomy, and those who could discuss the process with hindsight, again to look at priority differences. Those with cancerous conditions were not recruited since cancer was seen as bringing a different set of priorities and explanations, which were not relevant to the study in hand.

Recruitment of group 1 was via an advert at a beauty salon and through personal contacts, and they received an information sheet and demographics sheet to fill in and return. Group 2 and 3 were given an information pack and demographics sheet by the waiting list secretary at the hospital which
performs most hysterectomies for this geographical area. Group 4 were recruited through an advert at a beauty salon, personal contacts, and by the researcher asking those on the waiting list if they would mind a second interview after their operation. Again they received an information sheet and demographics sheet to fill out.

At this point, all participants were contacted by telephone to ascertain if they were still interested, and if they had any questions. All were informed of the aims of the study and likely questions, as well as being told that what they felt was important was important to the researcher. Because of the small numbers of respondents, all of those who returned sheets were asked to take part, thus it is an entirely self-selected sample. Everyone who volunteered then filled out a GHQ-28 (Goldberg, 1979) to screen for psychiatric disorder. This latter was deemed important in that the researcher was interested in accessing if possible the group of women who may be distressed post-operatively without pre-existing psychopathology, and was also a condition of ethical approval. The GHQ-28 is a well-validated screening questionnaire, which is quick to complete and acceptable to non-psychiatric patients. It has been used extensively in similar populations (Lloyd, 1990).

The different groups provided data in different ways as detailed below:

Group 1 were asked to provide written information using questions as a guide (see Appendix B) but to feel free to add their own thoughts

Group 2 were interviewed (see Appendix B) and some were asked to provide written material through a balance sheet

Group 3 were interviewed (see Appendix B) and some were asked to provide written material through a balance sheet

Group 4 were interviewed OR asked to provide written material using the questions set out in Appendix B as a guide for their own thoughts.
8.3 Interview procedures

Interviews took place at a time convenient to the participant and either at the University or in their own home. In line with the requirements of the ethics committee, each participant was shown a letter which was sent to their GP, informing them that their patient was taking part in the research.

Participants were shown the list of questions, and then asked to sign the consent form if still happy to take part (see Appendix A). The interviews were audiotaped and the words transcribed verbatim, with pauses, sighs, laughing or interruptions also being noted. Tone of voice and emphasis was only noted for portions used for discourse analysis. After the interview the researcher filled out an "impressions sheet" (see Appendix C) which recorded participants mood and body language, as well as the researcher’s personal reactions, ideas, etc (Padgett, 1998).

The researcher aimed for a high level of involvement, clarifying, prompting and responding to participant’s questions as required to facilitate and deepen discussion. Women were encouraged to talk about what was important to them, and also to ask the researcher about herself if they wished. Clinical interviewing skills such as reflective listening and summarising were used to clarify issues, and hunches or developing themes were checked out with participants themselves.

At the end of the interview, participants were asked if they would like to check their transcript and the themes taken from it. They were also asked if they would like to fill out some written material or be re-contacted after their operation, and advised to telephone if there were any questions at a later stage.
8.4 Written material

For written material, participants were provided with either a balance sheet (Janis & Mann, 1977) looking at the pros and cons of hysterectomy, or a list of questions to use as a guide for their own thoughts (see Appendix B). These were filled out at their leisure and returned by post. These have been typed verbatim for thematic analysis.

8.5 Self-observation/ research diary

Notes were kept by the researcher which recorded impressions, hunches, ideas, decisions and questions, all the way through the research process. Particular use was made of them immediately after interviews to describe the “feel” of the interview, during the transcription and analysis stages to record aspects of the interviews or hunches and themes which became apparent. The diary was used to supplement analysis only and extracts are presented in Appendix D.

8.6 Thematic analysis

The immersion in the data required for thematic analysis was aided by the researcher transcribing the material and making notes as she went along. As each transcript was finished, the researcher noted particular themes which appeared important to ask about at the next interview. When all the interviews were complete, all were read and re-read a number of times, until the main priorities for each participant appeared clear. Each group was then analysed separately, and then later compared for crossover or differences. The transcriptions were manually cut into meaning segments, starting with specific and small fragments, which were then grouped in piles which had a similar feel. Words which described these fragments were recorded, and impressions or ideas were noted or drawn out as the analysis proceeded. Once all the data had been segmented, these piles of fragments were read and
re-read, and moved to different piles if appropriate. Once the fragments in each pile appeared consistent, the researcher labelled each pile as a category, with words which described the category being brainstormed until a good fit was found. Two to five quotes were then selected as representative of that category. As links between the categories became apparent, they were illustrated diagrammatically, revealing over-arching ideas or themes. These links are presented in section 10.7.

8.7 Discourse analysis

Once thematic analysis was complete, the illustrative quotes for key categories in the hysterectomy and post-hysterectomy groups were examined in more detail. The researcher moved from reading for gist to noting how the words used, tone of voice, pauses etc, contributed to the conveyance of the meaning. This was done in a creative, freethinking fashion. This was not a complete and detailed analysis, but rather was used to supplement the main thematic analysis and to identify over-arching ‘stories’.

8.8 Observer Triangulation - “Inter-rater reliability”

A second rater, a female psychologist with previous experience of qualitative research, but without knowledge of the topic area or hypotheses, was given two transcripts selected at random from the pre-hysterectomy group. She then segmented the data and produced her own themes, which were compared with those of the researcher.
RESULTS

CHAPTER 9

DESCRIPTION OF PARTICIPANTS
9.1 Description of participants

The research paradigm chosen means that the results of this research cannot be expected to be representative of a larger population, but nevertheless, common themes or points to consider can be raised from these results (Padgett, 1998). Whilst the qualitative paradigm encourages the reader to view participants as individuals rather than averages in groups, there are advantages to providing a summary of demographic variables of the different groups. Firstly, in this case it demonstrates that demographic or illness variable differences between the groups are small, and hence differences in themes are unlikely to be due to differences in these variables. Secondly, this is provided to give an overview of some characteristics of those who were studied and who the results apply to. This is provided in addition to a participant synopsis provided at the head of each transcript.

9.2 Group frequencies

A total of 16 women took part in the project. They were grouped as follows:

- Group 1 = women from a non-clinic sample who were not awaiting any surgery  N=2
- Group 2 = women awaiting hysterectomy  N=7
- Group 3 = women awaiting endometrial ablation  N=2
- Group 4 = women who had undergone hysterectomy in the last 5 years  N=5

Two of the women who completed written material post-operatively had also been interviewed pre-operatively.

9.3 Age

The age range for participants was 31 – 51, with a mean of 40.6 years, standard deviation 5.4 years. Group 1 were the youngest group (mean age 33.5 years). Analysis of variance revealed no significant differences between groups in age.
There are two methods for scoring the GHQ-28, one using a Likert scale, which is used for comparing degree of disorder, and the second where responses are scored 0, 0, 1 & 1, used for detecting psychiatric 'caseness' (scores over 4/5). Using the Likert scale, scores ranged from 11 – 37, with most participants scoring very low on the depression subscale, but perhaps scoring a little more on the other subscales. Scales are labelled as A (somatic symptoms), B (anxiety & insomnia), C (social dysfunction) & D (severe depression).

Although there is some variability within groups for the subscale scores, no statistically significant differences between mean group scores were found. Figure 6 below illustrates the similarity between groups in terms of age and GHQ scores.

Figure 6: Comparison of groups – age and GHQ-28 scores

Bar Chart 1: Comparison of groups
Age and GHQ-28 scores

<table>
<thead>
<tr>
<th>GROUP</th>
<th>Group 1= no surgery</th>
<th>Group 2 = pre-hysterectomy</th>
<th>Group 3= endometrial ablation</th>
<th>Group 4 = post-hysterectomy</th>
</tr>
</thead>
</table>

Seven out of the sixteen participants had seen a counsellor or their GP for advice around psychological distress, either due to stress or anxiety symptoms, at some time in the past. Treatment was brief for all participants, and none had needed to see a psychologist or psychiatrist.
9.5 Relationships

All but one of the participants considered themselves in stable marriages or cohabiting, with the other participant being divorced but in a relationship.

9.6 Children

Fourteen participants had between 1 and 3 children. Of the two without children, one woman had been sterilised at age 28 because she did not wish to have children (hysterectomy group), and the other in the no surgery group felt she would like children in the future. Some women in the pre operative group (5 out of 7) said they may have liked to have more children, but only 1 in the post-operative group felt she would have liked more children.

9.7 Occupation

The women who participated were involved in a number of occupations, including health professionals, white collar workers, manual workers, a student, and two were unemployed. There was probably an over-representation of higher-paid, professional-type occupations.

9.8 Medical condition and treatments tried

One of the non-surgery group had no problems relating to her womb, but the other had suffered with painful periods. Everyone else described their difficulties as heavy, prolonged or painful periods, and some had diagnoses of endometriosis, fibroids or polycystic ovaries. Most felt their condition affected their lives between 8 and 10 on a scale of 1–10 (10 being terrible/constant effects). All women had tried a number of treatments, including painkillers, contraceptive pill/hormonal tablets, D&C’s, diathermy or resection. 6 of the 14 in the surgical were advised to have surgery by a medical professional (GP/gynaecologist), with the rest citing the effect on their health or ability to function as carers/workers.
RESULTS

CHAPTER 10

THEMATIC & DISCOURSE ANALYSIS
Low-level categories which emerged from the data are presented first, with a description of each category and an illustrative quote. Pseudonyms are used throughout, and blue coloured type is used where the researcher’s questions are included in quotes. Discourse analysis is used to supplement thematic analysis for the pre-operative group only. All categories are then summarised in tabular form in section 10.5, before being compared for similarities and differences, and links are shown diagrammatically in section 10.7. Throughout, theme/category names are shown in bold type.

10.1 Capturing the data – non-surgical group

Only a small amount of written data were gathered from 2 participants who were not considering surgery. They were asked to write about their considerations and the pros and cons of a hysterectomy for menorrhagia. Themes are illustrated below, but only briefly since the main focus of the analysis was on the pre and post-operative groups;

a. Not bad enough

This relates to the idea that period problems were not seen by the general public or employers as ‘bad enough’ to warrant time off;

“To have time off for a heavy, painful period would be unacceptable – I imagine most women would make an excuse, as I would (and have!)” (Nadine – underlining is her emphasis)
b.  **Worries about recovery**

The women discussed the major impact on their lives of being incapacitated for such a long period of time. This was weighed against the incapacity they imagined women with period problems suffered;

"Hope is freedom in your life and freedom from pain, but that it weighed up against the possible after effects of not being able to work or do your usual activities afterwards".  
(Gina)

c.  **Scar**

There was a sense that scarring was important on two levels – firstly, the wound may be painful or infected, signifying the invasion of one's body; and secondly, with regards to body image;

"A fear is the scar it would leave – horrible! The pain when you move, and it would look awful for months, even years afterwards".  (Gina).

d.  **No possibility of children**

This seemed to be the saddest part of what a hysterectomy would mean. Maintaining the potential for having children was seen as important;

"The worst thing - No babies - ever! Something I’d always imagined I’d experience is taken away from me".  (Gina).

"While I have children and, at this time, don’t want any more, the knowledge that I could if I wanted to, is reassuring. To have that control over your body, life choices etc taken away must be upsetting".
e. Sexual attractiveness/desire

For both women, the end of the potential to have children was felt to impact on their sexuality or libido;

“I believe my partner would feel uncomfortable about my having had a hysterectomy. One of the special aspects of our sexual relationship is that he has, and can, make me pregnant. I believe he feels ‘manly’ for this role and I feel ‘womanly’...[knowing that you can] create a new life together, is very sensual and powerful”. (Nadine).

f. Changes in femininity/womanhood

There was a sense that some aspect of femininity/womanhood may change, perhaps resulting in a feeling of ageing;

“No more periods!/ Yippee! But then it does symbolise that you’ve reached an age where you are no longer ‘productive’? That you have fulfilled your biological role? Personally, I wouldn’t feel as much of a woman after a hysterectomy, although I would feel as feminine” (Nadine).

Nadine was specifically asked what made her a woman, and what was “me” to her. This is what she wrote;

“What makes me a woman?
- my sexuality
- my children
- how my body looks and feels

My ‘me’ is my soul, my spirit – not one particular physical part of me. While hysterectomy would probably influence my feelings of sexuality etc, I wouldn’t
necessarily feel less of a person – just changed – and would have to get to know and accept the change”. (Nadine)

The sense was that hysterectomy would not diminish her sense of self, but rather it would require an adjustment about one aspect of her sense of self.

g. **Premature ageing**

For both participants, there was an assumption that hysterectomy might bring hormonal changes, which would signify early ageing, with the loss of bone density and the need for replacement hormones. There were worries about the longer-term impact of these hormones on health. As illustrated in an earlier quote, there was also the thought that the end of periods, equated with menopause, would mean that they were no longer “productive” (Nadine’s words).

“What about osteoporosis and HRT and complications from that? That you get after menopause, when you’re older?” (Gina)

10.2 Capturing the data – pre-operative group

Themes and discourses drawn from interviews with the pre-operative group are shown below.

a. **Physical effects**

The condition had a profound effect on women’s lives. The physical effects were numerous and included bleeding causing soiling of clothes/bed sheets, pain, anaemia and tiredness, and the effects on other organ systems (e.g. headaches, digestive problems).
"Well at the moment its every ...its every...I only have like a week off, and then I start all over again. I get a real bad headache... And I just feel real drained, me eyes get real heavy and me stomach starts hurting and I'm bleeding. And then the week after, I just bleed. It just floods all the time. And I'm at work and I can't cope with it half the time, they sometimes send me home cos I'm that bad. I'm just drained completely, it just drains me". (Mary, lines 12-18)

"Yeah. I'm like that all the time. And I get real bloated, I feel sick...and then I don't eat". (Sarah, line 202)

The frequent use of 'real' emphasises the reality and seriousness of the effects, as well as implying a need to be believed - one could infer from this that the women were perhaps disbelieved by those around them. The account is filled with the sense of drudgery, and the period problem is referred to as "it", something alien to the women or outside of themselves.

b. The effects of these physical symptoms influenced all other areas of women's lives.

This included ability to work, have a social life, enjoy hobbies or sports, holidays, and their ability to participate fully in family life. It also impacted on coping resources, and was often 'the last straw', making them feel as though they could no longer cope;

"Oh yes, yeah even down to the socialising as well if I don't feel right or if I'm in pain, or um even if I'm feeling bloated and tired I just can't be bothered to go out. Whereas normally I like to go to keep fit classes, yoga - I do a belly dancing class as well - so all these things it annoys me because you're paying in advance for them, so I'm losing money as well". (Tina, lines 115 - 121)

"I never take time off work, I always put my job first, I think they're paying me so I always go to work, umm even when I'm dying!

You struggle in?
Oh sometimes its horrendous and its one of those jobs where you do have to have full concentration all the time. So sometimes I do make mistakes which I’m not happy about. So I suppose it does affect my work as well". (Stephanie, lines 69 – 74).

These behavioural restrictions led to a sense of having to plan life around periods, which was difficult as for many women their was no certainty about when it would arrive. There was often a feeling that in some way, the participants were no longer in control of their own body, but their body was ruling them, and their womb or periods seemed to have a mind of its own;

“When I’m in pain I just visualise it squeezing. Its squeezing me inside. Or twisting. Squeezing and twisting like you’re wringing out a cloth, so it totally distorts its shape, that’s how I see it. And maybe becomes purple rather than being red. So it almost takes on a life of its own then? Mmm, yes. Its certainly completely out of my control". (Tina, lines 467-471).

The language used in the first two quotations gives a sense of diminishment – women’s lives were narrowing – and they illustrated the sacrifices they had to make to their periods (including financial).

c. The emotional effects of these restrictions were evident.

All participants spoke of having to struggle on, despite feeling fed up or low in mood. There was a sense that they were tired, not just in the physical sense, but weary of the continual struggle (‘psychically tired’). There was an acknowledgement that they could not keep fighting – fighting a losing battle;

“Mmm, yes when I’m poorly yes. Cos I push myself to do it cos I think its not beating me, its not beating me, but it does sometimes” (Hilary, lines 118-119)
"Cos I'm getting real fed up with it, and depressed when I'm on, I start crying sometimes, because I'm so low. And I think, I shouldn't be like this". (Mary, lines 316-318).

Mary’s last sentence (above) also illustrates the overall effect of their condition that the women noticed – it prevented them being themselves, which was apparent to those around them. Hopes generally centred around the idea that they would get back to ‘normal’, and this would be evidenced by indicators such as a return to previously enjoyed activities;

“As my husband says, he’d like me back again! Yes.

Yes. So he’s noticed?

Oh yes definitely. The enthusiasm back in me and the energy” (Stephanie, lines 94-96)

“I just want to be back to normal.

Back to being yourself?

Yes...I want to be like me again”. (Stephanie, lines 282-285).

Again, the use of “it” implies an external entity, something to be battled against with all one’s resources. The prevailing discourse was seen to be ‘uncontrollable bodies’, which had taken on a life of their own, or were letting them down.

d. Comparing themselves to how they were before, and to other women

Comparison was used in a number of ways. Firstly, as we have already seen, it was used to compare themselves now to how they were previously. Their image of themselves prior to onset of the problem was used as a benchmark for estimating how serious their current difficulties were.
Secondly, comparison was made with respect to other women, usually of the same age, with respect to their experiences of periods or how they had been after hysterectomy, in order to decide whether their blood loss was abnormal, or whether hysterectomy was the right option;

“Yeah, [name] had it, she works with me, she had hers done six months ago. She seems alright actually, she wasn’t as bad as what I was. But she said it’s the best thing that happened to her. She said, I’ve got no periods, no headaches, nothing. And I think, she’s alright, so I should be!” (Mary, lines 451-454)

Mary’s choice of words “that happened to her” is interesting in its passivity, and could be taken to infer the lack of choice or control over the event women believe they have.

There was sometimes almost a sense of alienation for the participants, for a number of reasons. This could be alienation from most women, as Tina who has decided not to have children felt, meaning she found it difficult to access the usual support networks;

“Yes. Because I’ve not used the helpline myself because I’ve not really – from the details that the people give who are on the helpline, I don’t feel like I’ve been able to match myself to somebody who’s offering that support, because a lot of women have had children before…So you have to match yourself to somebody before you feel reassured that they might be able to support you”. (Tina, lines 342-347).

Or this could be a sense of alienation from the woman’s peer group if they were not experiencing similar problems;

“No because like I said, them at work, we’re all nearly the same age, all of them’s been missing periods, they have for quite a long time. And I’m having more, I have about three sometimes in a month! I’ve never ever missed one, ever. I’ve gained
them, I've never missed them... I know, that's what I can't understand. Why am I like this then?" (Hilary, lines 172-187).

The discourse here is one of difference and abnormality, difference from one's peers or other women in general, with the feeling that their experiences or feelings were not the norm.

e. Assumptions

Some of the participants had difficult experiences with medical professionals, or sometimes (male) friends, family, or employers where they felt misunderstood, not taken seriously, or where more generally assumptions were made about their wishes or feelings. All felt this was a uniquely female experience and so it was difficult for men to understand, and also that medical staff were not trained to deal with the emotional side of things. However, this did not diminish the pain of this experience.

“He thinks I'm nutty when I say that! But I said to him, you're a man, you don’t understand”. (Mary, lines 301-302).

“Because I do know a lot of GP's do fob it off still as just general period pain, which a lot of women suffer with” (Tina, lines 38-39).

“Very professional, medical point of view. And the woman’s feelings have to be taken into account an awful lot.

So not just the symptoms but the feelings as well?

Yes definitely. They look at the medical side of it, but they don’t always look at how the woman feels about it themselves”. (Stephanie, lines 397-401)

Women’s accounts here demonstrate a belief that men and women’s points of view are poles apart, with women’s perhaps being trivialised. This demonstrates the risks women take in asking for help.
Particularly upsetting for most women was the assumption that at their age, with a completed family, and no wish for more children, they would automatically feel happy about losing the ability to have a child.

"Absolutely astounded when he said this! I said oh! He said, considering your age you're past childbearing, you don't want anymore children, I suggest a hysterectomy. And straight away I just said no, I don't want one!" (Stephanie, lines 125-127).

This is discussed further under section j. The predominant discourse running through this section seems to be the invisibility of the individual woman and her voice. She may feel different to the norm, but may be grouped with other women with less serious problems. Stephanie’s quote illustrates the physician making assumptions about her feelings and best interests in the manner of a parent – Stephanie’s refusal therefore sounds almost childlike, as her position as a speaking adult goes unrecognised in the encounter.

f. Choice/no choice

On entering the field, the researcher was interested in the decision-making process and what made women choose to have a hysterectomy. What became apparent during data analysis was that this was not a true choice for most participants. All other treatments had failed or the side effects were unacceptable, and there was a sense of running out of options. This was contrasted with the unbearable nature of their present situation;

"So it just seemed to be an inevitable consequence really of all these years of pain really" (Tina, lines 46 – 51)

Women frequently expressed reluctance to go through with the impending operation, wishing they could avoid such major surgery but acknowledging they could not carry on as they were
now, often using the words "I’ll have to have it". There was a sense of being 'caught between the devil and the deep blue sea’;

“When I think afterwards – oh god! When I go in I’ll ask her [nurse] ... but I know for a fact I’ll have to have it done. Even though I don’t really want it, I’m going to have to". (Hilary, lines 385-387).

Hilary’s language (“have to”) conveys the sense of coercion she perhaps feels, and her sense of powerlessness in the face of perhaps her condition (or medical opinion?).

Listening to their accounts, women talked of becoming resigned to the idea of surgery rather than actively seeking it – a kind of surrender.

“That’s what I want, I just - if I had no more, god it would be lovely. But I don’t think its going to. I know I’m going to have to. [sighs]” (Hilary, lines 466-470).

g. Bewilderment/searching for meaning

Most participants had asked themselves or others, why me? Or, what did I do wrong? There was a sense of injustice, as well as an attempt to search for understanding;

“Yes, yeah. What have we done wrong? I don’t know, I don’t know what it is. I eat healthy as well...but...

Even that hasn’t helped?

No, no. I don’t know what it is.

Is that one of the things, that you’d like to know why?

Why I’m like that, yeah. Yes I would actually, I’d love to know why I’m like it.” (Mary, lines 146-151).

“Because really I do keep fit as well, I do keep myself fit, so and then...when I’m
at work I see people who smoke, and I mean I've never smoked in my life! And they drink real heavy, and there's nowt wrong with them, and I'm thinking, what on earth's the matter with me?" (Hilary, lines 129-132)

The tone of bewilderment stems perhaps from the fact that the women complied with a kind of health morality code, and yet still became ill. Discourses here are that of sin and punishment, with women searching within themselves for an explanation.

h. The meaning of the operation itself

The participants' reluctance to have the operation stemmed from three main sources; firstly the nature of surgery, secondly the recovery period, and thirdly the potential consequences of removing the womb. The first element of the surgery was the short-term consequences of the operation itself, the pain, the anaesthetic, the possibility of dying, the invasiveness of the removal of a body part and the pain of the subsequent scar.

"Just that I might die in the operation.
Right, yes.
Cos you don't really know do you. You know, the anaesthetic and that, things like that – say if owt happens to me while I'm under the..." (Hilary, lines 341-344).

"I'm sure it's the anaesthetic that makes me feel depressed, and I suppose once that's out of your system you can start building up. But, the operation – umm, I don't want a scar, I don't want to wait for that to heal. I don't want to go through the pain"
(Stephanie, lines 37-39).

Hospitalisation and surgery were sources of mystery and therefore trepidation for the women. Hilary's use of "just" (also in her next quote) belies the magnitude of her worries.
There was also a worry that short term pain or discomfort might persist beyond the time they were in hospital, as succinctly put by Angela;

“...if you don’t get better. Well I know you’re going to be poorly. Like the first couple of weeks you feel drained of energy don’t you, but...you know”. (lines 95-97).

i. The inactivity of recovery

All women dreaded the inactivity of recovery, which was seen as almost soul-destroying by some.

“I’m thinking god I’m going to be off three months, and I’m going to be sat there, and I won’t be able to do nowt. I know what I’m going to be like – I get bored anyway!” (Hilary, lines 258-260)

“Umm...and I just can’t bear the thought of being incapacitated for a long period of time. I’m a doer, not for somebody to do for me! I make a bad patient, a really bad patient! So I’ll be frustrated more than anything and I think that is the biggest fear, yeah” (Stephanie, lines 20-23).

Stephanie’s quote illustrates another point which was often expressed by the participants, that of having to switch roles and take on a “looked after” role which was alien for many of them. Dependency was feared.

“I don’t like being waited on particularly – there’s things I know that I do better than [husband] so I’d want to be doing certain things as quickly as possible really. But I know that things like hoovering he’ll have to do for a while, so I’ll leave that up to him”. (Tina, lines 205-208).
There was a general feeling that becoming a patient, and surrendering to the care of others, would be a difficult transition to make and maintain for the recovery period. Again, the women emphasised that this passive or dependent role was not usual for them, that they were usually capable and independent. This may have at least three ‘functions’, to present a strong front to the researcher, to make the listener aware of how difficult the recovery will be for them, and to make it known that this is not their preference. This relates to the earlier ideas of being believed or taken seriously, that they are not ‘swinging the lead’.

j. The meaning of removing the womb

Women also spoke of less immediate concerns which they felt would impact upon them further on into recovery. These were, the loss of childbearing potential, concerns about their sex life, the loss of body integrity, the loss of positive aspects of periods. It was clear that different women placed differing amounts of importance on these consequences.

Regarding children, as previously mentioned, many felt saddened at the loss of the potential to have children. This was despite the fact that all of the women interviewed did not actually want another child. Keeping the choice themselves rather than allowing someone else to take away that choice, even where the possibility of conceiving was very slight, was often important to most.

“Well, the fact that somebody says, you aren’t having any more children. You know, I mean I know, and I know that I don’t want any more children, but the fact that somebody does say that to you does make you think oh, well maybe but....

So taking that choice away from you even though you’ve thought maybe you won’t have any more?

Yes, yes. We’ve already made the decision we won’t have any more, but the choice is being taken away from you should you want to”. (Stephanie, lines 142-148)
For Hilary, the removal of her womb had a spiritual meaning, in that she believed that she would be unable to have children in her next life. Missing out on children meant missing out on grandchildren and having support in her old age;

“Well it would be awful wouldn’t it, because you wouldn’t be able to have children would you. Oh, I don’t know, I think it’s awful. And people who can’t have kids – I mean I’ve had three and I love my bairns, and...I mean they’re grown up now. But I’ve got grandchildren as well, and you...it must be awful not to experience having a baby and having your own children....because you haven’t got a womb, or you can’t have them for some reason. It must be awful, mustn’t it?

You miss out on all...children, grandchildren...

Everything! And you’ve got no family left really have you when you get old”. (Hilary, lines 279 – 286).

Hilary’s words suggest something about the experience of having children as being a defining experience for a woman, as well as having a wider meaning in terms of the continuity of life and preventing loneliness in old age. Her words in particular echo the societal discourse of the ‘tragedy’ of childlessness in a culture which privileges fertility over infertility.

Whilst periods were (unsurprisingly) seen as very negative for most participants, for some there were positive aspects they would miss. Even when periods were not missed, there was an acknowledgement that periods marked time in a familiar way;

“Right. So there’s almost a sense of kind of marking time? The problems with the periods are making time into very discrete slots? Is that something you’ve found? Or is that putting words into your mouth?! No, that is exactly the case. I’ve always kept a journal of my periods – well certainly in the last couple of years I’ve kept a journal”. (Tina, lines 258-262)
"Umm...yes, well having a period actually, we’re that used to having a period aren’t we, albeit that it’s painful. It will seem strange not having one. Nice... but strange!

Umm, if you could keep the periods but lose the pain, would that be an option?

Oh yes, absolutely, yes! To just feel well, that would be fine.

I’m quite interested that you said that, can I ask a bit more about that? What’s the thing about periods that’s good? I mean...

Well there’s nothing good about a period really! But its being a woman, I’m used to it...you know, its in us. We have a cycle, and its something that happens”. (Stephanie, lines 202-210).

Stephanie’s comments include the researcher in a sense of sisterhood through the common experience of being menstruating women – again, this is seen as the norm, and perhaps privileged over being menopausal, etc.

For Stephanie, her period was also an indicator of her fertility and functionality;

“I suppose as well you still know that you’re ovulating, things are still working.

So that period lets you know that you’re still able to have children?

Yes”. (Stephanie, lines 228-231).

The suddenness of the loss of her periods after surgery was also a concern for Stephanie, who noted that during the menopause, she would have time to adjust to the change.

For some, removal of their womb seemed to threaten their body integrity;

“I don’t know. I don’t like the thought of like taking away part of me body”. (Hilary, line 233).

“I think its something sometimes other women say as well, I don’t want a piece of me to be taken out.
Yes. Because then there’s nothing” (Angela, lines 291-293).

The two quotes above return to the passive ‘they take it away’ idea mentioned previously.

It may be that worries about body integrity were linked to worries about sex. Women found this more difficult to talk about, and tended to focus on worries about physical ability to have sex, although some mentioned desire and desirability to partner.

“But umm, I was reading something and you actually – there’s your vagina and your cervix and they cut it away, take your cervix away and then you’re sown up aren’t you?. Will it still be OK afterwards for sex?” (Stephanie, lines 238-242)

The overall sense for this section was of fears of endings – fertility, periods, sex, familiarity.

k. Partner

Women spent little time talking about their partner or their views on hysterectomy. Most spoke of their partner worrying about them now, or the support that they would need from them whilst recovering. Although all were asked “Will your partner see you as the same or different after the operation?”, most did not know or replied using “I think…”, in a way which suggested they had not discussed it fully together;

“Oh, he’ll just think I’m the same, yeah, I’m sure he will”. (Stephanie, line 238).

“He’s optimistic about the surgery but I think he’s probably worried about how I’m going to be afterwards, because he does understand that it is major surgery” (Tina, lines 133- 135).

There was a feeling for some women that if their relationship changed for some reason, and they met someone else, the capacity to have children might then become important;
"Probably the only one thing is, and you can't anticipate how you feel in the future, I suppose it would be around kids. I mean if I had a, for whatever reason, if suddenly my relationship changed, that could … Because I've been married previously, and my first husband always said he wasn't bothered about children, but when I left him, and he took up with somebody else, the first thing he did was get her pregnant. So I doubted that he was telling me the truth initially". (Tina, lines 620-625).

This seemed to express the idea that the participants thought that childbearing potential or having a womb - fertility - might be important to some men, and locates fertility as the cultural norm for women.

1. Doctor-patient relationship

All participants identified the need to trust the surgeon. A number of aspects were key to developing that trust, which included length of relationship, knowing who would perform the operation, feeling he would take time to listen, ability to give information and be perceptive to feelings, and see the patient in a holistic manner. All these, plus the reports of others, impacted on their view of the surgeon's competence and the likely degree of care he would take.

"The whole person rather than just the medical. And I think that would help, if they could look at that, if they could treat you as a person. So if they're dealt with as a person instead of patient number 84. Yes". (Stephanie, lines 430-437)

"I've built up a trusting relationship with him. That is the only other area of concern that I've got, that it might be someone who doesn’t know me, doesn’t look after me as well". (Tina, lines 168-170).

"I'd like to meet the person who's doing it, know exactly what they're going to do" (Stephanie, line 371).
Participants were again struggling to be seen and heard as individuals, as people and/or as adults. The surgeons were seen to have particular responsibility for the relationship, as they were the most knowledgeable about the procedure and about the women's conditions.

m. Coping strategies

Women described three main coping strategies which they used to deal with their periods, and two of these were mentioned with regards to recovery. The first of these was willpower, where they simply used sheer determination to cope;

"I'm determined to get over it – I think you've got to be positive think positively about it. It's a worry, and I'm not looking forward to it, but I'm going to get over it, as thousands have. So I've got to just think like that really.

Sort of go at it, go get it, get better?

Yes, I'm not going to let it get to me really" (Stephanie, lines 266-270)

The second of these was the use of medication/alternative methods for pain relief or to lift mood. Many used exercise to help maintain their emotional health on a day to day basis, and most felt that the inactivity of recovery would be difficult emotionally. However, no-one seemed to have concrete plans of how they would spend their time whilst recovering.

There is a return to the battle metaphor to describe how they would get through recovery, and the problems of recovery are seen as another 'it' to be battled against. The sense throughout is of a continuous struggle – fighting the condition, fighting to be seen and heard, and fighting to get well.
Threats were derived from written material and interviews with 2 women prior to their operation.

a. **Physical and practical effects of the condition**

Similar to the pre-hysterectomy group, the participants described the debilitating effects of their conditions on their health, emotions and general life. There were severe restrictions on where they went, what they planned, what they wore and so on, such that they planned their lives around their periods.

"I've become obsessed by it. Because if you're having a period that lasts about two and a half weeks, and there's like gallons of it, you know, you continually have to be like dealing with it. You get this little clots and floods and stuff like that, so all the time you're thinking, as I walk along is this just going to come down into me shoes... it rules out tampons and things like that and you end up with these things, and you feel like you're wearing a nappy all the time. Its horrible...typical sanitary wear doesn't work for the worst time". (Elaine, lines 112-120).

The quote from Elaine's interview illustrates the complexity of the effects of heavy bleeding, which need consideration. The women felt they had to wear clothes which could disguise bulky sanitary wear, bags which could hold clean and used sanitary wear since there may be a disposal problem, be able to access toilets quickly, and be constantly alert for flooding which might cause social embarrassment. These feelings of embarrassment were a result of the stigma/taboo associated with the condition;

"And I think as well, like err like I said the thing that like supposing, supposing I like a scar, and I knocked a scab off and started to bleed onto my clothing, people would sort of rush
and help, umm but if I, if I were to have an accident and menstrual blood were to come on me clothes or anything, when I stood up everyone would be like, ugh! Horrified, you know, and its err got this kind of taboo around it if you like”. (Elaine, lines 14-17)

The tension of dealing with the period seemed exhausting, and came on top of the tiredness caused by the condition itself;

“I just feel absolutely drained every day really” (Ellen, lines 32-33)

b. Emotional effects

The restrictions on life and constant fear of embarrassment, the draining effect of the problem were all seen to result in lowered mood or self-esteem by the participants;

“You’re getting quite fed up as well as feeling physically tired? Yeah. I do yeah! It just doesn’t stop! I think I’ve only had one day where it stopped and I thought “oh good!” But it hadn’t”. (Ellen, lines 42-47)

“So objectively there is nothing wrong with me … But this undermining is sort of what you think about you know when you get depressed as I say, and just after a stupid little comment in a TV program…But I think well perhaps its all true then”. (Elaine, lines 422-427)

For Elaine there was a feeling that her period problems were a trigger for distress about other things;

“I felt sort of helpless and dependent and needy and that kind of thing. And I think I went through a period of grieving for me divorce which I’d not actually done so far, I think it triggered a lot. You could say that was always waiting to be triggered by a big event anyway. So I had a lot of depression around that” (Elaine, lines 442-445).
c. Searching for meaning

This relates to the women asking questions such as why me, what did I do wrong, and what's causing this problem, as illustrated by Elaine;

"I'm kind of worried about the underlying problem – if I've got fibroids then that's that, womb tissue that isn't doing anything, excess tissue is a cancer worry, and also with my ovaries producing all the hormones all over the place, will that give me breast cancer in two years time or something?" (Elaine, lines 164-167)

d. Running out of options, but still having a choice

The women felt that they were running out of treatments, their conditions were worsening or becoming unmanageable with the towels available. They could not think clearly about the longer term until the bleeding stopped which would buy them time to consider whether or not they wanted a hysterectomy, or to let them deal with other life events;

"The doctor who I saw – he just said, oh if it doesn’t work, this is like the last thing I can try before your hysterectomy… But he didn’t want to do it now, plus as I said I couldn’t have one at the minute with me husband as he is. (Ellen, lines 108-111)

"Its only recently as I’ve been coming up to it that I’ve been thinking about afterwards. I was so focused on getting the intensity of the symptoms stopped that you don’t care about the long term" (Elaine, lines 205-206).

e. Changing view of themselves

The women interviewed expressed their dislike of the change in themselves or how they felt perceived by others due to their condition, and in how they would be during recovery. There was a feeling that they had changed from being independent women, with responsibilities/caring
for others to feeling “helpless and needy” (Elaine’s words). There were worries about having to become a patient or allow themselves to be cared for after the operation;

“I can’t do nothing for so long – I mean I don’t know how long you can’t do anything for – but, he said, oh, we’ll get by, but I said, no, you know what I mean? You can’t – I can rely on my mum, but I’m that type of person what can’t expect somebody to do everything for me, you know what I mean?” (Ellen, lines 326-329)

The women seemed to see themselves as copers, who got on with life by being determined. They sought information about their condition and treatment, and it was only when they perceived their problem to be undermining their ability to cope and to fulfil their normal roles that they decided the operation was needed;

“I’ve got to be strong for my husband and my son, he’s only just turned thirteen and his dad’s been poorly since, well he’s been poorly for twelve years, but he’s been poorly since last February, getting on for a year now you see. So, I’ve got to go different places, he’s got to go to Sheffield like and that, so I’ve got to be well set for me to do that, do you see what I mean?” (Ellen, lines 35-39)

f. Comparison

Comparison with their self as they were before, and with other women’s success stories were used as cues for the operation;

“The woman on the program sounded like me and she was a nurse. She was like changing every ten minutes, which must have been really difficult for a nurse, what with lifting and stuff cos that makes it worse. And umm she sounded just like me and it seemed to be working for her though it was early days. And then when I told my friend I was having this
done, she told me that [name]... had had it done and it had worked for her (Elaine, lines 35-39).

There was also a need to avoid becoming a negative stereotype;

“I don’t want to get into cabals of women talking about it ... what I mean is I see cabals of women and I feel that they want to draw me into these things. So I only talk to people who I know won’t draw me in, its not become a way of doing life. Gynaecological troubles you know. I don’t want to be that, its just horrible” (Elaine, lines 469-472).

g. Reluctance

Both women expressed some reluctance regarding the operation, and negative perceptions of hysterectomy. Their reluctance centred around a number of concerns — concerns about the actual operation, recovery, ending the choice regarding children, ageing and loss of attractiveness, concerns about relationships.

Worries about the operation itself included wondering whether the operation would be successful, pain, dying, the invasiveness of the operation or needles, and complications such as incontinence. For Elaine the worry about bleeding to death was associated with horror stories from illegal abortions;

“...I did have strange thought when [consultant] said to me I said can I go home on the same day and he said yes probably, unless I puncture your uterus which is ... But I always associate puncturing of uterus with like illegal abortions where you bleed to death and die. And I thought am I going to die?” (Elaine, lines 494-496)
Both participants noted that they had not chosen a hysterectomy because it was so radical and required a longer hospitalisation, which would result in longer spent being a patient – an unfamiliar role which was almost feared, as discussed earlier.

Both participants spoke with some slight sadness about ending the possibility of having children, although for Ellen this was something she'd already decided when she was sterilised after her husband became seriously ill;

“As I say, I’ve, we’d decided not to have any more children because of our circumstances, so no, its not as if I think it’s a final thing now. No”. (Ellen, lines 120-121).

For Elaine who had no children, she would no longer have that opportunity;

“Err I’ve got no children, and this will end that. Now I’m not really bothered but it won’t be a choice any more, it puts an end to choice. But that’s a complex life decision, so I will feel that a choice has gone” (Elaine, lines 183-185).

The loss of the ability to have children seemed to be bound up with thoughts of ageing and loss of sexual attractiveness, in their own and societies eyes;

“You think has it dulled my sexual attractiveness and that kind of thing. I became hyper sensitive to people referring to - you know you read in magazines that life begins at 40, and lots of women looking really good. I was really neutral to them, I mean its neither here nor there whether they are 40 or not, I don’t think about it. And I felt then well perhaps you are unattractive to men at a certain age”. (Elaine, 400-404)

“So these are the images which go through me mind like I’m finished, that its irreversible”. (Elaine, 412-413)
This also illustrates the idea that after endometrial ablation or hysterectomy, forming relationships with men may be more difficult. Women who could not have children may be seen as unattractive or incomplete – indeed Ellen was advised not to be sterilised in case her husband died and she wished to remarry. Elaine, who was divorced and in a new relationship illustrates her dilemma;

“I don’t think men who are in long term relationships who’ve perhaps had there kids will see it as a big deal, they’ll see it as, the womb has done its job, lets get rid of it kind of thing. But I don’t think it’s a good – I just would not tell anybody I was in a new relationship with. I wouldn’t tell them at all. Cos I don’t think there can be a good outcome from telling them. Best just to leave it”. (lines 254-258)

h. Needing to trust the surgeon

Like the previous group, the women identified the need to trust the surgeon, along with similar characteristics required, such as listening, giving accurate and honest information, seeing them as a whole person not a set of symptoms, and involving them in the process. Elaine was quite clear about what she did not want;

“This guy came out with like a bow tie on, I thought this is like a piece of theatre, a drama starring the consultant, because it was all so stereotyped and everything, I thought you could just get an actor to do that! [laughs] So I sometimes think they’d rather play to the gallery than just get down and talk to you, and that just annoys me” (Elaine, lines 323-326).

As well as being clear about what she did want:
"I need to be involved in the process. I'm not a doctor, but I am ... I do have a PhD in science, I do have a higher level educational job and I feel that I am, and they should be able to interact, even if you've got an IQ of 70 or whatever. They should try and get to the right level...I expect to be treated as an equal, I don't see it as an unequal relationship, we just have different expertise's" (Elaine, lines 90-93).

Both women had had experiences where they felt misunderstood, not taken seriously or their wishes were not respected.

i. Improvements

Both women expressed ideas which they felt would improve the service they received and the information available. This included normalising the condition through providing information at well woman clinics or family planning clinics. Someone to talk to, preferably a female nurse who was trained in both medical and psychological issues, and who was available after appointments with the consultant. There was a recognition that the consultant was busy, and that as a man, it would be difficult to talk to him about some issues;

"I think it could be a man, but in general a woman might understand it more in terms of perceptions of sexual attractiveness to men, it would be difficult out talk like that to a man. A woman might be better. They know as well all the difficulties of sanitary towels and everything as well

Without you having to explain?

Yes, yeah". (Elaine, lines 542-546).

There was a feeling that due to the stigma and hidden nature of the condition, technology to deal with it was not very advanced, and there was no advice regarding products or treatments and so on. Both women felt that they needed to information from nurses and other women about what to expect from their treatment.
10.4 Capturing the data – themes from post-operative group

These themes are drawn from extensive written and interview material with 5 women between 3 months and 4 years post-hysterectomy.

a. Effects of condition

For the participants in this group, the effect on life of menstrual problems prior to the operation was also huge. This included flooding and soiling, anaemia and tiredness, and the effect on ability to do their job or enjoy life. In short, it was seriously impairing the quality of their lives:

“Yes it was affecting my life the first two or three days of each period I was absolutely hopeless at work I was like a zombie I had to drug myself up with pain killers and felt so ill and so crippled up with pain I could hardly function” (Esther, p8)

“I was bleeding for about 2 weeks out of four, and for about a week a month I was having to get up in the middle of the night and do silly things like go and sit in the shower because it was like somebody had turned a tap on” (Emma, lines 11-13)

Emma described her quality of life “narrowing by inches”, all the while impacting on her coping resources (see later).

b. Fear about underlying reason

A couple of women expressed fears that either pre-operatively or when their uterus was sent to pathology, that their condition may have been a symptom of cancer;

“So you’re always wondering about that, is there more to it” (Emma, line 184).
c. No other option

All reported that they were told or felt they had run out of less radical options, and that hysterectomy was the only treatment left. Most women expressed the idea of giving in or resignation to having the operation;

"I never thought that I would have any other choice apart from hysterectomy" (Tina, written material)

"That this was the only option and at the time I was feeling so grim I thought well maybe they’re right. Maybe this is the only option and I’m going to have to do it" (Emma, lines 65-66).

d. Reluctance

Four out of the five participants expressed reluctance about having the operation, with the other expressing excitement, because she felt that she would finally feel better. Reasons given for reluctance varied according to what was important for each women, but can be summarised as concerns regarding losing the womb (discussed further later) and concerns about having a major operation. The latter included worries about paralysis, dying, instruments left inside, and so on, and only became current in the run up to the operation;

"I know that the uterus has a role in hormone production, it has a role in all sorts of things that I was unwilling to relinquish it, let alone have my ovaries and cervix and everything else removed as well" (Emma, lines 54-56).

"Oh I was scared of pain, I'm a bit of a baby about it I suppose really, I was really worried that when I woke up after the operations that it would really hurt terribly and I was worried how I would cope with the pain" (Esther, p8).
Feeling unprepared

Most participants felt unprepared for some aspects of recovery. Whilst many had anticipated/ prepared for post-operative pain and being out of action for 3 months, many felt entirely unprepared for the length of time it took to 'get back to normal'. Two participants said this took 2 years. Participants felt **frustrated** with their lack of progress in certain areas, e.g. regaining of full fitness, adjusting to the scar, and so on, which seemed to **knock their self-esteem**. The hopes expressed were typically a wish to ‘return to normal’, and when this was not met within the expected and sanctioned 3 months, participants felt devastated and believed that this feeling was **permanent**;

> “Sometimes when I felt that the scar wasn’t getting any better and I would never regain abdominal muscles...I used to get quite fed up, but I tried not to dwell on it...I would have thought that twelve weeks would be it and on many levels it was. But I wasn’t back to feeling the way I felt before surgery for two years. And I wasn’t prepared for that time scale at all” (Emma, lines 281-286)

> “I am afraid I am going to feel like this forever. If so, I wish I hadn’t had the op” (Sally, written exercise)

Related to this was the **lack of appropriate information** mentioned by several women, relating to what they might expect, e.g. effects on their sex life, how to stagger a return to work and so on. One participant described herself as feeling “misled” about how she might feel post-operatively. There was a feeling that **other women’s accounts** could help prepare and **normalise** how women were feeling.

Fears and worst aspects post-hysterectomy

The most difficult things for women to adjust to were usually related to their **fears** prior to the operation, or **aspects of their life** which were **central to their emotional wellbeing**. These
differed from woman to woman, but included the scar or appearance of stomach, loss of childbearing ability, inactivity/loss of fitness, sexual enjoyment.

“I am very active - I was so restricted with what I could do for so many weeks that as I look back I realise I lost confidence. I lost the physical confidence to do things and it made me lose confidence generally” (Esther, page 3)

“[re:scar]I felt disfigured. Yes disfigured” (Emma, line 348)

What was most striking was that the finality of removing their womb and ending fertility, coupled with physical frailty or appearance after the operation made participants feel prematurely old. This was often bound up with feelings of a loss of attractiveness, which contributed to any relationship or sexual difficulties;

“You have got this ugly scar on you, and you're walking about like an old lady. I mean you are not very attractive to your partner like that are you, and you don't feel physically attractive. So that takes a lot of time to get over, you don't just suddenly get better in a day or two” (Esther, p15)

“I felt ugly because I had this great wound across there and you go in the bath and look at yourself - Oh God that's awful. I hated having this great wound there, I felt quite ugly to look at” (Esther, p12).

g. Feeling changed

This feeling of having prematurely aged and lost attractiveness, along with needing a great deal of support in the first few months post-operatively, meant that participants felt changed. The way their body felt, looked and responded had changed, and consequently their sense of their own capabilities changed. There was a fear that this change was permanent, and even if things improved, that they would never again ‘be themselves’ in the way they had been prior to the operation.
"No that was a big concern as I was recuperating, oh god what’s this done to my sex life. And it wasn’t quite as bad as I’d feared although initially I thought, no, this is not how it used to be. It’ll be sad if it’s going to be like this forever… I guess like many other things you relearn things. You make new neural connections so it’s not bad – but its not as good as it was. And that is a bit sad”. (Emma, lines 377 – 382)

“I didn’t feel the same person because I wasn’t doing the job as well as I could, because of that I lost a lot of confidence” (Esther p5)

“It changed my shape as well and that really bothered me. I’m quite proud that I still had my slim figure, its my one attribute - I thought at least I have got a slim figure if nothing else. Then it changed my shape, because the muscles go very slack above the scar area. I was really self-conscious because I thought I had a pot belly above where the scar was”. (Sally, written material).

h. Long term view of benefits - resolution

For most participants, it was only as they began to adjust to their operation and its effects that they began to appreciate the benefits of being without their menstrual problems. These included more energy and enthusiasm, better health in general, freedom to carry on with their lives unhampered, and greater coping resources to help them deal with life events;

“I didn’t actually feel happy about not having a period - I don’t think I felt the benefit of that for a good year or so afterwards. It was only when I started to feel really well and back to normal that I thought, Hey I haven’t got the periods either, this is great! But I didn’t feel the benefit for a long time” (Esther, p12)
L Lingering sadness

Whilst it was apparent that the women did adjust to the impact of having a hysterectomy over time, they talked about being left with a ‘lingering sadness’ (Emma’s words) for the changes and losses they went through. This is best illustrated by Emma and Esther’s words:

“Yes it was the final closing of doors. You have to look at it in other ways - it may be the ultimate freedom from all sorts of concerns and worries” (Emma, lines 572–573)

“In the darkness of the night you feel emotional - Oh I have no womb, I can never have another baby. I’ve no choice in it any more. But then my daylight voice says don't be silly because you weren’t going to have any more anyway. But you are just conscious of that, there is a little tiny bit of sadness there”. (Esther, p24)

j Wishes and feelings misunderstood/not respected

Like previous groups, participants reported instances where their wishes/feelings had been misunderstood, or worse, trivialised. They were understandably angry at this response to their feelings, or felt guilty for being ‘weak’.

“I said to my GP ‘ugh the scar’ and cried. He said lets have a look, and he said you realise you’re being perfectly ridiculous! Which made me feel about nine and very silly. But it still didn’t help the fact that I felt bad about it” (Emma, lines 234-237)

“Once I had my three months sick leave people expected me to go back and be as normal. They were not tolerant at all that you might be emotional or a little bit weak, they just don't want to know” (Esther, p18).

There was a feeling that men and partners may not appreciate the full implications of the operation
“I feel he is wanting me back to my ‘normal’ independent self very quickly” (Tina, written material)

“I’ve never seen myself as a rabid feminist, but I do not think that men can appreciate how it feels. And therefore I don’t think they are in a position to go around being bracing and robust” (Emma, lines 504-506)

There seemed to be an expectation that recovery only required enough effort. This linked to their coping strategies prior to the operation, of struggling on regardless of pain, tiredness, and so on.

k. Ending recovery, taking up the reins again

Whilst some found the inactivity of recovery difficult, such as Esther, who felt unstimulated and that the inactivity lowered her mood, most women enjoyed the time off and easily filled it. However, all agreed that returning to work once more was difficult;

“If you have three months off work, to go back to working full time after having 3 months off is a big jump, and that's what I didn't have any help with. It should have been a staggered return to work or return to work on light duties with a gradual build up” (Esther, p17)

For Tina, her time off helped her re-evaluate her job and decide to look for a different one which was less stressful.

l. Medical staff

Medic’s came in for a mixture of criticism and praise. Staff who took a client-centred approach, who took time to explain and listen were trusted. Those who made assumptions, or as in Emma’s case, seemed reluctant to address questions came in for criticism :
"Because I said to him at one point straight up, how's it going to affect my sex life, and you could see him sort of gulp! And he sort of blurted out 'well there's been some Scandinavian research — gulp'..." (Emma, lines 116-118)

Emma also felt that surgeons' personalities predisposed them to radical interventions, to promoting hysterectomy as the preferred option, and that to an extent women collude with this;

"I think the thing that is irritating is what I call the assumed and received body of knowledge that this is the only treatment. And of course you have to have this, you're mad if you resist having it. Or you know don't you realise that your quality of life would be much better etc etc. And then you say what aspects of the quality of my life are we talking about? Because what might be the quality of my life might not occur to you" (Emma, lines 500-504)

"I felt very tempted to say to the gynaecologist, how would you feel if I came along and chopped your balls off?...I felt under male establishment pressure. I felt that there were a lot of women colluding with this pressure, that once you reach a certain age and you've had your kids, this is a totally redundant organ" (Emma, lines 49-53)

10.5 Links between participant groups

Table 1 overleaf shows the extent of crossover of themes between groups. There are many similarities between the groups. The most striking similarity is the "no choice" theme for all but the endometrial ablation group, which disputes the decision-making hypothesis made. Comparable categories for the three surgical groups emerged for 11 out of the 13-15 total categories for each group, with similarities in most subthemes.

An apparent difference is the non-surgical group's identification of fears around the meaning of removing the womb, similar to the surgical groups, but only noting scarring in relation to actual
operative fears. In contrast, the operative groups identified a number of such fears including
dying, pain, anaesthesia and so on. This suggests that as the operation approaches, worries shift
to more immediate concerns, and perhaps even overpowering longer-term fears.

A hypothesised difference was that endometrial ablation patients would identify keeping the
womb as important, perhaps for self-concept. However, changing view of self emerged as a
theme related to their condition for both pre-operative groups, rather than an operative fear for
one group. There was a sense that the length of recovery and actual surgery were of more
significance than feelings regarding the womb.

The post-operative group themes were important in confirming that the most difficult aspects of
hysterectomy were the feared aspects of hysterectomy, although some were not anticipated.
These included recovery (although none were prepared for the length of time required for
emotional recovery), loss of childbearing ability, concerns regarding sexual enjoyment, feelings
of ageing and loss of attractiveness. Most groups felt these feelings of loss would be permanent,
but those furthest from the operation noted that after 2 years, they had for the most part adjusted
to changes. What they had been unprepared for included scarring (Emma & Esther) and the loss
of physical mobility (Sally & Esther).
<table>
<thead>
<tr>
<th>Non-surgical group</th>
<th>Pre-hysterectomy group</th>
<th>Endometrial ablation group</th>
<th>Post-hysterectomy group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical effects</td>
<td></td>
<td>Physical &amp; practical effects of condition</td>
<td>Effects of condition – quality of life</td>
</tr>
<tr>
<td>Influence on other areas of lives, Body ruling them</td>
<td>Planning round periods</td>
<td>Emotional effects</td>
<td>Depleting coping resources</td>
</tr>
<tr>
<td>Emotional effects - Prevented them being themselves Hoping to be back to normal</td>
<td>Emotional effects</td>
<td>Undermining ability to cope</td>
<td></td>
</tr>
<tr>
<td>Fighting a losing battle</td>
<td>Running out of options</td>
<td>Stop the bleeding to buy time</td>
<td>No other option – resignation</td>
</tr>
<tr>
<td>Not a true choice - Running out of options</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reluctance – Resignation / surrender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison – themselves previously &amp; other women</td>
<td>Comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sense of alienation</td>
<td>Changed view of self</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not bad enough</td>
<td>Assumptions – being misunderstood or not taken seriously</td>
<td>Being misunderstood</td>
<td>Wishes/feelings misunderstood/ not</td>
</tr>
<tr>
<td></td>
<td>Assumptions about losing the ability to have a child</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Comparison of themes from each group
<table>
<thead>
<tr>
<th>Respected</th>
<th>Searching for meaning</th>
<th>Fear about underlying reason - cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bewilderment/ searching for meaning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Why me? What did I do wrong?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>searching for meaning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Searching for meaning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scar – wound, body image</td>
<td>The meaning of the operation itself</td>
<td>Reluctance about actual operation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reluctance – major operation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Scar, appearance of stomach</td>
</tr>
<tr>
<td>Worries about recovery</td>
<td>The inactivity of recovery – Switching roles</td>
<td>Reluctance – recovery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feeling changed</td>
</tr>
<tr>
<td>Premature aging</td>
<td></td>
<td>Inactivity &amp; loss of fitness</td>
</tr>
<tr>
<td>Sexual Attractiveness/desire</td>
<td>The meaning of removing the womb</td>
<td>Ending choice re: children</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of childbearing ability</td>
</tr>
<tr>
<td>No possibility of children</td>
<td>Loss of childbearing potential</td>
<td>Ageing and loss of attractiveness</td>
</tr>
<tr>
<td>Changes in femininity/womanhood</td>
<td>Concerns about sex life</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Body integrity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Loss of positive aspects of periods</td>
<td>Loss of childbearing ability</td>
</tr>
<tr>
<td>Partner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fertility important to men</td>
<td>Concerns about relationships</td>
<td></td>
</tr>
<tr>
<td>Trusting the surgeon</td>
<td>Needing to trust surgeon</td>
<td>Medical staff – criticisms</td>
</tr>
<tr>
<td>----------------------</td>
<td>--------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Length of relationship, Knowing who will perform the operation, Taking time to listen, Giving information Perceptive to feelings, Holistic view of the patient not the problem, Competence and care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Willpower, Medication &amp; natural remedies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improvements – information Normalising, someone to talk to</td>
<td>Feeling unprepared – lack of appropriate information</td>
<td></td>
</tr>
<tr>
<td>Frustration, knock for self-esteem, permanency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long term view of benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking up reins again</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lingering sadness</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Two interviews from the pre-hysterectomy group were second coded by a female clinical psychologist with experience of carrying out qualitative research. The analysis was carried out blind to the background literature and to the aims of the study. The crossover of themes is shown below in table 2:

Table 2: Comparison of researcher and second coder themes from pre-hysterectomy interviews

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Second coder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical effects</td>
<td>Physical strain</td>
</tr>
<tr>
<td>Influence on other areas of life</td>
<td>Limitations</td>
</tr>
<tr>
<td>Emotional effects – stopping them being themselves</td>
<td>Feeling like not self</td>
</tr>
<tr>
<td>Hoping to be back to normal</td>
<td>Positive expectations/hopes</td>
</tr>
<tr>
<td>Fighting a losing battle</td>
<td>Feeling defeated</td>
</tr>
<tr>
<td>No true choice</td>
<td>Running out of treatments</td>
</tr>
<tr>
<td>Reluctance</td>
<td>Difficulty in decision</td>
</tr>
<tr>
<td>Comparison – self before and other women</td>
<td></td>
</tr>
<tr>
<td>Assumptions – being misunderstood / not taken seriously</td>
<td>Need for support / understanding</td>
</tr>
<tr>
<td>Bewilderment/ searching for meaning</td>
<td>Why am I like this? Making sense of it</td>
</tr>
<tr>
<td>The meaning of the operation itself</td>
<td>Fears of the operation</td>
</tr>
<tr>
<td>The inactivity of recovery – switching roles</td>
<td>Fears of the consequences of operation</td>
</tr>
<tr>
<td>The meaning of removing the womb</td>
<td>Changes in self &amp; identity</td>
</tr>
<tr>
<td>Loss of childbearing potential</td>
<td>Being unable to have children (choice taken)</td>
</tr>
<tr>
<td>Partner – fertility important to men</td>
<td></td>
</tr>
<tr>
<td>Trusting the surgeon</td>
<td></td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Alternative ways to improve condition</td>
</tr>
</tbody>
</table>
A high degree of crossover was obtained between researcher and second coder, with crossover for 9 out of 12 main categories and some subthemes. This gives confidence that themes emerged from the data itself relatively unaffected by the researcher's biases, and form a trustworthy data summary.

10.7 Links between themes/ categories

Links were made between low level themes and ideas about discourse for the pre-hysterectomy group, and are shown diagrammatically in figure 7 overleaf. Many of the themes seem to converge around ideas of being out of control, helpless and dependent, or the ideas of difference/ not being 'normal'. Much of the discourse seems to be around not being heard/ seen, which strongly relates to feeling out of control, helpless & dependent. These ideas are discussed in more detail in chapters 11 & 12.
Figure 7: Illustration of links between low-level categories

- Effects of condition – physical & effects on life
- Coping strategies – willpower, exercise, medication
- Emotional effect
- Searching for meaning – self blame
- Fighting (but failing) – the uncontrollable body
- Not being seen/heard – lack of choice
- Assumptions
- Doctor-patient relationship
- OUT OF THEIR CONTROL
- HELPLESS & DEPENDENT
- Recovery
- Endings?
- Fears of surgery
- Removal of womb
- NOT 'NORMAL'
- Worries about partner
- Comparison & difference – to previous self & other women
DISCUSSION

CHAPTER 11

MAIN FINDINGS
11.1 Summary of main findings

This section focuses on an amalgamation of themes and discourses from the different groups of women. ‘Women’ should be taken to refer to the women in this particular study, as conclusions can only be drawn in relation to those studied. A more general discussion in relation to the research aims and wider considerations follows in chapters 12 & 13.

11.2 Effect on women’s lives – the uncontrollable body

Menorrhagia has a profound effect on women’s lives and self-esteem. These effects were extremely close to those found by Marshall (1998) in her qualitative study of menorrhagia (e.g. staining, restriction, effect on roles, sex life, tiredness etc).

Women may feel as though they have lost control/mastery over their body, and as though this is “not me”. The need for control and mastery is thought to be a fundamental human drive (Rubin & McNeil, 1983; White, 1959), and control over one’s body is seen as crucial in self-esteem (Fox, 1997). Perceived ‘locus of control’ (Rotter, 1966) has been demonstrated as important in adjustment to stressful events, according to the attributional theory of motivation and emotion (e.g. Abramson & Martin, 1981; Weiner, 1996). Women’s accounts gave indications of changes in how they viewed themselves prior to hysterectomy, as a direct consequence of the effects of their condition. This suggests that literature assumptions regarding hysterectomy alone as a destabiliser for self-concept may not paint the full picture. It is interesting to compare this section with themes from Dell & Papagiannidou’s (1999) qualitative study, who suggested that the hysterectomised body is seen as disembodied from the self; i.e. women feel they still have no control over their bodies even after surgery.
11.3 Fighting but failing - surrender

Women awaiting hysterectomy feel as though they have run out of options and run out of coping resources. As menorrhagia becomes unmanageable, women are no longer able to utilise an appropriate and effective task-oriented response (Carson & Butcher, 1992; p147). The result is a sense of disempowerment, that they have fought to the point of exhaustion using all their resources, yet have still failed. Women described “giving in” or “having to have it” in speaking of hysterectomy, all reminiscent of coercion, lack of choice and the word “surrender”. Studies have shown that some relief from intolerable situations can be gained by ‘admitting defeat and withdrawing psychologically from the fight...[but] at the expense of a sense of adequacy and self-esteem’ (Carson & Butcher, 1992; p405). Hysterectomy therefore, despite its promised benefits, is perhaps an unwelcome symbol of that ‘failure’ to cope, impacting on self-esteem. The literature shows that perception of lack of choice (closely allied to control), is liable to result in poorer adjustment to life events (Field, 1993).

11.4 Searching for meaning – self-blame

For most participants there was a search for a reason or answers, relating to a fundamental human need to explain. Uncertainty, or the lack of an attribution (whether positive or negative) may serve to increase the stressfulness of a situation, since it allows free rein to our imaginations to think the worst (Brody, 1995; Gross, 1996). The language used by women throughout their accounts is reminiscent of that used in cancer where the prevailing image is of fighting an invader (Bailey & Clarke, 1989). One could therefore argue that the lack of a causal explanation for their condition meant that the fear of cancer underlay the search for meaning. Indeed, Nadine speaks of this in her account, suggesting that an “internal cancer” (i.e. of the reproductive organs) is perhaps more feared than other types of cancer. This is pointing to something fundamental about these areas of the body for women (and perhaps men for their correlate).
Women’s examination of their own behaviour as a possible cause for their condition is suggestive of an internal locus of control (Rotter, 1966), and many also gave accounts of health behaviours carried out in order to stay healthy. Clearly, some women in the study felt responsible for their illness, and asked “what did I do wrong?”, echoing the self-blame found in depression and low self esteem. Commonly, depressive self-blame occurs when a ‘failure’ is perceived to be under internal control (Abramson et al, 1978). For women with an internal locus of control, and high expectations of managing their menorrhagia themselves, the realisation that they can no longer manage (need treatment) may have more devastating consequences than for women with an external locus of control (i.e. the belief that the physician will manage their condition).

The ideas of self-blame may also be linked to wider discourses, such as the prevailing ideology of individualism in Western cultures (Fox, 1997), as well as the position of women in society. The former refers to the cultural norm which holds the individual responsible for their own actions / situation – this is particularly so in terms of the body where health messages constantly exhort us to eat well, keep fit, and so on. Women asking ‘what did I do wrong’ may be seen to reflect discourses of blame which have been the traditional lot of women.

11.5 Reducing cognitive dissonance

As already mentioned, women do not seem to actively weigh up pros and cons for the operation, instead coming to feel resigned to hysterectomy as their only option, whilst still feeling extremely reluctant. This reluctance may outweigh the benefits of hysterectomy for quite some time, even when women feel they can no longer cope with menorrhagia. This provides almost textbook examples of what have been termed ‘avoidance-avoidance’, and ‘approach-avoidance’ motives in stressful situations (Gross, 1996; p137). That is, for many of the women, either both options open to them (continuing as they were versus a hysterectomy) were undesirable (avoidance-avoidance) OR the solution (hysterectomy) contained both desirable and undesirable elements (approach-avoidance). Thus hysterectomy was a ‘no-win’ situation.
As hysterectomy approached, most then attempted to justify the surgery, in a process akin to reducing cognitive dissonance (Festinger, 1957). Fears were contrasted with how bad things were now, and positive accounts from other women may also be used to ‘convince’ themselves that this is the right option. This seems to form part of the process of adjusting and accepting the operation, adjusting perceptions of a loss of control to more acceptable accounts of it being the ‘right decision’.

11.6 Unfulfilled Hopes – anger and disappointment

The most commonly expressed hope was to “get back to normal” through having a hysterectomy. Research shows that when women feel ‘not normal’, ‘there may only be a social stereotype to draw from. When the stereotype is negative, self-esteem is threatened’ (Singer & Hunter, 1999; p71). Elaine eloquently expresses such a negative stereotype when she speaks of “cabras of women” (see section 10.3).

Post-operatively, participants discovered that it was not possible to get back to normal within the expected three months. Hopes are said to form part of our assumptive world (Cantril, 1950); this refers to our total set of assumptions, based on past experiences, which directs current and future behaviour. They also relate to how we would like ourselves or the world to be ideally (Kelly 1955; Parkes, 1971). Common sense tells us that a large discrepancy between real and ideal self/outcome will result in disappointment, and the literature backs this up, linking discrepancy to alterations in mood and esteem, and preoccupation with identity dilemmas (Fox, 1997; Parkes, 1971).

For those who were further from their operation, there was a sense of adjustment to a new vision of themselves, rather than a recapturing of an old view. Such changes in self-view, whether positive or negative, are seen as painful and requiring time to adjust, according to Parkes (1971, 1993).
11.7 Stepping into the void

Some women may be wary of losing an organ of which they have been highly aware for 20+ years, with that awareness increasing in the last few years as menstruation has become problematic. Given this awareness and familiarity, how they will feel is an unknown quantity, not just immediately afterwards but in the longer term. It is therefore difficult for them to prepare for the operation and recovery. Research on coping styles suggests that such a step into the unknown may be more problematic for some individuals than others, dependent on coping style (although the findings are by no means conclusive; DeLong, 1970; Lazarus, 1974).

Coping styles aside, changes in the aspects of ourselves with which we are most familiar, are said to be the most difficult to adjust to. Further, the irreversible nature of the actual and feared changes may contribute to the stressfulness of the procedure — Sloan (1978) notes that 'all irreversible procedures are considered drastic' (p603) and as such are regarded with fear.

11.8 Operative fears - handing over control

As the operation approached, women became anxious regarding operative complications, such as death, instruments being left inside, pain and so on. Fears regarding surgery have been linked to the loss of control experienced during the procedure (Carnevali, 1966), as well as having a basis in fact! For participants who may have an internal locus of control, the act of handing oneself over to the surgeon would have been extremely difficult. Indeed, research demonstrates that patients' attributional styles should determine the type of preparation for surgery (for internals this is cognitive restructuring, externals it is relaxation training) (Pickett & Clum, 1982).

Fears of death or the manner of death are often at the root of surgical fears, and represent a fundamental human fear. Rowe (1983) describes the two meanings of death as either the end of life altogether, or the passage from this life into the next. Either way, death means that we must
lead a satisfactory or good enough life, and being faced with possible death inevitably means facing our shortcomings. Thus major surgery may amount to a forced crisis and sudden confrontation of Erikson’s (1980) tasks of later life – integrity versus despair – much earlier than expected, and in a shortened space of time.

11.9 Removing the womb - endings

Longer-term worries for many centred around changes in sexual functioning, body integrity, the unfamiliarity of no periods, and what that symbolised (e.g. the end of fertility, ageing, changes in womanhood), linking with Sloan’s (1978) observations of the losses of hysterectomy, including:

- loss of a status associated with the feminine mystique. Then comes the loss of security of having one’s self intact, and especially one’s genital organs...Finally, there is the loss of acceptance – acceptance as a woman, be it symbolic, threatened, or real (p602).

Most participants anticipated sadness at loss of childbearing potential, seeing it as a loss of choice and control over their own bodies, and the end of an era. The parallels with Dell & Papagiannidou’s (1999) study, are readily apparent, where the uterus was seen as the ‘cultural signifier’ (p396) of a woman’s fertility (and sexuality), and fertility as culturally privileged over infertility.

The loss of childbearing potential is seen as final and, unlike menopause, adjustment cannot occur naturally over a period of time. The finality is equated with ageing and the loss of attractiveness for some, all opposites of cultural norms in our society (Fox, 1997). Physical frailty and the length of recovery compound the sense of rapid and premature ageing. Ageing itself is an oft-feared occurrence for men and women, perceived to signify a loss of independence, mastery and status prior to death (Dietch, 1995), all of which are connected with
self-esteem. Thus the symbolism of hysterectomy may be that of endings – of choices, of independence, of life as currently known.

11.10 Switching roles – becoming and unbecoming a patient

Many women expressed concerns about the inactivity of recovery prior to the operation, but few had made concrete plans of how to pass the time. This may be important as participants’ usual coping strategies (exercise, carrying on regardless, etc) may be impractical during recovery, further decreasing mastery and self-esteem.

The post-operative group felt unprepared for the length of time to fully recover or adjust emotionally (up to 2 years). There were also difficulties in returning to work after such a long time off and while they still felt physically and/or emotionally fragile. After one major adjustment of roles (to that of patient), there was a need for a further adjustment (back to previously held roles). This was difficult when they still felt changed (by the effects of their condition) or changed in a new way after the operation. Participants felt they were expected to be ‘back to normal’ once able to take up their pre-operative roles, and felt guilty or weak if this did not occur. However, given the changes which may have occurred since the women’s conditions were first apparent, it is unsurprising that they should feel changed; ‘Getting well does not necessarily mean getting back to normal because there is no normal to get back to’ (Brown Travis, 1988; p252; Maher, 1982).

11.11 Assumptions

Regarding interactions with medical staff, participants were fairly clear about what they did and did not want. Women resented assumptions about their wishes regarding children, and the equating of not wanting more children with being happy to end childbearing ability. This
parallels the 'useless uterus' discourse, first declared by the Greeks (Sloan, 1978, p599), and which is still a prevalent cultural attitude today (Osborne, 1984).

Most women recalled instances where they felt misunderstood or their wishes were not respected. They felt the validity of their claims was questioned, or they were seen to be being melodramatic. The idea of problematic menstruation as psychogenic or exaggerated, was seen to be a societal attitude by those in the non-surgical group, and reflects the findings of a survey undertaken by BBC Grapevine (1982).

Whilst most participants did not explicitly state the wish for a female gynaecologist, there seemed to be an implicit attitude that men, by virtue of their gender, could not understand women's experiences. Of note are studies which suggest that female doctors are easier to talk to than male doctors, for both patient genders (Sawyer, 1979). Taking on board the experiences of women in this study, and patients in general, it would seem that female gynaecologists might provide better patient satisfaction than males. It is interesting to relate these notions back to feminists' and historians' reporting that healing was traditionally the domain of women (Scambler & Scambler, 1993). Government directives now emphasise the importance patient satisfaction, and it will be interesting to observe whether this influences recruitment of more female doctors / gynaecologists.

11.12 Needing to trust the surgeon

Participants identified the need to trust their surgeon. In trusting the surgeon, patients alter their perception that menorrhagia is uncontrollable, instead seeing it as externally controllable by the actions of the surgeon, giving them hope and optimism (Gross, 1996). This is vital in changing the meaning of the illness, and hence reactions to it and therefore outcome (Brody, 1995).

Aspects of the relationship which assisted the development of trust were; length of relationship; knowing who would perform the operation; being listened to; adequate information about
options, expectations and success rates; being perceptive of feelings and offering information to answer the ‘afraid to ask’ questions (e.g. sexual outcome). Surgeons needed to take their time in interactions with patients, and see the patient as a whole person, not a set of symptoms. When these conditions are not met and trust does not develop, women may remain pessimistic about the chances of surgery easing their suffering, and so be more vulnerable to negative outcomes. Themes in this area correspond well with Wade et al’s (2000) study of women’s health care needs in hysterectomy.

Most women agreed that their present surgeons provided a good service, but as stated, all had experience of interactions which left them feeling angry and belittled. Such paternalistic attitudes and assumptions of ‘doctor knows best’ may be seen as stemming from societal views of women as dependent and emotionally incompetent (Brown Travis, 1988; p243), and which venerate medicine and medical professionals as all-knowing, all-curing and hence all-powerful (Scambler & Scambler, 1993). Experiences such as these are ultimately disempowering for women in general, and for women with menorrhagia in particular, impacting as they do on already low self-esteem.

11.13 Lack of information – preventing informed choice

Lack of information to enable participants to make informed choices or prepare adequately for the after effects of surgery was identified. The information given was seen as either inadequate or not retained, and most participants still had questions about procedures during the interviews. Lack of adequate information is the most frequent source of patient dissatisfaction in the health service (Field, 1993), affecting the doctor-patient relationship, outcome, and so on, as already discussed.
11.14 Longer term view of benefits – resolution

Women's accounts suggested that resolving their feelings about the many meanings of hysterectomy took time. It was only then that benefits could be realised. Anger was expressed at the lack of preparation women felt they had had for length of recovery. The implication again is that surgeons do not take a holistic approach to care, but instead see physical healing as full healing.

11.15 Core theme/category

The development of a core theme or category is seen as the desired end-point for most qualitative research (Henwood & Pidgeon, 1995). To summarise such a range of themes is difficult, and a number of core themes seemed relevant to the whole process. Strauss (1987) identifies the following key features of the core category:

- It must be related to all other themes
- It must recur throughout the data
- It forms the key element of the general theory of the study

Much discussion has centred around choice and control, and linking this to the attribution theory literature. The major theme therefore which seemed to fit most experiences at some stage of the process was disempowerment, through perceptions of lack of control and choice. This is situated within the wider discourses of women's struggle to be seen or heard as individuals through the process, in a society which groups women as fertile/infertile, young/old and so on.
DISCUSSION

CHAPTER 12

BROADENING DISCUSSION
12.1 Discussion with respect to research questions and aims

The purpose of this section is to evaluate whether the study met its aims and was able to answer the research questions. It will also consider potential explanations for the findings.

Aim 1: To capture the experience of menorrhagia and hysterectomy, through enabling participants' voices to be heard.

Question 1: What is the experience of menorrhagia and hysterectomy?

The first aim and question were addressed by the research. A snapshot view of what it is like to have severe pain and heavy menstrual bleeding was developed, and similar themes regarding the profound effect on their lives emerged from all groups, regardless of the cause of their menorrhagia or circumstances. It was apparent that menstruation had in many ways taken over women's lives, dictating what they could or could not do, wear, etc, and when. Their accounts used images of 'fighting an enemy', and fighting an 'uncontrollable body', in trying to regain control over their lives.

Discourse analysis and comparison with the non-surgical group revealed the extent to which women felt it necessary to emphasise the abnormality of their condition. This may be in response to a societal attitude which sees difficult periods as the lot of women and problems coping with that as indicative of psychological weakness or exaggeration. This appears to be in opposition to feminist beliefs which contend that menstruation is now seen as a medical condition rather than a natural occurrence (Scambler & Scambler, 1993) — instead it appears that women may find it difficult to have it accepted when their menstruation is abnormal. This non-acceptance was seen to extend to some medical professionals as well, with their insistence on 'objective' blood loss measures, which do not account for the manner of blood loss.

Attribution theory was used to explain many of the research findings, and this was thought to be the most useful conceptualisation of the process. Menorrhagia provides a good example of a
stressful and uncontrollable condition; it is relentless in its frequency and effects. For those with an internal locus of control, who believe in their own ability to master events, the progressive wearing down to exhaustion may be doubly difficult. Women’s worldviews and sense of mastery were seen as shattered by the experience. This relates to some of the trauma literature which finds that those who cling to beliefs of a just world and their own invulnerability may be more affected by trauma than others who do not (Weston et al., 1998). The links with learned helplessness models are apparent, and some degree of psychological distress in women with menorrhagia is therefore unsurprising.

When women find their only way out is a hysterectomy, they are faced with a ‘double bind’ situation, where neither option is desirable, and hence they may feel as though they have no choice. Such situations with perceptions of loss, entrapment, defeat and lack of control are common triggers for depression (Brown, 1996). Hysterectomy itself then may be symbolic of giving up hope that they may effect a change themselves. The consequences on self-esteem of giving up this internal locus of control, for a belief in an external saviour must be enormous. On top of all this, hysterectomy itself fits the criteria for a difficult psychosocial change, as outlined by Parkes (1993) since it

- Demands a major change in assumptive worlds
- Has lasting consequences
- Takes place over a short period of time

Accounts of low mood post-operatively are therefore entirely understandable within this context. It is interesting to note that the time scale noted by the participants to ‘get back to normal’ (around 2 years) closely approximates estimates of grieving (Weston et al., 1998). The processes described by both Esther and Emma seem to mirror some of the stages of grieving linked to changes in self-esteem (summarised from Adams et al., 1976), i.e.
Immobilisation & shock – Esther describes a kind of euphoria for the first week post-operatively

Minimisation & denial – trying to deny the feelings of loss (Emma)

Depression or self-doubt – devastated by the scar, anger at the surgeon (Emma, Sally), feeling as though confidence would never return, and so on

Acceptance of reality – beginning to let go of the emotions relating to the hysterectomy

Testing – the return of coping skills and trying out new behaviours – Esther describes this in relation to starting to swim again

Searching for meaning – Emma describes the life events she was able to cope with because she had had the hysterectomy

Internalisation & integration – feeling ‘back to normal’ again

The grief process seems a reasonable analogy to the changes which occurred after hysterectomy for the women interviewed, but in hysterectomy, there are no helpful rituals to ease transition (Notman, 1974). It is doubtful however that the women would have accepted such a comparison – most felt their feelings were out of proportion to the surgery. The latter in itself was a source of distress.

In terms of allowing participants’ voices to be heard, the researcher’s need to ‘tell the story’ in a certain way will have obviously influenced the choice and presentation of participants’ data. However, it is hoped that quotations retain their original meanings and context, so that the reader may hear the ways in which women’s lives are turned upside down by menorrhagia, and not immediately righted by hysterectomy.
Aim 2: To illuminate those elements of the experience of menorrhagia and hysterectomy which are missed by the current literature

Question 2: What is important to women about this experience and about the treatment process?

The most important finding which appears missed by current literature relates to menorrhagia’s relationship to self-esteem/self-concept. Women’s descriptions of their experience of menorrhagia contained elements of despair and frustration at the loss of control over their lives and bodies. They may have experienced embarrassment and humiliation through infraction of social taboos such as hiding menstruation (e.g. through flooding), and keeping the genitals private (the gynaecological exam) (Scambler & Scambler, 1993).

Their comparisons of themselves now to how they were previously or to their peer group centred around feeling “not normal”, almost less than themselves, given the restrictions on their lives. Work by Argyle (1969) contends that comparison with a reference group is vital to self-concept development, with how we measure up affecting self-perception and hence self-esteem. Feeling different, alienated, or ‘worse-than’ therefore would logically affect self-concept. This gives further weight to the idea that self-concept may be altered prior to hysterectomy.

The women seemed at pains to illustrate that low mood was unusual for them, implying that it was a direct result of their menstrual problems. This is in line with literature which finds a high degree of psychological distress amongst gynaecology clinic attendees (Gath et al., 1982), but refutes the usual conclusion that gynaecological disorders are therefore psychogenic. Indeed, the feelings of loss of hope and helplessness that the women describe in the face of their worsening conditions, are acknowledged as central to depressive reactions, regardless of one’s theoretical orientation (Carson & Butcher, 1992). The participants recognised that it was certain that no matter what they did, their period would arrive and would disrupt their lives. As already discussed, this is closely aligned to ideas of learned helplessness (Seligman, 1974), and Bibring’s (1953) psychoanalytic description of the ego in depression, which is seen to have ‘lost
his incentives and gives up, not the goals, but pursuing them, since this proves to be useless' (p39). Thus it seems more logical to suggest that for women with menorrhagia, their menstrual disorders resulted in low mood and loss of self-esteem, rather than the other way around.

Participants resisted saying they could no longer go on as they were, and required medical treatment. For the researcher, this again contradicts the assumption that menstruation in general is medicalised, and that menorrhagia is a frequent, ‘hysterical’ complaint (Scambler & Scambler, 1993). It is however in line with Zola’s (1973) model of pathways to consultation. This model suggests symptoms result in physical, personal and social effects, but these are accommodated to by the sufferer. Consultation (to either lay or professional persons) only occurs when these accommodations break down, for any one of the following reasons;

- An interpersonal crisis
- Perceived interference with work activities
- Perceived interference with social or leisure activities
- Sanctioning by others who insist help is sought
- Symptoms persist beyond an arbitrary time limit set by the individual (p677-89)

At the point of interviewing those awaiting hysterectomy, participants found their condition had resulted in most of the above, and at least one was implicated in their decision to seek help.

Seeking treatment in itself requires a change in women’s assumptive worlds from “coping” (independent) to “needing help” (dependent); another process which may impact on self-esteem (Parkes, 1971). In seeking treatment, women must assume the so-called ‘sick role’; Field (1993) in a discussion of Parson’s work describes 4 main aspects to that role, with patients being seen as;

- released from normal expectations
- unable to recover by their own efforts
• wishing to recover as soon as possible
• seeking professional medical advice and co-operating with the physician in the treatment of their illness (p108).

A number of these elements of the sick role posed difficulties for the women interviewed. Firstly, problematic menstruation, as a normal female function (albeit of abnormal intensity etc), may be seen as trivial or 'not bad enough' to warrant release from normal obligations, by society as a whole. Women also often have multiple roles which may be difficult to extricate themselves from (McBride, 1990) (an account by Ellen particularly springs to mind). Secondly, being seen as unable to recover by their own efforts appears tantamount to admitting defeat, which, as already discussed, had major implications for self-esteem. Thirdly, with hysterectomy the only option open to them, they may feel unable to comply with medical advice, since the option is undesirable. It may be difficult therefore for women to assume the sick role that would allow them to seek treatment.

The most important theme expressed by participants in relation to the medical encounter was that of making assumptions. Women felt that either implicitly or explicitly they were disbelieved (e.g. through being asked to keep diaries of menstruation), written off (assumptions regarding fertility) or railroaded into hysterectomy (being told immediately on consultation that this was the only option). Field (1993) suggests that such mismatches between patient and doctor attitudes may be explained in terms of differences in definition and language. Medical professionals are seen to use the language of 'disease', requiring objective verification of disease processes, which in turn may be amenable to 'cure'.

Patients, by contrast, tend to use the more holistic language of 'illness', i.e. going beyond the physical and affecting both psychological and social functioning (Field, 1993; p100). (Interestingly, this lay definition more closely resembles that of the World Health Organisation). Thus what the patients experience as disbelief may be verification through diaries to the surgeon, being written off as focusing on the problem in hand, and being railroaded as ensuring
the quickest and most effective solution to the problem. Thus the lack of concordance between physician and patients' attitudes is explicable in this way, but this kind of reductionist approach by surgeons however is no longer acceptable in today's sophisticated society. Charles & Barry (2000) conclude that doctors underestimate patients' needs for information and support as opposed to just treatment.

A more radical criticism, generated from the feminist literature, which could be applied to the issue of assumptions by surgeons, is that they reflect patriarchal discourses within society and in particular the medical profession. The power differential which is implied by 'doctor knows best' or indeed any discourse which privileges some groups over others, positions women as objects rather than speaking subjects, and further disempowers them (Cocks & Allen, 1996). It has already been demonstrated that this increases the risk of loss of self-esteem, pre-operative depression and hence post-operative distress. At a more basic level however, mismatches between doctor and patient expectations prevent the development of a trusting relationship, leading to dissatisfaction, poor adherence to treatment advice, and loss of hope, all of which may prolong or complicate post-operative recovery (Marinker, 1997). Surgeons therefore have their own pivotal role in post-operative psychological outcome.

Questions 3 & 5: What are the hopes and fears which surround hysterectomy? How accurate are these hopes and fears? AND What aspects of hysterectomy are difficult?

There seemed to be a number of undesirable consequences of hysterectomy which contributed to the desire to avoid hysterectomy despite the costs of menorrhagia. Many women feared ending child bearing ability, but although they were left with a “lingering sadness” (Emma's words), it did not appear overwhelming, perhaps because they had anticipated and prepared for it. Fecundity is taken as the norm and indeed venerated in our society (Dell & Papagiannidou, 1999), and the state of childlessness is looked on with pity, with technologies made available to 'correct' this 'unnatural' state of affairs. Ussher (1989) notes that there is still a close connection between motherhood and womanhood in Western cultures, and sees 'pregnancy,
childbirth and motherhood are an intrinsic part of women’s experiences, regardless of whether or not we decide to give birth to children’ (p76). It may be natural therefore for women to have sadness at relinquishing the potential to bear children, even if no more children are wanted.

Relating to the loss of childbearing ability, some feminists resent the construction of menopause as pathological, and in a sense this makes it difficult to claim that hysterectomy may be a difficult transition for women. However, there are fundamental differences, such as the speed of the transition, the stage in life it occurs, it being a non-normative experience, and so on, aside from the elements inherent in surgery which mean that hysterectomy does not compare easily to the transition at menopause.

Many participants focused on their scar as a source of distress, which they felt unprepared for pre-operatively — this is allied to Dell & Papagiannidou’s (1999) descriptions of the scar as a ‘fetish’ object signifying loss. There may be a number of reasons for this. Firstly, the scar may be the visible indicator of the changes in expectation women have made already, and must now make in relation to their expectations. Secondly, our culture emphasises physical attractiveness and youthfulness for women, and the scar may be the manifestation of an operation which makes them ‘old’ (no longer “productive” to use Nadine’s words), as well as disfiguring them (Emma). Whilst women’s roles have altered beyond only procreators and homemakers, childbearing ability may still be seen as an attractive attribute by men and women, and thus the scar again may signify that this attribute is gone. Finally, some participants felt ill prepared for the length of emotional recovery, expecting as they did to be fully fit in all senses after 3 months, the time scale given in medical advice to heal. Again, the differences in expectation may result from physician versus patient definitions of ‘better’.

Preparation has been shown to aid adjustment (Parkes, 1971), and hence there is perhaps an argument for presenting a number of ‘typical’ hysterectomy stories to enable patients (and perhaps families or employers) prepare for surgery and recovery, as well as to dispel myths. In
this way, the need for information and comparison with other women is satisfied, giving more accessible ideas of what to expect than perhaps are currently provided.

**Question 4: How and why do women decide to have a hysterectomy? What influences their choice?**

It was a surprise to the researcher, who had felt that women would actively weigh up a number of options and pros and cons, that they felt they had little choice in the matter. It was demonstrated earlier that Zola’s (1973) model of pathways to treatment predicts when women will consult for menorrhagia, and re-consult for hysterectomy. For most women there was a prior awareness that their treatment options were limited, which may further delay consultation for treatment. This may be of greater importance for conditions such as fibroids, as the larger they get, the more difficult treatment may be.

Most participants mentioned that the initial advice of the surgeon was to have a hysterectomy, but for many of the participants this advice came too early in the consultation process. The tasks of the surgeon are clear therefore — to match the patients’ pace and to minimise differences in attitude and expectation by checking out patient expectations at each consultation. This has been shown to improve patient-physician congruence (Marshall, 1998). Likewise, to reverse feelings of disempowerment engendered by menorrhagia, to increase activity and involvement in the decision making process so as to enhance perceptions of choice and control.

**Question 6: Are changes in femininity or self-concept cited under fears or as reasons for post-operative distress?**

There was no spontaneous expression of femininity or self-concept being dependent on the uterus for the surgical groups, but there were some aspects of womb functioning which seemed to relate to ‘womanhood’. On examining the data, it seems more pertinent to suggest that when
menstruation or fertility are an important aspect of a woman’s ‘life space’, hysterectomy will be more likely to disrupt one’s self-view. Parkes, quoting Lewin (1935), defines life space as parts of the environment, persons and parts of the body and mind with which the self interacts, and in relation to which, behaviour is organised (1971, p103).

Menstruation plays a large role in women’s lives, for good or bad, from their early teens onwards. Both Sloan (1978) and Ussher (1989) regard menstruation as uniquely female and hence symbolic of motherhood and womanhood. Even if no symbolic meaning is attached to it, it occupies a significant proportion of women’s life space and thus self-view, particularly perhaps when it becomes frequent and problematic as in menorrhagia. Any changes therefore will impact on self-view.

It may perhaps be argued that it is not the uterus per se which has a role in self-concept, but rather the extent of the importance of its functions to the woman. Thus for women who place greater value on their role as child bearer or on menstruation as being symbolic of fertility (as with Stephanie), these functions and hence the uterus, may feature more greatly in their self-concept. There seemed for some women to be a separation between femininity, womanhood, and personhood, but insufficient data were gathered to begin to tease out whether these were global differences or individual differences in terminology.

It has not been possible to provide an unequivocal answer to this question. What is clear however is that menorrhagia impacts on self-esteem and so probably self-concept. Likewise, hysterectomy, as a psychosocial transition changes a woman’s assumptive world in many ways. The functions of the uterus do play a large role in women’s lives and therefore changes to them could be argued to impact on self-concept. However, this does not on its own seem enough to explain all cases of poor adjustment to hysterectomy, as previously outlined.
Aim 2: To carry out trustworthy research in accordance with pre-defined criteria.

The criteria for carrying out trustworthy research were set out in chapter 7, and include triangulation, member checking, negative case analysis and leaving an audit trail. The triangulation strategy meant that a number of different perspectives were obtained, and it is hoped that a fuller picture of women’s experiences was therefore obtained. With hindsight however, the use of focus groups and longer term case studies would have greatly enhanced the data set, and enabled some of the themes to be tested out with more confidence. A second criticism here relates the difficulties the researcher found in carrying out the discourse analysis, and it is difficult to know whether this was carried out in the ‘right’ way. Psychology typically concerns itself with phenomenology rather than social practices, and it is felt that this study perhaps reflects that, despite the researcher’s attempts to address discourse.

Section 10.6 has already compared the researcher’s themes with the second rater’s themes, and a high level of concordance was found between them, as well as key quotes for each theme. Whilst this was only carried out on a small sample of the pre-operative group data, it offers confidence that the themes truly reflect participants’ experience rather than the researcher’s biases. A further vote of confidence was obtained from the participants who checked the themes, all of whom felt that they reflected their experiences. There was also some concordance with the literature. Points of concordance give confidence that, despite the restricted sample, the resultant themes may well be generalisable to other women suffering with heavy blood loss.

For reasons of brevity, the whole research diary is not included in this thesis; however, the researcher has summarised relevant notes to help illuminate the decision-making processes. Whilst there will undoubtedly be points where questions arise for the reader, it is hoped that inclusion of diary samples will give confidence that the steps of the research were carefully thought out. In summary, it is felt that the second aim of the research was met, and perhaps the best judge of that is the participants themselves, all of whom felt represented by the themes.
12.2 Critique of the study

No study is perfect, and all will contain flaws. The original study design was to use multiple methods for each group, and to go on to test out whether some of the themes could be predictive of adjustment. However, the former was not possible due to small numbers of volunteers, and the latter due to time constraints. Undoubtedly, both would have provided richer data.

Statements can only be made about the women interviewed, although there was some sense that saturation (where no new insights occur from data collection; Glaser & Strauss, 1967) was reached, implying that some of the range of women’s experiences was captured. However, the small number of volunteers (roughly 25% of those approached) was surprising given the large number of hysterectomies carried out. The sample consisted of all white, mainly well educated, working women, living within a particular region and attending a particular hospital, which will undoubtedly affect the data obtained. It is interesting though that these women, who theoretically would be expected to be involved in the consultation process, were unable to obtain all the information they needed, suggesting something about the consultation process.

Research has been carried out which suggests that many women welcome the operation, and only a minority are dissatisfied (around 5%, dependant on the study and criteria used; Richards, 1978). Given the themes developed in this study, perhaps only those who were ambivalent about surgery, or who had suffered some difficulties post-operatively volunteered. Obviously this skews the data and those who actively request a hysterectomy or recover without difficulty may not be represented by the themes.

However, the qualitative paradigm contends that no data will be representative of all experience, no matter how well sampled the participants. Further, those experiencing difficulty are perhaps best placed to answer the research questions and fill in gaps in the literature, such that changes or interventions may be used to assist them. Therefore, the experiences of the satisfied majority are of less relevance for this study than those of dissatisfied or ambivalent women.
Criticisms of qualitative research are many, including subjectivity, lack of generalisability, lack of predictive ability, problems with reliability or validity, and so on (Silverman, 2001). However, the rationale for approaching the study in this way was clearly outlined, and the methodology has brought a number of new insights into the hysterectomy process. The project achieved its aims in allowing participants voices to be heard, capturing a range of experiences, and fulfilling trustworthiness criteria.

Improvements to the study with hindsight, would be

- the inclusion of self-esteem measures perhaps to test out the hypotheses regarding disempowerment and lowered mood
- making the study more longitudinal in design to monitor changes in self-perception
- the inclusion of interviews with partners to determine concordance in beliefs and their views about hysterectomy.

Views of significant others have been hypothesised to be of importance in determining self-perception (Argyle, 1969) and recovery from illness (Bailey & Clarke, 1989).

A final issue is the naivety and lack of experience in this method of the researcher, who underwent a baptism of fire with the project. Qualitative research differs from quantitative research in that there is no ‘recipe book’ to follow when carrying out analyses. The researcher therefore may not have developed themes and categories far enough, or may have missed vital pieces of the puzzle. Some confidence is to be gained however from the concordance with the second rater’s themes, literature and participants’ agreement with themes. It is hoped that the research diary will assist in illuminating analytical decisions.
The formulation overleaf attempts to capture the experiences of women from complaint of menorrhagia through to recovery from hysterectomy. Although it is undoubtedly simplistic, the formulation aims to move beyond description of themes, utilising attribution theory to draw out the process in ways which may allow prediction of how certain women may react.

The data described a main reaction to uncontrollable menorrhagia, which was an altered sense of self, based on comparisons. The resultant themes were “this is not me”, “this is not normal” and “this is out of my control”. It is hypothesised that, dependent on locus of control and prior experience, women seeking treatment will either perceive this as evidence of failure (internal) or coping (external). Either way, a switch in roles will be required, to a patient role, in which a certain amount of control is given over to medical staff. Dependent on the doctor-patient relationship, women will emerge from this process as feeling in control, with information and choices, or without choices, control or information. Those who feel in control will see hysterectomy as a decision and solution; those without perceptions of control will become resigned to hysterectomy as their only option.

It would seem from women’s accounts that the surgeon has the greatest responsibility at the consultation for developing a trusting relationship. Failure to develop a trusting and consensual relationship may reinforce feelings of helplessness and failure, and decrease the patients’ hope that hysterectomy will solve their ill-health (defined as more than just the physical menorrhagia).

Dependent on women’s feelings about the functions of their womb, women may perceive hysterectomy as desirable or undesirable, the latter with connotations of endings. During hospitalisation and surgery, control is handed over entirely to medical staff, which again may be more or less difficult dependent on locus of control. During physical recovery, women remain out of control, with their usual roles subsumed by family or others. However, once physical
recovery is complete, expectations from self and others of being 'back to normal' begin to have influence. The consequences of this expectation are to 'unbecome' a patient and utilise coping strategies to begin to adjust, OR to wonder why one is not back to normal and if this will ever occur. This latter is more likely to be the case in those who were unprepared for the consequences of hysterectomy, felt they had no choice, for whom hysterectomy was particularly undesirable, and perhaps those who have already experienced feelings of failure during the process. For both groups, time is then needed to adjust to the new view of themselves, which no longer includes the ability to have children, etc. All this is set within the local and broader socio-cultural context.

The formulation suggests interventions which enhance perceptions of choice and control, through listening to women's accounts, providing information and support, and improving the doctor-patient relationship.
Figure 8: FORMULATION OF HYSTERECTOMY PROCESS

UNCONTROLLABLE MENORRHAGIA

ALtered SENSE OF SELF
THIS IS NOT ME
THIS IS NOT NORMAL
MY BODY IS OUT OF MY
CONTROL

Role switch

External LoC

Internal LoC

TREATMENT SEEKING
Surgeon/consultation
characteristics

INFORMATION
CHOICE
CONTROL

Decision Belief

LACK OF
INFORMATION
CHOICE
CONTROL

Resignation
Less belief in cure

HYSTERECTOMY
HANDING OVER
CONTROL TO
MEDICS

Solution

Endings

PHYSICAL
RECOVERY

I am back to
normal

I will never be back
to normal?

Adjusting to a new view
of self

EMOTIONAL
RECOVERY
CONCLUSIONS

CHAPTER 13

MOVING FORWARDS
13.1 Future Research

The study provides a useful jumping off point for future research - firstly, it could be broadened to take account of improvements suggested in chapter 12, fleshing out the knowledge gained. Secondly, themes could be used in a prospective, longitudinal study to determine their relative importance to women, and the formulation tested for prediction of post-operative adjustment. Thirdly, intervention studies could examine the effects of preparatory material, a pre-operative counselling session, or changes in the medical consultation, for outcome improvements. Finally, developmental studies are needed which assess the relative importance of the uterus and its functions in women's self-view across the lifespan, to verify the literature claims.

13.2 Implications for practice

The participants' accounts speak for themselves in identifying the ideal medical consultation, although all recognised that we do not live in an ideal world. On a broader scale, information about menorrhagia and options for treatment may be best provided via well-woman clinics, given their emphasis on woman-centred approaches.

All women interviewed said they valued the opportunity to talk, hence there may be a role for a gynaecological nurse with training in counselling skills, for a one-off discussion of options, to dispel myths, and to enable women to tell their stories in their own time. For some women, access to other's accounts of surgery was desirable, enabling them to prepare for any post-operative problems. There was a need to be more open and candid in discussion with women regarding successes and failures, how they might feel afterwards (emotionally), how long this would last, and a willingness to bring up subjects women may be too embarrassed to ask about (e.g. sex). This could occur via information sheets or even video, using interview extracts from 'real' women. There is also a need to lose the assumption that choosing not to have more children/sterilisation equals ending fertility is desirable. In these ways, a trusting relationship, the cornerstone of good practice, can be developed.
13.3 Conclusions

It is not easy to draw together the strands of such broad research. The research aims were fulfilled to some degree, in that a range of experiences were described, commonalties were discussed, and trustworthiness criteria were met. A formulation was presented which attempts to move beyond description of experiences, by utilising attribution theory.

It can be argued that perhaps it is time to move beyond asking whether or not women are more or less depressed after hysterectomy, and instead use women's accounts to understand, predict, and prevent distress. Three obvious themes run throughout the research; that is, the invalidity of many assumptions in the literature and the consultation room; the sense of disempowerment in menorrhagia and the hysterectomy process; and the sense of difference felt by women at all stages of the process. Disempowerment was felt to be the central theme. Consequently, empowering women with menstrual problems through changing the consultation process, provision of accurate and appropriate information, dispensing with assumptions and allowing time for women to tell their stories and come to their own decisions, must be the key messages of the research.

The main question of interest at the commencement of the research was whether hysterectomy influenced self-concept. It has not been possible to unequivocally answer this question, but the participants' accounts suggest that alterations in self-view occur prior to hysterectomy and as a result of menorrhagia. Women's fears of hysterectomy relate to its symbolism of endings—child bearing ability, attractiveness and ageing—and uterine functions were seen as important by most women, and so important to their self-concept. Prospective, longitudinal and developmental research is required to determine the course and nature of changes during the hysterectomy process, and to determine the centrality or otherwise of the uterus to feminine identity.


Beazley, J (1972). Dysfunctional uterine haemorrhage. British Journal of Hospital Medicine, 7, 573.


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Sage Publications.


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APPENDICES

APPENDIX A

Ethical Approval Letter
Consent Form
Information sheet
Demographic data form
7 November 2000

Ms R Crook  
Trainee Clinical Psychologist  
Dept. of Clinical Psychology  
University of Hull  
Cottingham Road, Hull

Dear Ms Crook

WOMEN'S PERCEPTIONS OF THE UTERUS AND EFFECTS ON HYSTERECTOMY OUTCOME - AN EXPLORATORY STUDY

LREC NUMBER: 07/00/123

Thank you for your letter dated 12 October 2000 enclosing the revised information sheet for the subgroup and answering the questions the Committee had raised. This was discussed at a meeting of the LREC sub-committee on 6 November 2000. The Committee was satisfied that all concerns have been addressed.

I note that ethical approval has already been granted for the study to commence.

Yours sincerely,
CONSENT FORM

I have read and understood the information sheet  YES / NO
I have asked any questions I might have  YES / NO
I agree to my interview being taped and transcribed  YES / NO
OR to my written material being analysed
I understand I can withdraw at any time  YES / NO
I would like to take part in the study  YES / NO
Signature________________________________ Date__________
Print Name________________________________

I am happy with the transcript of my interview/ written material  YES / NO
I am happy with the themes taken from my transcript  YES / NO
I agree to my transcript being included in the write-up  YES / NO
I would like a copy of the results  YES / NO
Signature________________________________ Date__________
Name:
Address:
HYSTERECTOMY FOR HEAVY PERIODS
RESEARCH PROJECT

INFORMATION SHEET

1. Who is carrying out the study?

The study is being carried out by Rebecca Crook, a trainee Clinical Psychologist, as the main thesis for a Doctoral course, at the University of Hull.

The study is supervised by Dr M Wang, Course Director, University of Hull, and by It is however, entirely separate to your hospital treatment, and no changes to your proposed treatment will take place through your participation in this research.

2. What is the study about?

I am interested in how women feel about their womb, its meaning to them, and their hopes, fears and considerations when they undergo a hysterectomy. This is a new area of research and is important in that it will assist medical staff in helping and advising patients in their decision making process before having a hysterectomy.

I am interviewing women who are waiting for a hysterectomy, those who have had a hysterectomy, and those who have not had a hysterectomy, but who are around the average age for having a hysterectomy.

3. I might be interested...

Initially, if you decide you are interested, you will be asked to fill out your name and contact number on a form, which you can seal in the envelope provided and post. I will then contact you and answer any questions you might have and explain the procedure in more detail if necessary.

4. What will I have to do?

Everyone who agrees at this point to take part will receive a questionnaire which asks about their mood and worries to fill out. I will then contact you to let you know which group you have been allocated to. The allocation happens at random using a "numbers out of a hat" type procedure. There are 3 groups;

Group 1 will only have to fill out the questionnaire
Group 2 will be asked to complete a "balance sheet" which looks at what they see as the pros and cons of an operation, or answer some questions in writing. This will take about an hour.
Group 3 will be interviewed, either at home or at the University, whichever is most convenient for you. This will take and hour to an hour and a half. If you are waiting for a hysterectomy, you may be asked if you would mind being interviewed before and after your operation. This will mean about 3 hours in total.

The interviews tape recorded and the researcher transcribes it word for word, with anything that might identify you removed, to protect your identity. You will be asked to check the transcription to make sure it is accurate.
5. **Will the doctors/anyone else know if I take part?**

Your GP will be informed in case you would like further assistance after the project. No-one else is informed. No-one at the University or outside, other than myself, will know your name and number, which will be destroyed at the end of the study. All your details are kept in a locked cabinet meantime. Taking part in the study WILL NOT affect your future treatment.

Your interview is tape-recorded and transcribed for accuracy but identifying details are removed from the transcript, and you can check this to make sure you are happy with it. After transcribing you can either keep the tape, or I will wipe it for you.

6. **What happens afterwards?**

Once all materials have been transcribed, they are analysed for common themes running through them. You may be asked to check these themes to see if they reflect your experience. The study is then written up and submitted as a thesis. The finished report may be published in a medical journal. If you would like a copy of the final report, I will ask you to fill in an envelope and this can be posted to you at the end of the study.

7. **What if I change my mind?**

You are free to withdraw from the study AT ANY TIME, and you don’t have to give any reasons. If you decide to withdraw after the group, your parts of the tape will be wiped clean immediately and your transcript shredded. There are no penalties for withdrawing, and neither will anyone at the hospital or elsewhere be informed.

8. **I have some more questions...**

If you have any questions, please feel free to contact either;

Rebecca Crook or Dr Wang at the University of Hull on 01482 465933

THANK YOU FOR YOUR TIME.
Please fill in your name and contact details on this sheet if you are interested in taking part in the study, and seal and post it in the envelope provided. If you feel happy to do so, I would be grateful if you could also complete the next section which asks about your current and past circumstances and your medical condition. I will then send you a questionnaire. When it is returned, I will contact you by telephone to explain in more detail about the project, and to let you know which group you have been allocated to, and to make arrangements.

Thank you for your valuable time.

Name ________________________ (Code Number)__________________
(researcher to fill in code for confidentiality)

Age_________________ Address________________________________________

Contact Telephone Number__________________________

Please could you answer the following questions so we can understand your circumstances. If there are any you do not wish to answer, then please leave them blank.

1. Relationships
   a. Are you married or cohabiting/single/divorced/widowed?

   b. Please tell us if this is your second marriage/longterm relationship?

   c. Do you consider your current relationship stable?

   d. Do you have children?

   e. How many and what ages?

   f. Did you wish to have more?

2. Occupation
   a. Please tell us if you are working or not
b. If so, state profession and job title

c. If not, please tell us what you used to do

d. And why you stopped?

3. Your medical problems

a. Please tell us what the condition was for which you had/ are having a hysterectomy?

b. How long have you had this problem?

c. What treatments have you tried?

d. How much did/does it affect your life on a scale of 0 - 10, where 0 is not at all, and 10 is it had taken over your life?

e. What made you decide to have a hysterectomy?

f. When was/ is your operation (date)?

g. Are/ Were you going through the menopause at the time of your operation?
4. **Stresses and Worries**

a. Have you ever seen a psychiatrist or psychologist for help, or have you approached your GP or a counsellor for help because of personal problems? Please state which profession you were referred to.

b. If so, when?

c. If so, please can you summarise what kind of problems you had?

THANK YOU FOR YOUR HELP.
APPENDIX B

Questions for interviews

Prompts for written material

Impressions sheet
NON-SURGERY GROUP: QUESTIONS AND PROMPTS

I am interested in what you have to say about various aspects of being a woman, having a womb and hysterectomy. Anything which you think is important is important to me, but I have written some guides below. If you have any other comments to make, please feel free to do so. You can use your own words, quotes, songs or poems, or drawings, to illustrate what you mean.

1. Tell me if you've ever had any problems relating to your womb, or periods? What effect did these have on you and how you felt about yourself? OR what effect do you imagine they might have?

2. How sympathetic do you think doctors are to "women's troubles"? How much would you want to know about treatment options or take part in deciding about treatment? What treatment options do you know about for heavy periods?

3. What do you think it would be like to have a hysterectomy? What would be your hopes and fears or worries?

4. What would it be like to have no more periods? Why?

5. What would it be like not to be able to have children? Why?

6. How did you think other people (partner, other men etc) would see you after a hysterectomy? How do these people see you now?

7. Do you think you would feel the same or different after the operation as a person? Do you think you would be as feminine or as much of a woman?

8. The recovery period for hysterectomy is quite long. What do you think that would be like for you?

9. Do you know anyone who has had a hysterectomy? What do they say about it, and how has that influenced what you think about the operation?

10. There has been lots of speculation about what makes us feel female. What makes you a woman? Does your "me" (your self) live anywhere in particular in your body/mind? Would this change at all after a hysterectomy?

11. Do you have anything further you’d like to say which you feel is important?
HYSTERECTOMY & ENDOMETRIAL ABLATION GROUPS

QUESTIONS FOR INTERVIEWS – PROMPTS FOR WRITTEN MATERIAL

I am interested in what you have to say about the decision making process in having your operation. Anything which you think is important is important to me, but I have written some guides below. If you have anything you want to ask me, please feel free to do so.

1. What are your hopes for after your operation?
2. What are your fears or worries for after the operation?
3. Do you think you will feel the same or different after the operation?
4. Do you think your partner will think you are the same or different after the operation?
5. Do you think you will have any regrets after the operation?
6. How do you think you will feel in your self after the operation – short and long term?
7. What reasons made you choose to/not to have a hysterectomy?
8. What had the biggest influence on your decision?
9. Is there anything else which you imagined or thought about but that you dismissed from your thoughts when you were making the decision?
10. Do you have anything further you’d like to say?
QUESTIONS FOR INTERVIEWS/ PROMPTS FOR WRITTEN MATERIAL

I am interested in what you have to say about the decision making process you went through before having your operation, and how accurate your expectations about what would happen were. Anything which you think is important is important to me, but I have written some guides below. If you have any other comments to make, please feel free to do so. You can use your own words, quotes, songs or poems, or drawings, to illustrate what you mean.

1. Tell me about the condition for which you had the hysterectomy?

2. Did you feel you had any choice over your treatment, and how much did you participate in choosing your treatments? Did you ever feel “caught between the devil and the deep blue sea” about it all i.e. you couldn’t go on, but you weren’t sure you wanted a hysterectomy?

3. What were your hopes for after your operation? And what were your fears or worries for after the operation?

4. What went through your mind when you thought about actually having the operation?

5. How did you think other people (partner, other men etc) would see you after the operation? How do people see you now?

6. Did you think you would feel the same or different after the operation as a person? How do you feel now?

7. How accurate were your hopes and fears?

8. Is there anything you wish you’d known or thought about beforehand? How could the doctors have improved what they did?

9. What was the recovery period like, and how did you cope with being inactive? Was this strange for you, and did it have any effects on how you felt about yourself?

10. Do you have any regrets after the operation?

11. How do you feel in your self since the operation – short (the first few weeks) and longer term?

12. Is there anything else which you imagined or thought about but that you dismissed from your thoughts when you were making the decision? Or has there been anything else which has crossed your mind since which has been difficult to explain to people?

13. There has been lots of speculation about what makes us feel female. What makes you a woman? Does your “me” (your self) live anywhere in your body/mind? Has this changed at all after your operation?

14. Do you have anything further you’d like to say which you feel is important?
Impressions sheet

Filled out immediately after interviews

Interviewee No. Date of Interview

Time Place

1. Tone of voice, Affective expressions, Body language

2. Setting – at ease. interrupted etc

3. Personal reactions

4. Ideas to follow up

5. Any feedback
APPENDIX C

EXAMPLES OF PARTICIPANT SUMMARIES & TRANSCRIPTS

Nadine
Stephanie
Ellen
Tina

Please note that in order to preserve line numbers from the original transcriptions, it has been necessary to use different sized text. It was not possible to include all transcripts given the space.
1. Written material (underlined words are her emphasis)

To my knowledge, I've no current problems with womb/periods - an abnormal smear test and elective colposcopy led to an intense fear of cancer (particularly an 'internal' cancer) and I spared no thought to any other aspect.

Re "womens troubles" – I think doctors are generally sympathetic – I don't think employers are!! To have time off for a heavy, painful period would be unacceptable – I imagine most women would make an excuse, as I would (and have!)

I can't imagine having a hysterectomy – while I have children and, at this time, don't want any more, the knowledge that I could if I wanted to, is reassuring. To have that control over your body, life choices etc taken away must be upsetting.

No more periods!! Yipee! But then it does symbolise that you've reached an age where you are no longer "productive"? That you have fulfilled your biological role?

I believe my partner would feel uncomfortable about my having had a hysterectomy. One of the special aspects of our sexual relationship is that he has, and can, make me pregnant. I believe he feels 'manly' for this role and I feel 'womanly'. I know this sounds a bit silly, but to be in a relationship and to have the knowledge that you have, and could again, create a new life together, is very sensual and powerful.

Personally, I wouldn't feel as much of a woman after a hysterectomy, although I would feel as feminine. Recovery from any major operation would be horrendous in terms of the impact on family, social and work life.
What makes me a woman?

- my sexuality
- my children
- how my body looks and feels

My ‘me’ is my soul, my spirit – not one particular physical part of me. While hysterectomy would probably influence my feelings of sexuality etc, I wouldn’t necessarily feel less of a person – just changed – and would have to get to know and accept the change.

(bolded word are her emphasis)

2. Balance sheet

Gains for self – end of heavy periods

Losses for self – how I’d feel during/after surgery, i.e. anxious that it would all go ‘ok’. I’d have concerns and many questions about the longer-term effects on my hormones etc due to my age (premenopausal!).

Gains for significant others – I would hope that longer-term I would feel healthier and therefore function better at work and home.

Losses for significant others – time away in hospital away from children and time needed to convalesce.

Self-Approval – no more worrying about contraception

Self-Disapproval – Never being able to have another child – the finality and irreversibility of the situation
Approval from significant others – [none]

Disapproval from significant others – I believe my partner may consider me ‘less womanly’.

There’s an attraction for a man in knowing his partner can bear his children?
PRE-HYSTERECTOMY GROUP – INTERVIEW

1. Participant Summary – “Stephanie”

‘Stephanie’ is a 44 year old woman, who is married with a stable relationship. She has one child aged 16, and did not wish to have more. She currently works as a clerk.

‘Stephanie’ has suffered from endometriosis for 4-5 years, which has a big impact on her life – she rates it as 6/10 (0 is not at all, 10 is taken over). She has tried progesterone, but this has not been successful. She decided to have hysterectomy because the problem was worsening and she suffers with anaemia due to the heavy bleeding. She has not been through the menopause.

‘Stephanie’ has seen a counsellor in the past (some eight years ago) for a bout of depression. Her score on a measure of current worries and concerns was within the usual range.

2. INTERVIEW

‘Stephanie’ date of interview 01.02.01 At her home (R: stands for researcher).

1. R: Ok so, the first question I usually ask people is, what made them say yes to doing the research?

2. Because I know that its taken me two years to decide to have the hysterectomy, and I think it would be nice if I could contribute to any feelings other women have. And err hopefully come to terms with it myself.

3. R: Right. So it sounds like you’ve struggled with making the decision?

4. Yes, yes I have, really struggled with it. In fact I still think when it comes through the door saying come in for it, I’ll want to back out of it.

5. R: Yes

6. I still feel that way, I think, can I carry on with it?

7. R: You’ve got some significant worries about it?

8. Oh yes, very much, umm…albeit that the consultant was very very good at explaining what it would entail. He was very nice about it – but its still…its still an operation. Am I going to feel different? (laughs)
15. R: Right. So its worries about the actual operation, and worries about how it will be afterwards?
16. Yes, definitely, yes.
17. R: Can you tell me a little bit about some of those worries?
18. Umm. I fear the operation. I am terrified of operations, and I've had a couple of... I had a
19. laparoscopy to establish what was wrong with me, and I remember feeling really depressed after
20. that operation. And it was - I'm sure it was the anaesthetic. Umm... and I just can't bear the
21. thought of being incapacitated for a long period of time. I'm a doer, not for somebody to do for
22. me! I make a bad patient, a really bad patient! So I'll be frustrated more than anything and I think
23. that is the biggest fear, yeah, that the fact... I've managed feeling ill, going through pain, umm,
24. uncomfortable - in fact I am just talking about it! [laughs]
25. R: So these are big things for you?
26. Oh yes, definitely. I want just to be normal. But having said that, umm - a colleague of mine, his
27. mother had a hysterectomy just before Christmas, and she's up and about, and she's been quite OK,
28. and getting back on with life. So you've got to look it from that point of view as well.
29. R: So kind of weighing up - you've got this positive example, and on the other hand like you
30. said after you had a laparoscopy you felt quite down
31. Yeah very
32. R: So maybe worried that after the operation you'll be quite down as well?
33. Yes, feeling depressed after the operation. Umm, as I say, I am a doer, I'm a person who likes to
34. get on with things and all through the condition I've felt I've had to [unable to hear]
35. R: So if you can't get on with things and can't do things, that's going to affect your mood, or is it
36. the actual operation?
37. Oh I'm sure it's the anaesthetic, I'm sure it's the anaesthetic that makes me feel depressed, and I
38. suppose once that's out of your system you can start building up. But, the operation - umm, I
39. don't want a scar, I don't want to wait for that to heal. I don't want to go through the pain. But
40. weighing up that against what I'm suffering now, I've got to do that because I'm suffering a lot
41. now. So I've got to think about that. And hopefully after that I won't suffer any more.
42. R: So you've had your problem quite a long time now haven't you?
43. Yes
44. R: How many years?
45. I've had it umm I would say for about the past... I've actually had umm 18 years ago I had
46. precancerous cells of the cervix, and they cleared up, and I've had regular smears from there. But
47. the past five or six years I’ve had extremely heavy periods and painful periods, and I was
48. diagnosed as having endometriosis, and its causing other problems because its making me
49. anaemic.
50. R: Right
51. And umm because of the anaemia I’m tired and I seem to build myself up during the month, and
52. then I get my period and I’m back down again, so it’s quite difficult. And I think its causing other
53. problems as well because I’m having problems with my bowel. And it’s all the endometriosis
54. that’s adhesed. So I think in the long run I will feel much better.
55. R: So the main things are the pain and the inconvenience and also the point you said about
56. becoming anaemic, which takes you a long time to sort out –you just get it sorted out and then you
57. go back down again
58. Yeah, yeah
59. R: What kind of effect is that having in your life in general?
60. Umm I don’t do a lot of the things I used to. I used to do – I’m on a fundraising committees
61. and...I don’t do them now because I find I’m real tired all the time. I was meeting myself coming
62. back and I was pushing myself to the limit. So I said right, I’ve got to stop doing them to get my
63. sanity back, for me to feel better. Although I’m not as tired, I still don’t feel inclined to go and do
64. those things at the moment. I used to go to the gym three times a week, but because I’ve been ill
65. I’m out of breath so quickly, and I take the iron but as I said, I have a period and it just goes again.
66. So, I’m sure I’ll feel much better after I get rid of the anaemia.
67. R: So it’s stopping your social life...hobby-wise...
68. Yeah, everything really. If I think about it like that. I still go out a lot socially, but yeah I suppose
69. it has really! Because I don’t feel like inclined to doing it. I never take time off work, I always put
70. my job first, I think they’re paying me so I always go to work, umm even when I’m dying!
71. R: You struggle in?
72. Oh sometimes its horrendous and its one of those jobs where you do have to have full
73. concentration all the time. So sometimes I do make mistakes which I’m not happy about. So I
74. suppose it does affect my work as well.
75. R: I wondered if you were worried at work that someone might pick upon these mistakes?
76. I’ve got a very very good boss, she’s very understanding so she appreciates that it’s out of
77. character with me. She knows what standard of work I do and how it can deteriorate, so I aren’t
78. worried about that.
R: That's ok?

Yes, fortunately – I could have somebody who was totally a pratt about it couldn't I.

R: Yes. Umm so you're struggling into work, but I guess maybe some days you don't feel up to
much cos you're struggling

And then I just go home and veg out basically.

R: Yes. So I'm getting a picture of you as quite an active sort of person maybe

R: But this is...the endometriosis is stopping you doing that?

R: Stopping you being yourself?

Definitely. It is yeah. I'm not – well I haven't been...I think more so over the last year I just
realised that I couldn't keep pushing myself to do it. So I'm hoping that I'm going to get a new
lease of life and be active again! I mean I am still active I do do things but not to the extent of what
I used to.

R: So getting back to 100% - is that your ideal?

As my husband says he'd like me back again! Yes.

R: Yes. So he's noticed

Oh yes, definitely. The enthusiasm back in me and the energy.

R: Yes, so it's kind of zapped your zest for life really?

It has yeah.

R: And your husband's noticed. What about the rest of your family, have they noticed? Do you
think it has an effect on them at all?

Umm. I'm sure it does my daughter because she's 16...she's umm, I try to be tolerant, but perhaps
I don't have as much tolerance as I could. And she can't understand why I'm crabby and I try to
tell her why, but they don't always understand themselves what they're going through! Hormonal
changes! So...

R: So I mean best case scenario, the magic wand is waved and everything is brilliant, what's your
life going to be like, how's it going to be different after the operation, if everything goes absolutely
according to plan?

Hopefully I will be back at the gym, I will be back at my committees, I will be back full of zest
and energy. That's what I'm hoping. Mmm.

R: Is that kind of more long term, or is that short term..
111. Long term, long term. I don’t expect it to happen overnight, no. I’m realistic about that. In fact I
112. suppose I’m getting quite used to having a peaceful life, so it’s a natural progression anyway not to
113. do so much! But as I say, I’ll want to get back probably to the gym, so hopefully, fingers crossed,
114. yeah. I mean we went skiing at Christmas, and we were skiing five hours a day for a week, and I
115. was absolutely shattered but felt good, even though I was really tired! So I’m sure there’s still
116. plenty there!
117. R: So you’ve been worried that you’d kind of lost your go for good?
118. No, not really — well part of me thinks, part of me thought, is it my age? Is this sort of natural to
119. slow down, and me mum keeps telling me it is! And I think, I’m only forty-five! [laughs] When
120. I’m sixty-five maybe I will think like that! But I’ve still got lots of years left so...no. I’m sure it’s
121. the endometriosis and the anaemia definitely.
122. R: Yep. So your mum was saying it’s your age, and your consultant seemed to have that idea as
123. well?
124. No, well I seemed to get the impression that — I was quite shocked when he diagnosed
125. endometriosis and he said, what I suggest is a hysterectomy. Absolutely astounded when he said
126. this! I said oh! He said, considering your age you’re past childbearing, you don’t want anymore
127. children, I suggest a hysterectomy. And straight away I just said no, I don’t want one. I hadn’t
128. even thought it would be anything like that, and I said is there any other treatment that I could
129. have? And that’s when I was put on progesterone, but unfortunately [sighs] its made the periods
130. slightly less but its still painful really. So its just really its gone on and on and I’m getting worse
131. and worse and worse, and as he said, I went to see him and he said, it will not get any better. It’s
132. not something that’s going to get any better, so he said I’m making the right decision. He said it
133. would have to be my decision. In some ways, you — I wanted him to say, you’ve got to have it, it’s
134. a life and death situation, in some ways I wanted that because its been very very hard for me to
135. come to the decision to do it.
136. R: So...it’s almost, he was saying you had a choice, but to make the choice was difficult
137. Yes
138. R: And so you needed a shove?
139. Yes, yeah. I did really.
140. R: Can you tell me a bit about — well you’ve said about some of your worries, but what was the
141. one thing which made it so hard? What’s the one thing that really stood out for you?
142. Well, the fact that somebody says, you aren’t having any more children. You know, I mean I
143. know, and I know that I don’t want any more children, but the fact that somebody does say that to
144. you does make you think oh, well maybe but....
145. R: So taking that choice away from you even though you’ve thought maybe you won’t have any
146. more.
147. Yes, yes. We’ve already made the decision we won’t have any more, but the choice is being taken
148. away from you should you want to.
149. R: MMm. Were there any other choices which you felt might be taken away?
150. Well — I did ask him about this endometrial ablation is it, yeah, I asked him about that and he said
151. it wasn’t appropriate for me, umm I don’t know why. Well I think he said something about it
152. being in the pelvic region. So I don’t know...do you...
153. R: No! its not my field ![laughs]
154. No you won’t know will you! ![laughs] I’ve got no idea really as to why, he did perhaps tell me but
155. I don’t remember.
156. R: No
157. But that’s it really, I umm think at the end of the day, you’re taking part of you away aren’t you? I
158. mean how would you feel?
159. R: I don’t know actually is the answer — I think now I don’t have children or anything I think it
160. would quite devastating.
161. Oh yes!
162. R: But I don’t know how I’d feel later on. — I don’t think you can know until you’re put in the
163. position.
164. No, no.
165. R: Perhaps you can’t even know until afterwards?
166. No.no. I mean my sister had one three years ago and she has had a lot of problems since. This is
167. the other side of the coin as well. So ... and I can’t honestly look at her and say she’s been given a
168. new lease of life, because she hasn’t, she seems to have gone the other day. So I mean there is
169. that fear, I don’t think it’s a magic cure.
170. R: So you’ve got the other lady who you said it had gone really well, and then your sister who it
171. really hasn’t done much for. Has that been an important factor for you, has that been something
172. that’s been putting you off? I know not having a choice about children was very important, how
173. about seeing other people’s bad experiences?
174. Oh that has put me off, yeah. You’re just putting yourself in their hands and umm things do go
175. Wrong. Hopefully not in my case.
176. R: So there's an element of trust there?
177. Yeah, a big element of trust, you've really got to trust them implicitly really. And you don't know who's doing it.
179. R: Would you feel happier if you'd met the surgeon before and you knew exactly who was going to do your operation?
181. Yes. I actually asked [consultant] if he was performing the operation, and he said he couldn't guarantee he would do the operation, but he would certainly be there when it was performed.
183. Because I feel as if I know him, having seen him for so many years, with me having regular smears and check ups, I feel as though I could trust him. I mean I've no idea, but I just feel yes, if I knew he was doing it. If I could afford to go privately I would have done.
186. R: Right, so is that something about the NHS?
187. No it's just to guarantee it would be him performing the operation, that's all, it's not about the NHS.
189. I feel they offer a really good service
190. R: Yes
191. It's about guaranteeing one person
192. R: Yes, the person you've got to know and trust?
193. Yes.
194. R: And like you said earlier, they're taking a part of you away. How important is that part of you do you think?
196. Well it's a painful part at the moment, so... umm... I don't think it's... well its important in that I need it to have child, umm... I don't know how I feel about that.
198. R: Is there anything else that it does or that you think about it? I mean some people have thought well things that pass through their mind and they think, don't be silly, don't think about that. Is there anything like that that worries you at all?... Things other than the childbearing side that you think are important or you might miss even?
200. Umm... yes, well having a period actually, we're that used to having a period aren't we, albeit that it's painful. It will seem strange not having one. Nice... but strange!
204. R: Umm, if you could keep the periods but lose the pain, would that be an option?
205. Oh yes, absolutely, yes! To just feel well, that would be fine.
206. R: I'm quite interested that you said that, can I ask a bit more about that?
207. Yes!

208. R: What's the thing about periods that's good? I mean...

209. Well there's nothing good about a period really! But its being a woman, I'm used to it...you know, its in us. We have a cycle, and its something that happens. I suppose its like because...well they were testing to see if I was menopausal which I was hoping in some ways that I was, because then I knew that it was coming to an end, but I wasn't. But I suppose in a way that would affect you...but you get used to it over a period of time, it doesn't just stop.

210. R: So you'd have a chance to adjust, get used to it?

211. Yes I would.

212. R: Is it, you say its something that's a cycle – is it kind of a rhythm, marking of time thing, or is it more about being a woman...

213. PMS!! Yes [laughs] Actually, I'll get rid of that won't I! It'll be wonderful! Be great, I won't be getting the knife out! Umm yes, I suppose it is really if you think about it, but then sometimes I organise my life around it! My period... like when I was going skiing, Oh I don't want my period when I'm skiing, and that will be all taken away, I won't have to think about that. But we're used to it aren't we! Its something that happens all the time and you get used to it.

214. R: Predictable?

215. Mmm yes. I think I will miss it you know in away, in quite a strange way really, because its caused me a lot of difficulty and trouble, yet it just does mark time doesn't it. Strange.

216. R: I guess...somebody said to me that it was like the old car they had which kept breaking down but it was still their car!

217. No! [laughs] I wouldn't use that as a description, its part of you. I suppose as well you still know that you're ovulating, things are still working.

218. R: So that period lets you know that you're still able to have children?

219. Yes.

220. R: Everything still working fine?

221. Yes. Yes. It does really.

222. R: Is there anything else about it that you might miss?

223. Umm...no...I don't think so. That will be it.

224. R: We talked about whether you will feel the same or different, will your partner think of you the same or different?

225. Oh, he'll just think I'm the same, yeah, I'm sure he will. But umm, I was reading something and
239. you actually – there’s your vagina and your cervix and they cut it away, take your cervix away and
240. then you’re sown up aren’t you?
241. R:  Mmm
242. Yeah. Will it still be OK afterwards for sex?
243. R:  I don’t know.
244. Yeah, cos when I read that I was quite shocked actually.  Cos I thought, I wonder if it makes any
245. difference? Because there’s obviously that other channel there isn’t there?
246. R:  That’s something you’ve thought about?
247. Yeah ...
248. R:  I think that’s a common worry for women I’ve spoken to.
249. Yeah
250. R:  Wanting to know, will I still be OK.
251. Mmm
252. R:  Some people say, yeah it will be great because I won’t have to worry about my periods!!
253. Yeah [laughs]. Yeah – more often!
254. R:  [laughs]
255. he can’t cope with me now!! [laughs]
256. R:  They can’t can they! [laughs] Do you think you’ll have any regrets after the operation – I
257. know we’ve talked about some of the worries but..
258. Oh I’m hoping not but I’m not looking for any regrets or thinking about anything, I’m just hoping.
259. R:  Trying to be positive?
260. Yeah, yes, so no I don’t think I will.  I...I don’t know, I think in a way that once I get used to not
261. having a period I’ll be fine and start feeling better.
262. R:  There’ll be a kind of adjustment?
263. Yes. Just getting over the operation really.
264. R:  Mm. I know you talked about some of the worries you’ve had, are the worries short or long
265. term? Things about the operation, about being able to do stuff...
266. I’m sure that’ll just be short term, in the short term umm and ...I’m determined to get over it – I
267. think you’ve got to be positive think positively about it. It’s a worry, and I’m not looking forward
268. to it, but I’m going to get over it, as thousands have. So I’ve got to just think like that really.
269. R:  Sort of go at it, go get it, get better?
270. Yes, I’m not going to let it get to me really.
271. R: Which I guess fits in with the way you seem to be?
272. Yes, yeah.
273. R: Keep going?
274. Yes keep going..umm ...hopefully.
275. R: Mm, absolutely. Umm..we've talked a bit about why you chose to have a hysterectomy, and
276. the things that stopped you for a while, ...we've talked about your biggest kind of fear, but what
277. was the biggest influence to have one?
278. The biggest influence to have one is the fact that I aren't functioning properly, I know I'm not, I'm
279. not functioning 100%. I don't do what I want to do because of it...so that's the biggest thing.
280. Because I'm sure, well I hope at the end of it I will be getting that energy back, back to what I was.
281. I'll cope with the after effects of the operation, I'll cope with losing my womb, I'll cope with that
282. because I'm sure I can deal with that mentally. I just want to be back to normal.
283. R: Back to being yourself?
284. Yes. Not feeling absolutely knackered all the time – doing something and thinking I can't be
285. bothered, I want to be like me again.
286. R: Yes, so things can't go on the way they are?
287. No they can't, I know I can't, now I've come to a point where I don't go to the gym, and I used to
288. love it. I don't play netball and I used to love it. I... I don't do those because I haven't got the
289. energy to do them anymore. So no matter how much iron I'm taking its just drains away once a
290. month. And I just replace it, drain it away, replace it, drain it away, and it's a vicious cycle, and I
291. can't keep going like that.
292. R: No,
293. Yes I can cope with the pain, you can get pain relief, you can get things to help you, but you see its
294. the feeling of tiredness that's worn me down. That's made me decide to have this[sounds very
295. tired]
296. R: That lack of energy?
297. Yes the lack of energy more than anything. Yes.
298. R: So that's the one thing that hopefully will be different.
299. Yes, and if its not there'll be trouble [laughs]
300. R: Yes [laughs]
301. I'll be going back saying, put it back in![laughs]
302. [interruption]
R: I guess we're kind of—you've given me lots of information and we're coming to the end of the questions. Number nine is a bit of a funny question, is there anything else you imagined or thought about but you dismissed from your thoughts when you were making your decision? Kind of, little doubts, or images or words that come into your mind when you think about having the operation, and you say, don't be silly! Was there anything like that for you?

R: What if I die.

R: Yes.

R: And then I thought, don't think about that because you wouldn't know anyway. So yes.

R: You might die on the operating table?

R: Mmm Or after or anything, you know

R: Yes. Have you had any information or reassurance about that, or is that something you've kept to yourself?

R: I kept it to myself. Yes, so no, nobody's reassured me.

R: I think it's a common worry for a lot of people.

R: It must be but then I thought well if I do I won't know anything about it. But you do think about it, it does happen doesn't it.

R: Was there anything else like that?

R: No nothing really.

R: If somebody else was in your position, what would you want to say to them? OR what would you want them to think about?

R: Umm...in position, with the same circumstances?

R: Yes. Or somebody who was trying to weigh up ...

R: Its hard before you've had the operation, I don't think I could give them advice, because I'm still very ...I think its not going to happen, there's going to be some magic that happens to me over night and this clears up. Umm I know that's silly! I suppose the reason I'm doing that is when I initially said I would I kept waking up thinking oh god I don't want to have this done and thinking about it. So now I think, what's the point in worrying, wait till a couple of weeks before hand when I get to know about it and then worry.

R: So you're putting out of your mind at the moment?

R: Yes, yeah.
This is probably bringing it all back!

I'm not letting it dominate my life because there's no point in worrying until it happens is there.

No. Tell me if this isn't right, but it sounds to me like you've made a head decision to go ahead and have it, you've weighed up the pros and cons but is it something that like when you wake up in the night, like a gut feeling a gut worry?

Well initially when I'd first made the decision I couldn't stop thinking about it, I felt, oh I've made the wrong decision. Umm I kept wanting to go and say take me off the list. And then when I got the letter through there was like an option on there if you no longer wish this surgery...but...I suppose, once...[doctor] said he wanted it done sooner rather than later so the quicker it gets done the better really. Yes, then I can move on.

So you're kind of hold at the moment, waiting.

Yes.

But once you have the operation you think you'll be able to adjust?

I think I'll be able to cope with it, I do. Knowing me, I think I will. I know there's going to be that initial, but I know that, I'm not making it happen because I'm thinking it. That is me, I know that I will be very frustrated not being able to do anything, being incapacitated and waiting for people to do things for me. Umm, as my husband says I've got to learn to be patient if he doesn't do the washing as I would have done it [laughs] or he doesn't clean up like I would! I've got to say that he's doing his best, and I agree I've got to let things slide. But when you're used to having standards and maintaining them...but I've got to think it's a short time. What I intend doing before I go in is getting myself really organised with everything so I feel that I can sit back and relax.

Yes

I'll get myself all geared up to go in.

So its going to be that inactivity thing that's going to be the most difficult?

Yes. That will be the hardest thing for me. And the physical side of it. But that's the mental side of it, the inactivity. But the physical side, the pain, the discomfort, all that, I'm not looking forward to it. But mentally it will affect me the fact that I can't do things, I can't drive anywhere, so that will annoy me.

Yes...umm..what would you have wanted the consultant to talk through with you that perhaps he didn't? I don't mean it as a reflection on him.

Umm, just...more about the operation really. Umm, because I did say at the time, would I be able
to have the keyhole, the suction. And he said, he would have to assess it when I was under anaesthetic. And I feel why does he have to wait while I'm under anaesthetic, why can't he assess it now, and that's what I want to know really. Why can't he let me know if I'm going to be cut or have that now.

R: So you'd rather know in advance exactly what was going to happen, who was going to do it?

Yes. Yes I would. I'd like to meet the person who's doing it, know exactly what they're going to do, I don't want to wake up and say, have I got a cut or...and that's, I feel sure that he could assess it beforehand. What's the difference me being in an operating theatre? If he could explain to me then fine.

R: Yes

Because ideally I would like the suction.

R: Yes-less of a scar?

Yes. Yes.

[interuption]

R: Coming to the end anyway I guess — is there anything else which I haven't asked which you feel is important?

No not really. No I think you've covered everything about the decision and how I might feel. I just hope that the surgeon's do take note of what women have to say and umm..actually.. from my own experience [doctor] has been lovely, very very understanding, so I can't complain, but I think a man doesn't fully understand. And he actually admitted that, he said to me you know I can only begin to understand from the medical point of view, but we can't from any physical point of view. Cos he doesn't experience what we experience. I think there needs to be a lot more empathy with the patient and I hope...but I can't be critical myself

R: No

Mine has been very good, but I think, they don't understand. I mean I'm hoping that they will understand me whilst I'm there in the hospital, my feelings about it. I'm sure the nurses will, they're women! But its whether the surgeon's do, how they feel about it.

R: So is there a sense that, being men, they might be approaching it from a different point of view?

Yes. Definitely.

R: From a kind of..umm...

Very professional, medical point of view. And the woman's feelings have to be taken into account.
R: So not just the symptoms but the feelings as well.

Yes definitely. They look at the medical side of it, but they don't always look at how the woman feels about it themselves.

That's something that perhaps they need to get inside that?

They need to address that yes. They need to address how... the physical effects of the operation which they will cope with, or they'll get medication for or nursed for. But there's the mental side of it.

People can't take a pill for it?

Yes. Yes and perhaps I don't know how I'll feel but if I needed to talk to somebody about it, it would be nice to know it was there. If I needed it that I could actually go and talk to somebody about it. Umm, its nice to know its there. I think you have a follow-up with the surgeon afterwards and that.

Yes. And you feel that if you had any problems it would be a good time to bring it up?

Yes, if I felt that. They should certainly ask you the... how you feel physically after the operation, but they should also say how are you coping with it mentally -- not perhaps mentally, but how are you coping.

So being you the person rather than

Rather than the physical, yeah..I think they should ask that, I'm sure that would help.

...I'm curious as well because you said you felt they should take women's views into account, is that something that you feel been missing, as in its men doing it, or is that something you think doctors do, don't take the patients views into account?

Yeah I think doctors can tend to be very medical and perhaps conditions aren't always just medical, there's a lot that's underlying issues as well. I think if they could establish some of them first and can umm... but they are busy people, you know. They don't have the time do they, so you can't be critical of them. They're looking at what the patients telling them..umm..but I suppose I've been fortunate -- we've got a lady doctor at our practice and she's lovely, she can home in....Consequently you can never get to see her! [laughs] Everybody wants to see her. But she's very very good, she's perceptive and understands what people are meaning not just from a medical point of view. But I think she really understands how people feel.

She's more looking at the whole person?

Yes, yeah. The whole person rather than just the medical. And I think that would help, if they
could look at that, if they could treat you as a person. I mean I...I'm actually seeing [doctor] privately because I'm in the hospital saving scheme so I do feel I get a totally different treatment. I go and he will sit and talk to me for half an hour, and I feel that ...well I would never have seen him, I'd have seen an understudy or whatever they call them. And it would have been quite clinical or..whereas he is, its very different. Because..I think I'm perhaps going on that experience but I do know people on the NHS and its just too clinical, there's no feeling. So if they're dealt with as a person instead of patient number 84. Yes. R: So is there a sense that maybe privately you feel you're getting a chat, whereas on the NHS you just get a consultation? Yes, yes. I'm sure it is. I'm paying for him to give me a service, he is going to give me that service. Its just one of those things unfortunately, he won't have the time to sit and talk to me for half and hour on the NHS. But if he could just spend perhaps 10 minutes it would help. R: Yes. It would definitely help.... That's about it really.
1. Participant summary

Ellen is 38 years old, and has been in a stable marriage for a number of years. She has one son aged 13, and had decided not to have more children due to her husband’s poor health. He has heart failure. She had recently stopped work, previously working in a canteen, so she could care for her husband.

Ellen began to lose blood every day about a year ago. She has tried diathermy and cone excision twice, but these have not helped. On a scale of 0-10, it affects her life at level 10. She feels she cannot carry on like this as well as caring for her husband, and is on the waiting list for an endometrial ablation. She is not going through the menopause, and has never had psychological problems.

2. Interview with Ellen

Date of interview: 19.01.01
At University

(Blue type is the researcher, black is Ellen)

1 I guess the first thing I wanted to known was what made you decide to take part in the research – I’m very grateful that you decided to.

2 Well I just thought it would help, that’s all. I mean I don’t mind helping as I say, I’m trying anything I can, and as you say, I hadn’t heard anybody else who’s had it. So I thought if I can help anybody I will.

3 So you were kind of giving anything a shot?

4 Yeah I was yes.

5 Ok. I know you’ve had this problem for a while now, haven’t you, and it affects your life

6 quite a lot.

7 Yes it does because I feel permanently as if I’m going to start. You know, my chest,

8 everything! I’m real heavy, I’ve got no go, and as my husband is, I’ve got to feel better than what I do now.
So most of the time you're feeling quite drained and tired?

I lose every day. Yes. So I have done for, since, well over a year now.

So that sounds like it's affecting your life and the way you can care for your husband?

Yeah, yes that's it. I thought, I can't leave it, I've got to have something to try and make it a bit better.

How about your social life and things like that, does it get in the way?

Oh awful! I don't really have one really, I don't go out, no

I guess caring for your husband...

Yes Caring for someone and then with its, he's not working, he'll never work again so...

Yes. So this thing is having a big effect on your life at the moment.

It is, yeah

So what are your hopes for after the operation?

Just to feel a bit better really. Not to feel so tired — cos as I say, my husband can't do anything, so I've got to do absolutely everything. I mean he can, he gets up, but that's it then, and he can drive but that's it then, I've got to do it all.

So you need to feel better in yourself so you can do the things you've got to do?

Yes that's the reason, so...

Right. So at the very kind of, best case scenario, how do you think you'll be, if we could take a picture of you, how you'll be afterwards?

Hopefully a lot better. I can't feel like I do now. I just feel absolutely drained every day.

Yes, so

Yes. I imagine that might take quite a toll on you emotionally?

It does, because I've got to be strong for my husband and my son, he's only just turned thirteen and his dad's been poorly since, well he's been poorly for twelve years, but he's been poorly since last February, getting on for a year now you see. So, I've got to go
different places, he’s got to go to Sheffield like and that, so I’ve got to be well set for
me
to do that, do you see what I mean? So hopefully…!
So to keep you able to look after everybody, you need…
As I say he notices that I’m not, y’know…
Not a hundred percent?
Yes. Well you are, on the outside you are, but on the inside he knows I’m getting tired
now, its getting, it wears you down.
You’re getting quite fed up as well as feeling physically tired?
Yeah. I do yeah! It just doesn’t stop! I think I’ve only had one day where it stopped and
I
thought “oh good!”. But it hadn’t, so…
That sounds terrible! Dreading waking up almost is it?
Well I just flood every day all day. Yeah. I have got worse since I’ve had the
injections,
I don’t know if I should do, but presume I should do from what he’s said about it. But
err…I can’t wait, its three weeks! I’ve had me hot flushes and that he said I would
have,
so…
So how have you managed to keep so cheerful as you seem today?
I don’t know! I don’t know really. As I said, if I didn’t have a child I wouldn’t maybe, I
think though that he sees his dad, he sees a lot with his dad, all he’s ever known from
thirteen months old is his dad being poorly. But this time he’s old enough to understand
what is wrong with him. So I try and keep as normal for him. I mean, cos when I was
working, everyone said, oh how do you go? But you do, you just... keep going
Yes. So its pretty much your husband and son that keeps you going?
Yeah if I didn’t have any children I’d be, maybe I’d be different, but, so yeah, you do.
Something in you comes, you think well I’ve got to... don’t you? So..I do.
You find inner reserves of strength...?
Yeah you do. I keep going, as best I can.
So I guess after the operation, maybe you would - things will be easier, it’ll be easier to
get going, you wouldn’t have to keep...keep struggling on?
Yeah, mmm, that’s what I’m hoping I can’t feel like I did.
So physically you’ll be better, how about sort of mentally, emotionally?
Well as I say I’m hoping to because, I just feel so drained. Hopefully when I have it
done
they said I maybe won’t have any more periods whatsoever, hopefully! So I’m hoping
I’m lucky like that, so..I don’t have the - not hassle, cos you always have them don’t
you
but...I have my share everyday! Yeah....
So you’ve had more than your fair share really?
Yeah I’ve had more than my fair share so I’m hoping if I don’t or if they’re not as
bad....
Do you have any worries or fears about afterwards at all?
No no ...No because I decided to get sterilised – what, how many years, oh it’ll about
six
years ago. Only because as my husband was...he was at work then, after his stroke I
got
him back to work with his disability. But as I say I’ve always known he could get
worse
and maybe need an operation. I didn’t know he’d go into what he’s got now, but um so
we decided as [son] got older, I wouldn’t have any more really, one was enough,
luckily!
So there’s no worry there that you would want to have more children?
No that’s not no
So that’s not a worry. Umm I guess the other thing is, are there any worries that...that it
won't work?

Umm not worries, I'm just hoping, I've got to keep positive. If it gets me a bit better than
what I am now, until I get too bad that do need a hysterectomy, it's to try and prolong it.
So you're hoping for a little bit of improvement at the least, anything would be better than
now?

Yeah yes! Just two days off would be!

That would make a big difference to you?

It would, yeah.

Do you think you'll feel the same or different after the operation - I guess as a person?

Umm. I'm presuming I'll feel a lot better. Yeah. I can't feel like I do now. I can't feel as
tired and as drained as I do now. So hopefully I'll change every way - not every way,
you're still the same aren't you, but it'll just make it a bit easier, you'll have a different
outlook really - I'm hoping!

You'll be able to be brighter and more positive and ...?

Yeah, a bit more go. You do all the things you have to do but...

You'll have some energy left over at the end of it?

Yeah.

Right. Umm do you think your partner will think you are the same or different after the
operation?... Do you think he'll see a difference...

Umm. I think he will yeah. Cos as I say over the last year he's gone from being at work
to being able to do nothing, to come downstairs and that's his lot. Go upstairs on a night
and that's his day. So... I think it will do, it will get easier for me.

Right. Just thinking about, well you're having an endometrial ablation now, what made
you decide to go for that rather than hysterectomy? Was it doctor's advice...or...was it
you who felt you wanted that first or...?
Yeah. Umm He just suggested - the doctor who I saw - he just said, oh if it doesn’t work,
this is like the last thing I can try before your hysterectomy, but he said he didn’t want to
give me one - well he says I’m young I’m not that young, I’m thirty eight aren’t I, I don’t
class myself as young! But he didn’t want to do it now, plus as I said I couldn’t have one
at the minute with me husband as he is. So he said hopefully this will stop altogether, it’ll
be like the next best thing, till whenever, if it does come back I’ll get to work.
So it was more around recovery and...
Yes. I couldn’t be out of action for so long. So I don’t know if he knew that, I mean I told
him when I first came, so he suggested that, so I’m presuming that’s why.
Right. Just thinking about, kind of switching to the future, if you do have to have a
hysterectomy, how will that be? Will you have worries about that, that are maybe
different to the operation you’re having now?
Umm. No not really. No. As I say, I’ve, we’d decided not to have any more children
because a of our circumstances, so no, its not as if I think it’s a final thing now. No.
And again, I guess the same sort of questions, do you think you’ll be the same or
different
say if you had a hysterectomy as opposed to this, and do you think your partner will....
Umm. Err. He’d more than likely see me as the same, but as I say it just makes it a bit
easier
Makes life easier?
Yes makes life easier, that’s all I’m looking at. That’s all I’m doing. I’m not doing it for –
I need something done but – it’s the pros and cons at the moment. Yeah. But initially, he said before if he couldn’t, he was hoping that the second time he did what he did before, he said hopefully it should work, but it didn’t. So he said look, there’s not much else I can do, only this, and then a hysterectomy, so..

You’ve tried a lot of things.

I’ve tried like two things, he’s done it twice, he said he couldn’t do it anymore, he’d have to do something else, so… That or go onto tablets or whatever, but… I’ve got enough with my husband on heaps a day anyway!

So [unclear]

No, no.

Can you tell me why that was?

Well when, before I got so I was, I was on the pill and I tried that many different ones and none of them agreed with me.

So you had a lot of side effects?

Yeah I did, yeah. My weight and everything.

So that’s not really an option?

No, no. With me being so like I said, he said there’s no point really, cos you’ve chose not to have any more, you know what I mean. You could have it reversed but, no! It was bad enough having it done, I’m not going to have it reversed.

So that’s been the right decision for you?

Yeah. You don’t think so at the time, like I was only thirty-one, and [son] wasn’t very old.
But I had to wait for that even, cos with me only having one, and the condition of me
husband, they kept saying, what if you get remarried and this that and the other? So I
had
to wait years. I had to wait about three years for that, even though I knew I wanted it
doing when I was like in my late twenties.
So you were kind of ready for it?
I was yeah.
But people were saying you might change your mind?
Yeah. They might change, and like he had stroke when he was twenty four, and he had
his
first operation three months later, so of course I've always sort of thought well I won't
have any more, I've sort of looked after him, so, but I still had to wait years for that.
How does that make you feel?
Quite cross, cos I thought, well I've made me mind up! It's as if you might change your
mind, and I was like, well no.
So you felt quite clear that you knew what you wanted and that was that?
Yes, I was, yeah.
Is it the same with this operation now that you know what you want?
It is, yeah. It is now, yeah. As I say, no matter what it is if I had a hysterectomy, if I
had
to have one, it wouldn't change me, I've decided I didn't want no more children.
And that would have been your biggest consideration?
Yes it would. If I was - like when I...what annoyed me when I decided - like I would
have
been what, twenty-eight and my husband had been poorly for four years, when I was
twenty-eight I was ready to have, to be sterilised then. But they wouldn't - well, I
thought
I've decided now and then I've had to wait all them years!
Right. Yeah
So they still say oh I’ve got to wait you know, but what if you’re not... if you change your mind or, but no, I won’t!

I guess some women think they will miss their womb. Is that something...

No, oh no.

For you, it was the children thing and after that there was no more use for it?

Umm. Yes. My circumstances changed, my life changed, I look at it like my life changed,

so there was no way possible. I couldn’t – not afford to have an accident, I’m not saying –

but I wouldn’t have done anything about it if I had of done, but my life changed, sort of overnight, and my, your outlook changes. So I looked at it like that – I wouldn’t have time

for another one.

So because your circumstances changed, that part of your life was no longer so important....

No, no. I thought well I’ve had one, luckily he was healthy and everything, so I’ve never really craved for anymore. And even if something happened to my hus... I don’t think if

I got remarried now, I wouldn’t think well, I want another one, I ...I wouldn’t!

So it’s quite clear cut for you?

Yes, it is for me.

Mmm. Yes. Ok, do you think you’ll have regrets after the operation? Thinking again the

ablation and then later the hysterectomy if...

No. No not really.

You’re fairly, you’ve made up your mind?

Yeah.
How do you think you’ll feel in yourself after the operation, short and longer term I suppose? We’ve talked a bit about the short term haven’t we?

Umm.

I guess I’m thinking in the years to come...

Umm. It’s hard to say.

It’s a hard question, hard to imagine?

Yeah. I just hope it works! Umm... I don’t – err, I don’t suppose I’ll feel any different, you know. As long as it’s made it, made me feel better.

So as a person you’ll still be the same?

Still be the same, yeah.

But you’ll have more energy, more go...

Yes. As I say, a lot of what decision I made, when they said, ooh, you shouldn’t have been sterilised, I thought well I decided... I never thought anything of it. I never thought well I shouldn’t have been, I’ll have to have it... I never....

You never regretted it?

No I never regretted it. So I think well... I look at everything and think, well it’s my next step, and as I say, they’re just to... to make me feel better than what I am now.

And that’s the primary important thing for you now?

Yes, it is yeah. Cos as I say, until I feel better... I’ve got to feel better than what I do for like my son. Cos you always, I always look after my husband, as well, but that’s how I’m....

People are relying on you?

Yeah. So I think, I’ve got to... I’m the only one people rely on, so I’ve got to feel better... So... that’s what I’m looking at it like.... But when I go in!

Yes, mmm. It sounds to me like you’re very positive about it?

I am now, I have to be. Yeah, I’ve had to change my outlook on everything really.

Can I ask a little bit about how that came about, how did you do that, how did you sort of
turn things around for yourself?
Well... You just have to get on with it really.
So just by doing it?
Yeah. Just by doing it, and you know, you alter, you change, you change your life, and you carry on. Yeah
That sounds pretty brave.
I never used to be, but! No, no I don’t know. Cos a lot of people say to me, cos as my husband is now, I couldn’t live like... but you do. No matter what, if it’s for your husband, your wife... you do it. But yeah, so.
I get the sense that, no matter what happens, you’re just going to keep going, and try to get through it?
Yes, oh yes. Yeah.
And that you don’t look back so much... is that...
I don’t look back now, no, cos as I say, for me husband’s sake and me son’s, I’ve got to, look forward really, no matter what. I mean he’ll maybe get a trans..., he might not, we’ve gone over that, you know what I mean. So I think that’s something that keeps me going.
I’ve got to be all right no matter what happens, for me son’s sake really.
Yes.
I’ll just send my husband instead to have me needles! I don’t like needles at all!
Oh, no I don’t blame you!
I said, can’t you put me to sleep and then put the needle in! But no!
Oh they’re horrible aren’t they!
Oh ugh!
Ok. Umm, we’ve talked a bit about this anyway haven’t we, that the reason you chose not
to have a hysterectomy now is the recovery time?

Yes.

Ok, what had the biggest influence on your decision to have this operation?... What was

the biggest thing that really influenced you?... Cos, for some people it's the doctor, for

some people its partner...

Yeah. Well. Umm well no as I say, I didn’t...know that there was this operation, till the
doctor who come to see me, who does it, said try it. As I say I hadn’t heard about it or
anything – he give me a leaflet, and then I think, was it a few weeks ago, I think it was me
mum was reading in a book about this lady who’d had it, and she’d had what I was having
done. So its only things like that. Like he said, are there any questions but...I didn’t have
any really, you know what I mean?

So you read the stuff and it sounded ok?

Yeah. Yeah. My best option at this moment in time.

And again, was that about – you said you’d read that article, about somebody else, was
there anything in that that made you think, that’s the one for me?

Because she’d – well the lady in it who’d wrote, she’d had what I’ve done, well twice, and
that hadn’t worked, like me, and she was always like real heavy, she couldn’t go anywhere,
she didn’t feel like anything. So they told her about this, and said it...well they didn’t
know what the injection was called before I went for it, but she said it was in my stomach,
and that’s what I had. And it was the same one when I looked on the thing. And then
umm, she said it worked for her. So...
Was it that you felt that she was quite similar—her problems were similar to you?

Yeah. Well it was only cos my mum, she kept the err the little, she cut it out for me, cos

she said, that sounds like what you’re going to have done, so...But its only things like that,

as I say I never—I don’t know anybody who’s had it done...so

But it seemed to work for her?

Yeah mmm hmm.

She seemed similar to you?

Yes. But. The doctor who suggested it said it does sometimes work, sometimes it doesn’t,

so all I can do is just hope and try for you. Not many options to go really, left!

Yes. Mmm....Ok—this is a funny question—is there anything else that you imagined or thought about but you dismissed from your thoughts when you were making the decision?...Like, something that you said to yourself, Oh, don’t be silly!...Some people have like worries or whatever, nagging doubts that creep in. And most of the time they go,

no its fine, but sometimes you know, it just sits in there. Did you have any of those?

No, no not really. No. As I say, you can only look, think positive really. And hopefully,

it makes you better, whatever they do!

Did you have any worries about the physical side of the operation, that things would go wrong there?

No not really. It just means I’d be unlucky!

Right. You’ve seen plenty of operations really?

Oh yes, yes with other people. I don’t know—I do mind, but...yeah.

Has that helped you do you think to be positive about the operation?

Umm...

I guess about the doctor’s maybe?
Umm...maybe, yeah.

You've seen successful ones?

Yeah, there's both isn't there. I think the only doubt I have is, in case I have to stay in two nights, that's the only thing!

Right.

I said, nothing else matters, but I can't stay in!

So you're worried about having to stay in?

Yes it's afterwards. He says after what you've had done, its pain afterwards. That maybe the painkillers that you take home wouldn't be strong enough so they'd – depending on what time you go down, they'd....

Keep you in?

Yeah. I hope they won't, cos as I said, I don't want to! And me husband said, I'll come and see you in there, and I said, no! I usually go and see you! You've been in here three months, that's fine!

Why don't you want to stay in, what is it....

Ooh no! No...

Is it that you don't like hospitals? Or...

Well I haven't stayed in one since I had my son! No!

Would you be worried about your family, or...

Umm. I...Umm, as I say, I've got, not doubts, I've got more worries. Cos as I say, I've never left - cos when he's in hospital, he's in hospital, but I've never left him. I mean my mum lives where I live, not far away, but as me son is, he takes his dad's problems on.

All to him, you know what I mean? He thinks if I'm not there, he - not takes over, but - cos
in clinic — when he was in hospital, when they diagnosed him first with heart failure, then

he had his second operation, then he’s back in with heart failure now — and they wanted to

send him home for some reason, and he said oh no, its not fair on my wife. You know, she’s always looked after me and whatever, but she’s not said, I’ll wait to have me operation. And me son said, I’ll look after me dad. So I think if I’m not there, he’s — cos

me husband’s poorly through the night — like most nights being sick or whatever — and it’ll prey on my son’s mind, you know what I mean? That’s my biggest — I’m not bothered about the operation, apart from I don’t want to stay in! So...

Right, right, you don’t want to put that role onto your son?

No, no and he would do. Even though if me mum was there, you know what I mean?

So... I don’t mind me, but as I say, it’s the circumstances you live in, I live in now, that’s put a thing on it, you know what I mean? [Husband] says, well if you have to have a hysterectomy, you’ll have to have it, but I says, I can’t. I can’t do nothing for so long — I mean I don’t know how long you can’t do anything for — but, he said, oh, we’ll get by, but

I said, no, you know what I mean? You can’t — I can rely on my mum, but I’m that type of person what can’t expect somebody to do everything for me, you know what I mean?

You want to be doing it yourself?

Yeah, so...

It sounds like, all the things that you’ve talked about have not been worries or fears, or anything about you, or even considerations for you

No, no!
But it's been about the other people around you, that you've had to have these operations,
for them as much as anything else, so you can care for them?

Oh yes. Yeah. To care for them, yeah.

And that you worry about maybe not being able to do that?

Oh yes.

Is that your biggest thing?

When I come, they say, oh you can't do much for so many days or whatever, I thought, fine I'll get by that, but then I'm thinking, oh, I've got to iron, I've got to — you know, just

normal things. But yeah.

So that's the things that would pile up if you weren't there?

Yeah. But my mum said, I'll — but I just, it's bad enough with me husband, I mean he gets

up and that's it for the day, he can't do anything, that's it for the day. I mean, he's allowed to drive still, but he can't walk anywhere. So, as I said there'd be [unclear] Oh no!

That would be too hard for you, to be the patient?

Mmm. Yes.

That's not what you're used to?

Mmm yes, that's not me! Yes. So the operation I don't mind, just don't want them keeping

me in!

Yes. That sounds quite — given what you're saying, that you need to keep going.

That's the only thing, yeah.

Right. I'd like to ask a strange question, if you were forced to rest and not do anything, how would that feel to you?

Awful.

Can you tell me a bit more?
Umm. I've always been a busy person, I've always worked, only like when my son was little - I think I went back to work when he went to school. But in that time I'd had me husband poorly as well at home, so, right now, well its easier now because me son, he's just turned thirteen, he's not in very much, he's always out. But umm, not to be able to do... like I've gone from like working, I used to leave me husband but like I say, he's got worse, he can't go up and down stairs or whatever now, he's as good as is tablets are. When I went to work, my mum just called round on me more, he could ring up and I could go home. So I've gone from, I'm not working and looking after my husband, that's adjustment for me. So to think well I can't do anything, well... no.

It would be too much of a change?

It would, yeah. I mean I only just finished in like November, and its bad enough now! No, but I'm thinking like, oh I should be at work now you know what I mean! I'm still...

Still on the go?

Yeah, someone said to me, you never, well I said, I can't! I've always got to be, I can't just stop and not do anything, and I've never been able to do that. So that's the biggest – if I had hysterectomy I couldn't, no, I couldn't go that long without... You'd do it, you'd get by if that's my only resource, I would have to have one, and I'd have to get over that.

But, no... not at the minute.

Is it that you'd be bored, or would you get down?

I'd get down more I think. Cos as I say, cos that's what me husband says, cos when I went to work for like two and a half hours a day I worked, But like it got you out to see different people. He's been poorly from what, twenty-four, well like for twelve years. He
hasn't been as bad as he has towards the last year, but otherwise he’s gone from like
working, going out to work and everything, to being at home all day, every day. I mean
he
can't garden, he can't do anything like that. So it would get me down, well it would get
me
down more to think, well me and him sat at home, he can't do anything, if I couldn't do
anything then I would maybe get down. Whereas now I think, no I've got to do me
jobs,
I've got to take the dog, I've got to do the garden, I've got to wash the car. Things like
that – I'm always busy.
So keeping busy keeps you cheerful?
Yes, it does. Cos I mean he goes into depression which they said he would on the
medication he's on and that. So he's down, I've got to be all right for me son's sake,
you
know what I mean? So... I think I'd, if I was out of action, I'd go... down.
So that would be your worry, if you had a hysterectomy, sort of how long you were off?
Yeah, how long I was off.
You might get quite down?
Yeah, I maybe would.
Yes. Mm. As well as the practical stuff about...
Yes, that's what I mean. I'm not obsessed by cleaning, I'm not – but it's just your day to
day things that you take for granted that for me, it's not taken away, but I wouldn't be
able
to do them, that's the only thing. But I've got no thing, I've got no sort of thinking,
well I
don't want it because of this that and the other, that's the only reason I wouldn't have it
though.
Mmm. Why don't you think other women – say people who don't want it – why don't they
want it do you think? What do you think people worry about?

Umm, I suppose it depends on what you’ve had in your life, changes. I mean, say my husband hadn’t been poorly, cos who’s to say you wouldn’t have more than one, maybe I would, but I’m not saying I would have more than one, but me options would be open.

But overnight, they were taken away and I couldn’t have another one. So, I mean, I’m not saying that I couldn’t, but my decision is,... you can’t do both.

Right.

I mean, like I had, like, he was thirteen months old when my husband was poorly, so I had to divide my time between — I mean my husband couldn’t get dressed, he couldn’t feed himself, or anything — he had to learn to walk and talk again. So, I had like two to look after. So, I don’t know.... I’m not saying the time passed you by, but then your life’s changed, so the aspect of you having children again, me, had gone. You know what I mean, I wouldn’t think well when he’s five I’ll have another one, cos that’s too long a gap.

So, it depends on different women. If nothing had changed in their lives and they’d want an option to have others, I mean some women want them older, children, don’t they nowadays, then ...I don’t know.

So they’d think about children. Is there anything else they might think about?

Umm. Not liking staying in hospital maybe! Umm ...I don’t know, cos as I say, I’ve always known, once I decided, that’s it,

It’s hard to think about other options?

Yes that’s it. So I’ve never in my life while I’ve been married, I never thought oh well, if

I’d said have another one, I’m not saying I did something about it, I thought I’ll get
sterilised, then... I wasn’t thinking like that, if I don’t get on with my life, you know?

But

say it hadn’t happened like that, I had to have umm, I’m same as like my mum, I’m
adopted because she couldn’t have children, and she had the same problems as what I’m
having, which is funny, you know, so she understands. I mean she had to have a
hysterectomy at like twenty-three, twenty four, so she understands. She said she’s got a
maternal instinct that’s why she adopted me and my sister, but she said, when you’ve
got
your options taken away like that, its maybe different. But I’ve had one, I’ve had one
child...for me... that was enough really, and then my circumstances changed. But if
people have, their husbands or partners who they’re with are all right, it must be
different.

Yes, yeah.

All I want now is just to feel better. So if it takes that, I’ll do that. So..

Yes. Mmm. Other things that women have said they might miss is, umm their periods..

No! No no! I’ll be glad not to have another one!

Umm, that they’ll miss the womb itself because it’s a piece of their body...

No, no.

And also, some people worry about their sex life...

Umm, no, not really because I don’t really have one with me husband. Err no. Cos as I
say, you get by without that even really don’t you, yes. I can’t have a sex life now
anyway

as I am, you know what I mean!

Yes. So when you’ve got a condition like this, those options are gone anyway?

Yes, yeah. I mean we’re a right pair between us aren’t we! [unclear]. So no. No...

Right. Yes, that makes sense to me, that as your circumstances change, your options
change.

Yes, cos even when people said, oh you’re not very old, my husband was only twenty
four
and we’d only been married about four years, and like [son] was only thirteen months,
people said oh I couldn’t do that. And I said, you’ve got to, what choice do you have?
You know what I mean? No matter if he comes - like as I say now, he’s as good as his
tables – he’ll be in a wheelchair, oh I couldn’t do that….you would, you’d do anything.
You do what you have to?
Yeah. As I said, unfortunately, I’ve had this from a young age, what’s wrong with my
husband, but you get round it somehow. I said when [son] was little, it was, why
haven’t I
got a brother or sister? I said, well you haven’t. But he said, cos my dad’s poorly, and he
never thought nothing of it. But until…maybe as I say, not that your life’s mapped out,
its
just your circumstances, which you adjust to.
I think it’s fantastic that you’re so positive about it; I wonder if it’s a brave face?
Yes, maybe because like now, my only options are, my options are now I’ve got to keep
going for – yeah, we’ve got a lot to go ahead of us, my husband, he might get a tr.. he
might not. But I’ve got to keep him positive, if he gets one he’ll get a better quality of
life.
So I hope – and [son] says, why are you going in hospital, and I tell him, I have to be
open
with him, because he sees his dad, so I tell him in a round about way, I mean he’s old
enough now to understand. And err, so I keep positive for – you’ve got to. Cos I sort of
think, well he might not get one, he might die, they told me that, but I think, well till the
day comes, you hope.
There’s no point facing things before they happen?
No. So...
Sounds like a strategy that works for you to me.
Yeah. You just think, I can’t carry on as I am, its just wearing me down. You know what
I mean. But umm, with a bit of luck, I’ll start to feel better which helps me, and hopefully
then he gets better – or some better quality of life to what he’s got. You do.
Yes. Mmmhmm. Are you alright – what times your lift coming?
Oh about oneish, you’re alright. You said about an hour didn’t you so I told him then.
Yes. I mean you’ve whizzed through these, that’s brilliant
I’m boring!
No, no not at all! Is there anything that I haven’t covered that you wanted to say or that you felt was important? I know I’ve asked a lot of similar questions, but obviously they’re ones that I’ve made up, and you might have something you wanted to say?
Umm, not really no. Umm. I don’t know. Its hard to say isn’t it, cos until your…life changes, you don’t know do you. I mean some women don’t want this option or don’t want hysterectomy because they see it as final. I mean my mum had it years ago, she’s sixty eight now, she said then, it was, it was the end of everything, you know what I mean?
So she’s – whereas now, they’re older people having them later, so maybe its harder to compare to other women isn’t it?
Yes. So maybe everyone’s different to anyone else?
Yes. Mmm. I mean to me, yeah, at a certain age maybe if my life hadn’t gone as it is, I’d think maybe yeah, I didn’t want one, but as it is I think, I’ll do anything, just make me better. In just look at like that – well I’ve got to feel better than what I do now. I can’t be any worse than what I am now. No. …So…No…
That’s brilliant, thank you
1. Participant summary

Tina is a 38 year old health professional who is in a stable marriage. She has no children through choice, and was sterilised at age 32, again through choice. During the sterilisation, it was discovered that she had endometriosis, which causes her a great deal of pain during her period. Her condition is worsening, and currently has great effect on her life. She has tried the contraceptive pill and takes strong pain relieving tablets, but these have not helped. She has been advised by her consultant that a hysterectomy offers the best chance of improving her condition.

Tina needed a month of work one year ago for work-related stress, due to the pressures and expectations, and lack of support in her job. She saw a counsellor for 5 sessions, and they focused on setting realistic goals and “not letting the system grind” her down (her words). She scored below clinical significance for psychological problems on the GHQ28 prior to her interview.

2. Written material

I had a hysterectomy because of severe endometriosis. The worst things were the pain of the periods (first 2 days) and having no control over when I would start my period. The pain was so bad I’d have to take time off work each month. I used to pass out with it.

I participated fully in my choice of treatment. Drugs would not have been appropriate. I never thought that I would have any other choice apart from hysterectomy.

No pain, no periods, freedom to plan ahead without worrying about periods were my hopes.

After the op (now) I worry about relapsing – developing other gynaecological problems. I also worry about whether the job was a success.
I was cared at the thought of major surgery but reconciled myself to it as I’d heard positive stories from other people about the operation.

My partner enjoyed looking after me initially but I feel he is wanting me back to my ‘normal’ independent self very quickly. (he wouldn’t say this though). I feel self-conscious about my scar. It is about 7 inches long. People I know see me as they have always done I believe. Some have commented on how well I look. My close friends think I try to rush my recovery too much.

I thought I would feel very different after the operation but I didn’t. I feel that I’ve recovered really well and feel the same albeit tired sometimes. Hopes were very accurate. I don’t want to dwell on fears.

I would have liked to have known how I would have been stitched up — my wound looked dreadful straight after the operation — other patients with staples instead of stitches looked much better. I cannot think of a way to improve what they did apart from using staples.

My recovery period was very good. I managed to get to the pub after 2 weeks! I was exercising from day 1 of being home — walking every day. I was frustrated that I couldn’t do more than was advised. Everything heals so quickly on the outside — you cannot be sure how well things are healing on the inside.

Whilst in bed (for the first 2 weeks) I read absolutely loads — talked on the phone and slept a lot. I worried about being so inactive because I had recently suffered the bereavement of my father (December 17th 2000) — he had died of a deep vein thrombosis. I imagined my bottom and thighs becoming fatty and flabby — simply through the lack of exercise. I felt good about my healing but my body image was poor.

My only regret was that I didn’t lose more weight before the operation.
In myself I feel fine - longer term, I feel that I do not want to keep my current job because I'm around illness all the time. I want/ need to be around people who are wanting to get fit/ stay fit. I would like a complete change of client group. I feel very sensitive to other people's pain [at work] and given my experience with my father in hospital I do not trust the health system at all.

My 'me' is in my mind and body. It was so prior to the operation too. I sometimes feel that I am nothing like other women - because I have never wanted to have children. Fundamentally I am biologically female, but that is not necessarily what being a woman is about. I believe that sex role stereotypes dictate what being a 'man' and a 'woman' is all about. I have needs and those needs may or may not be met - being stuck in a 'female role' means that one's needs have to be marginalised. Now that I am not having periods I can focus more on how my body really feels. I am still ovulating but not aware of it any more.

I would like to comment that 'talking' can be great therapy, but for me, mixing with other patients going through the surgery / recovery period had a negative / scary effect. Every time a woman/ female told me about problems they had, I began to worry that I may be affected too, just by being in the same room as the person. Completely irrational I know, but I am not superhuman - I can focus on the positive so much easier when not around negative influences. My stay in hospital was the minimum 4 days. If I'd stayed any longer I believe that I would have had some complications to my recovery.

At home, space is needed to rest, sleep and gently exercise. Good food is essential and minimal stress. I was lucky enough to have all of the above. I do not envy anyone who had to recuperate and look after children.

I also feel that a trusting relationship with the consultant is vital.

The fitter one is physically/ psychologically before the operation, the better it is for one's recovery.

I returned to work 3 months after the operation, but am looking for another job.
I felt that I was quite fit at 6 weeks (physically) but was glad to emotionally come to terms with the operation over a longer period of time.

I was aware that my colleagues were struggling to work with staff shortages so felt pressured to return to work at 3 months. My GP was happy for me to have more time off.
APPENDIX D

Extracts from Research Diary
1. What I bring to the research in my role as researcher

I first became interested in the area by reading a feminist deconstruction of mental illness and treatment of women, and a statistic somewhere which said that male gynaecologists performed 60% more hysterectomies that female gynaecologists. I was outraged – the former identified the emphasis placed on a woman’s reproductive biology as a cause of mental illness over history, and the latter seemed to be spelling out a form of patriarchal control. I began to read around the area, and discovered plenty of research on women but very little with women. There seemed to be this assumption throughout that either women with heavy periods were making it up or somatising (“mad”) or that those who had felt depressed after a hysterectomy were somehow damaged goods or defeminised (gone “bad”). I wanted to know, is the uterus really that important, with perhaps the hunch from my own thoughts that no, it wasn’t.

I was also interested in what factors were weighed up by the woman in making a decision. This was a major assumption on my part, as I discovered during the analysis, that the women felt they even had a choice. I also naively assumed that in this “enlightened” age, all women would know their options, and want to make that choice. I can identify these now as being my values.

I also bring to the research a number of attitudes, of which only some will I be able to verbalise. Growing up, I was always acutely aware of injustice in general and in particular sexism in education – assumed I would take cookery not woodwork, would wear a skirt to school, would not take maths at A-level – and always fought against it. I have also had experiences with the medical profession which have left me feeling disempowered, because it was felt giving me information was unnecessary. In my present training, I have worked mainly with women, and felt that most of the work has been about empowerment at some level or other. I think that my involvement with this research is probably a way of trying to right what I perceived as a wrong in the way the literature about “women’s troubles” was presented.
I am also very different to the women who took part in this study – I am younger, I do not have menstrual problems, or children. I am from a different generation, where women probably have more choice and more freedom than ever before. I have not had to juggle a career and family and health problems.

Interviewing the participants as opposed to just sending them a questionnaire, I felt more involved than in previous projects, and more connected to and empathic with the participants. I have a vested interest therefore in telling their stories as they seemed to me whilst we talked together, and as I, with my experiences and attitudes, reflected on them later.

2. Diary

July 1999 – initial ideas – surgeons’ decision making processes for hysterectomy

Why do men perform 60% more hysterectomies than women?

Why do women have hysterectomies?

Could I compare hysterectomy and endometrial ablation?

Thinking about what makes a woman – looking at mastectomy?

Can you predict who will be depressed after hysterectomy?

What about male equivalent?

20.10.99

Sample of “normal” women at usual age for hysterectomy plus non-cancer hysterectomy groups.

Which types of hysterectomy – does it matter? No – no differences between methods

Need to choose between qualitative & quantitative.

21.10.99

There is not enough research or any instruments to use to look at self-concept and hysterectomy – need to use qualitative methods.
Pages 239 – 241 are missing in the original
31.7.00

New literature review, so questions are now more specific. Decided to analyse as I go along and then re-analyse at the end so that my questions can reflect themes coming through, and women can agree or disagree with my themes. Need to get women to check their themes if possible.

24.11.00

No volunteers and its been 3 months since the secretary started giving out packs!! Help.

Need to look for other ways of recruiting or other groups to interview. Decided to go for a non-clinic sample, help me access cultural beliefs or old wives tales about hysterectomy, also people not worrying about surgery. Perhaps need to get a post-operative group separate to the case studies since it will be tight on time to follow someone through from start to finish. Might also get people further from operation with a different perspective.

30.11.00

Giving up on the idea of focus groups, there is not going to be enough people or time in all likelihood. Had thought focus groups could give elements or constructs to use in rep grids with pre-hysterectomy interviews but this is unlikely because of time. Looking for non-clinic populations – to help bump up numbers and also to move away from pathologising the whole process. It might help me to access people with an average experience which perhaps wasn’t bad enough to seek help but did have some difficult aspects?

3.01.01

At last some data!

Some of my questions look quite ‘loaded’? Can participants see my underlying ideas behind it all? I’m trying to use reflective listening as much as possible and summarising to check out my thoughts without being too leading. Hard to know if this is working! Most people seem willing to talk and to find it helpful to talk. There seems to be no embarrassment. Will I only get those who are happy or unhappy rather than a mix?!
Half wishing I’d interviewed a consultant – it would be interesting to look for cross-over of themes and perspectives. Not much time though and this moves away from women’s perspective. They might find it threatening too? Having seen the information sheet they might present a socially acceptable front – it would have been better to tape consultations! Ideas for future research there.

Why am I interviewing non-depressed women? I keep forgetting that I am trying to look at the range of experiences rather than extremes.

3. Notes from analysis

Coping styles

I wonder if the old coping styles of exercise or gritting your teeth work after hysterectomy? No-one seems to have concrete plans for what to do, are they so focused on the op that they can’t think about anything else. Could this be an area for intervention?

Post-op interview ‘Esther’

Esther talks about turning into a middle aged woman and I realise how negative a stereotype that is. Women around menopause are seen as overemotional, irrational etc etc and everything seems blamed on the menopause. Older women are seen very negatively in the media and so on. We have more choices but someone somewhere is giving us all these straight jackets to fit into about being thin, being unwrinkled, fitness, diet, and smile smile smile. Unless you are an attractive middle aged woman – in which case you’re seen as preying on/ ‘teaching’ younger men – then you don’t exist.

Ellen
It seemed like Ellen could not distinguish between physically and emotionally tired. It almost as though her periods are sapping her will to live.

Elaine

Elaine talks about periods problems as a kind of social disease, stigma, embarrassment, hassle, being obsessed by toilets and not letting anyone know you’ve got your period, which was hard when she was bleeding so much. The effort of keeping within the social norms must be exhausting. I can imagine how humiliating it would be to get bloodstains on clothes – but why? Why is it embarrassing when its natural? Media is all about hiding, freshening, parachuting, etc etc. All shots of women’s bums so you can see that you can’t tell with this product. You wouldn’t get the same humiliation with sick would you, but you would if you wet yourself?

There’s something about excretion which society says must be hidden?

Hysterectomy – is it a failure to control body, or a last ditch attempt to regain control over body?

Fear of the unknown – you need to trust the surgeon because he’s the only one in the partnership who has done it before! Look at what’s needed to develop trust. Would a woman doctor have advantage in this? What women say seems like they want the opposite to the ‘don’t get involved’ idea. Difficulties in the relationship perhaps come in because of this? It’s striking how brave the women are taking such a huge irreversible step into something which is quite feared and secret.

Children

Everyone brought up children in one way or another which is interesting. This is something which we see as a future role for all women. Do boy/men see their future roles as fathers?

Choice/no choice
There was something about this whereby it seemed like surgeons were saying that hysterectomy was a foregone conclusion and that eventually women agreed or capitulated or something. But the reluctance was huge. Is this just another ‘fate’ of a woman – having to have a hysterectomy?

The meaning of the operation

Split into 3 categories because there seemed to be different aspects about the surgery, the recovery and the removal of the womb, each had different meanings. There did seem to be something about not being in control for the first two, but something about the loss of choices for the third.

Stops me being myself

I had an image of wounded soldiers, slowly bleeding to death. It seems like with every period the woman is somehow diminished. This is certainly not something to celebrate as feminists would have us believe! This lessening of herself before the operation means that hysterectomy is not the catalyst for changes in self-concept (if there are any?)

Comparison

Is used loads in the accounts. But that’s what we do don’t we, we compare ourselves to know ourselves. The women seemed to compare themselves and discover that they didn’t fit in somehow.

Choosing a second analyser

How do you choose? Is it better to have someone of the same sex or different, with knowledge of the area or not, etc? I’m going for [name] because she’s done it before, which will contrast to my first attempt at thematic analysis. I think a woman is important, and also she has experience of psychotherapy which will be useful in identifying meanings. To avoid confirmation bias I’m not telling her anything about the study, and hope this works ok.