PSYCHOLOGICAL ASPECTS OF HYSTERECTOMY

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Thesis submitted for the degree of Doctor of Philosophy in the University of London
As to a disease, make a habit of two things; to help or least not to harm.

Hippocrates, 400 B.C.
This thesis is dedicated

to Gerald for his never ending support
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Karen Wheeler, Carol Jones and secretary Jenny Hancock at the Hillingdon Hospital, Uxbridge; consultants: Professor Albert Singer, Ms. Heulwen Morgan and doctors: Kathy Tiernan, Amaju Ikomi, Tony Davies, nursing staff: Sister Sarah Connolly, Barbara Angel, Sheila Lalbachan, medical receptionists: Joanna Proestou, Jill Parkes and Liz Brown and secretarial staff: Margaret Ballard, Debbie England, Ros Douthwaite and Liz Hecker and Ann Loftus in charge of medical records at the Whittington Hospital, London; consultant Mr. Victor Lewis, nursing staff: Sister Sylvia Holland, Sister Audrey Collins, nurses Janet Jervis and Joelle Priest and secretary Daisy Peets at Watford General Hospital: consultant Mr. Nicholas Drew and clerical officer Sheila Richardson and nurses Ros Abraham and Jane Forman and secretary Veronica Shadbolt at Queen Elizabeth II Hospital, Welwyn Garden City; consultant Mr. Victor Robinson and Sister Margaret MacLeod and nurses Melanie Godfrey, Pat Wylie and Karen Clough and gynaecology counsellor, Angela Reid at Mount Vernon Hospital, Northwood.

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Psychological research into hysterectomy has focused on negative effects of the procedure such as depression. Although it is commonly performed in the absence of physical pathology, there is very little information about why this occurs. This thesis explores possible reasons.

Chapter One examines the role of the uterus, reproductive organs and hysteria and explores the historical, medical and psychological background of menstruation and menstrual disorders. Chapter Two looks at the psychological sequelae of hysterectomy by considering methodological issues, retrospective and prospective studies, expectations and satisfaction and women's knowledge of the reproductive system, the uterus and sexuality.

In Study 1 and Study 2 (Chapter Three) explores patients' expectations of
treatment. This was done by developing a standardized measurement of women's expectations of treatment \((ETQ)\). In Study 1 it was found that women who expect hysterectomy as part of the treatment process have high expectations of benefit and harm, whereas women's expectations in other treatments were not so extreme. In Study 2, women were randomly assigned to provide expectations of specific treatment. The results showed that the expectations of women in the hysterectomy group were the same as those in study 1.

The study in Chapter Four explored factors - physical and sexual abuse, depression, anxiety, somatization, hypochondriasis, feelings towards the womb, past and present menstrual problems - which might influence patients' desire for hysterectomy and their expectations regarding outcome of treatment. The results show that patients who have experienced sexual and physical abuse report higher levels of depression, anxiety and somatization and have more negative feelings towards their womb than patients who have not experienced abuse. There was however no difference between abused and non-abused patients in their desire for hysterectomy. Menstrual pain was found to have a greater influence on patients' outcome expectations of treatment than menstrual blood loss and depression. Also the women who desired hysterectomy had high expectations of benefit/harm as in studies 1 and 2.

The final study in Chapter Five explored how gynaecologists negotiate with patients presenting with menstrual problems and who had already undergone an investigative procedure. The results indicate that patients who are offered hysterectomy use specific strategies in their negotiation for treatment and they are perceived by the doctor as having a considerable influence on the outcome of the consultation. Patients who are offered other treatments are not outstanding in their strategies nor are they perceived as having a major influence on the outcome of the consultation.

It is reasonable to assume that there are a number of different factors such as
Psychological Aspects of Hysterectomy

high positive and negative expectations of treatment outcome, depression and negative feelings towards the womb, that influence patients to desire hysterectomy. Furthermore, in doctor-patient interactions, patients who are offered hysterectomy often use specific strategies in order to have this operation.
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INTRODUCTION

In the annals of medicine, hysterectomy is described as an ancient surgical procedure. During the first century A.D. in Rome, the Greek physician Archigenes was reported to have performed hysterectomy.

Hysterectomy means the surgical removal of the uterus (womb). The origins of "hyster" go back to the Greek expression hystero meaning either uterus or hysteria. Hystera, a kind of neurosis mainly affecting women, was once believed to arise in the uterus. The "wandering" of the womb was also associated with
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insanity. Thus, the relationship of uterus and the psyche and the impact of hysterectomy are of great concern to both medical and psychological researchers.

From earliest times the domain of obstetrics and gynaecology was ruled by women priestess/healers of Ancient Sumer, Assyria, Egypt, and Greece (Goldfarb & Greif, 1990). This rule continued throughout the Middle Ages, the Renaissance, and up to the Industrial Age. But as medicine became more distinctively a profession backed by the authority of technical language and a university education, so medical activity became the preserve of men.

Since the nineteenth century when Atlee (1844) first removed the uterus for myomas (non-cancerous tumours), it has become one of the most common surgical procedures in the U.K. (McPherson, 1983).

The upsurge of hysterectomy has generated an abundance of scientific papers which have contributed to our understanding of the indications, technique, therapeutic value and dangers of the operation (Miller & Arbor, 1946). Although the physiological complications of hysterectomy have changed considerably in response to research findings and medical advances in the last fifty years, little advancement has emerged in the perception of psychological aspects of hysterectomy (Gitlin & Pasnau, 1989).

Of concern to gynaecologists and medical practitioners is the widespread popularity, morbidity, mortality and cost of the operation. For example, the cost of operation in the private sector is estimated at £1,000 (BUPA, 1992). The estimated total cost of hysterectomies performed on the National Health Service
in 1983 was £50m (Coulter & McPherson, 1986). Annually, at present 74,000 women in England and Wales undergo a hysterectomy (Dept. of Health Hospital Episode Statistics, 1994). On current rates at least one in five women living in England and Wales will have a hysterectomy before the age of 65 (Coulter, McPherson & Vessey, 1988). Dickie, Greenspan, Strauss, Cowart, Scally, Peterson, DeStefano, Rubin & Ory (1982) estimate the mortality rate as six per 10,000 women with considerable morbidity associated with the operation.

Furthermore, only a small proportion of hysterectomies were performed in the presence of clear pathology (Amirikia & Evans, 1979; Grant & Hussein, 1984; Pokras & Hufnagel, 1988), the majority being for menstrual disorders of which 60% were for menorrhagia (McPherson, 1983). Some researchers (e.g. Fraser, McCarron, Markham, Resta & Watts, 1986) have indicated that only 40% of those undergoing hysterectomy for menorrhagia actually have objective menorrhagia. Therefore, some women may have operations for menorrhagia which are unnecessary (Granleese, 1990). The same could be said of women complaining of dysmenorrhoea. Studd (1989) stated in a review article that ‘the recent literature concerning menorrhagia deals solely with the aetiology and medical treatment. There is hardly a paper to be found in Index Medicus over the last 20 years which addresses the issue of hysterectomy for menorrhagia’ (cited in O'Dowd & Philipp, 1994). Hysterectomy is often performed on the basis of patients' subjective evaluation of their symptoms. Few studies report how frequently the preoperative diagnosis is confirmed by pathological examination of the hysterectomy specimen (Lee, Dicker, Rubin & Ory, 1984). Often when it is reported there is no clear pathology pre- and postoperatively. For example, even when gynaecologists attempt to investigate patients' menstrual
Symptomatology by either getting patients to complete menstrual charts (*to illustrate the length of their menstrual cycle and menstrual blood loss*); or having blood tests to detect anaemia or other abnormalities connected with menstruation, or undergoing hysteroscopy and/or dilatation and curettage, laparoscopy, often the results are negative¹. Yet many of these patients repeatedly report menstrual symptomatology and often desire a hysterectomy to resolve these problems. As a result, they often have this operation.

Much of the existing literature on outcome from hysterectomy focuses on negative effects, such as the occurrence of depression, other psychiatric disorders or psychosexual difficulties (Richards, 1973; Ballinger, 1975, 1977; Byrne, 1984; Ryan, Dennerstein & Pepperell, 1989; Wijma, Boake & Janssens, 1982), premature ovarian failure (Siddle, Sarrel, & Whitehead, 1987) and intestinal or urinary dysfunction (Taylor, Smith & Fulton, 1989). On the basis of such findings, suggestions have been made as to factors which increase the risk of postoperative psychological problems (e.g. Cooke, 1985). These include the absence of gynaecological pathology, young age, previous history of psychosexual or psychiatric problems, lack of social support or decreased feelings of femininity.

Several matters have been neglected in the literature to date. First, little attempt has been made to measure positive effects such as improvement in wellbeing, improved psychosexual adjustment and loss of pain and discomfort. Since women who undergo hysterectomy have often requested it, it is likely that their expectations of the procedure influence their evaluation of it and their

¹That is not claiming there is no underlying pathology, it is saying it is not apparent.
postoperative adjustment. For example, unrealistic expectations could lead to dissatisfaction and poorer psychosocial and psychosexual adjustment. However, systematic measurement of patients' expectations of hysterectomy and alternative treatments has been neglected by researchers. Also neglected in the literature is research attempting to identify the underlying influences on gynaecological patients' desire for hysterectomy. Researchers have tended to ignore such factors as sexual abuse, somatization, hypochondriasis and patients' feelings towards their womb that could explain why some patients desire hysterectomy.

Over the last twenty years surveys have increasingly emphasized that poor communication is the main cause of dissatisfaction with hospital care (HMSO, 1993). Therefore it is important to examine the influence of doctor and patient in the negotiation of a clinical response to the presentation of dysmenorrhoea and menorrhagia since many treatments of menstrual problems are based on patients subjective evidence.

The research in this thesis was essentially concerned with examining the indications for hysterectomy from a psychological perspective. It examined such factors as patients' expectations of hysterectomy; a range of influences on patients desire for hysterectomy, and, finally the negotiation of treatment between doctor and patient. This research builds on the foundations of previous investigations which have examined the psychological background of hysterectomy patients (e.g. depression, social support, femininity).

A greater understanding of the underlying psychopathology of gynaecological patients is required by both medical and psychological researchers. When these
two disciplines work in close collaboration our understanding of this issue can work for the benefit of those patients who are faced with the prospect of this operation. The ultimate aim of this research was to establish this link in order to understand the psychological aspects of hysterectomy so that gynaecological patients can obtain a better quality of life.

¹All projects in this thesis received ethical committee approval from the appropriate establishments.
Woman, in the interest of the race, is dowered with a set of organs peculiar to herself, whose complexity, delicacy, sympathies, and force are among the marvels of creation. If properly nurtured and cared for, they are a source of strength and power to her. If neglected and mismanaged, they retaliate upon their possessor with weakness and disease, as well of mind as of body.

- Edward H. Clarke, M.D., 1873.
CHAPTER ONE

THE UTERUS, MENSTRUATION, MENSTRUAL PROBLEMS AND HYSTERECTOMY

To fully understand the psychological aspects of hysterectomy, it is important to discuss the uterus and explore the historical background of menstruation and menstrual disorders. From this perspective, this chapter begins.

The Uterus

"The Uterus, it must be remembered, is the controlling organ in the female body, being the most excitable of all, and so intimately connected, by the ramifications of its numerous nerves, with every other part."

Dr. Frederick Hollick (1849)
The adult uterus is a pale red-brown, hollow, smooth-muscled, organ shaped like a upside down pear. At its neck is the cervix. The uterus is approximately 7.5 cm long and weighs about 70g with walls about 2 cm thick (Lewis & Chamberlain, 1990), with an inner lining of glandular (hormone-producing) structures (Cutler, 1988). It comprises of three distinct layers - the endometrium (an inner mucous membrane), the myometrium (a middle thickened mass of interdigitating smooth muscle) and the perimetrium (an outer serosal cover or visceral peritoneum) (Linkie, 1982). The two main functions of the muscle of uterus is to expel the products of menstruation and to expel the foetus and placenta. During menstruation and labour the muscle is highly active.

The uterus is unique to the female body whereas the ‘ovaries compare to the testes and the vagina to the penis’ (Goldfarb & Greif, 1990). However, to some physicians like Wright (1969), the uterus has a short life as it ‘has but one function: reproduction.’ Perhaps the uterus is the most maligned organ in the female body. Plato (427-347 BC) believed that women were ruled by their wombs. In his Timaeus he stated that:

The womb was an indwelling creature desirous of child-bearing. When it remains barren too long after puberty, it is distressed and sorely disturbed, and straying about in the body and cutting off the passages of the breath, it impedes respiration and brings the sufferer into extreme anguish and provokes all manner of diseases besides.

In order to respond to such a statement it is necessary to go back in history and explore the relationship between the female reproductive organs and hysteria.

Reproductive Organs and Hysteria

According to The Essential Medical Dictionary hysteria is described as a
Menstruation, Menstrual Problems and Hysterectomy

‘neurosis arising out of anxiety and frustration in which the patient presents bodily symptoms as an expression of mental disturbance.’ Today hysteria is often associated conceptually with somatization and hypochondriasis (see Chapter 4).

The relationship between the uterus and hysteria has a long history. Far back in antiquity hysteria was described as a disease of women and the disordered uterus and was considered by Hippocrates of Cos (450-370 BC), Graeco-Roman, Galen (c129-c200) and Roman, Celsus (c AD 25) to be the source of this illness and its symptoms (Cohen, Robins, Purtell & Altmann, 1953). Aretaeus of Cappadocia (AD c150-c200) suggested that this condition was prevalent in women who were either virginal or were deprived of male sexual relations. He likened the uterus to an animal:

...the middle of the flanks of women lies the womb, a female viscus, closely resembling an animal; for it is moved of itself hither and thither in the flanks, also upwards in a direct line to below the cartilage of the thorax, and also obliquely to the right or to the left, either to the liver or spleen; and it likewise is subject to prolapsus downwards, and, in a word, it is altogether erratic.

During the Middle Ages the ‘wandering womb’ was identified with demonological possession and was again credited with being a wandering animal but this time with a craving for bearing children. Considering the womb attracted such negative attributes, it is surprising that an early fourteenth century, French surgeon, Guy de Chauliac compared the uterus with the penis:

"The uterus is like a penis turned inside out... it has in its upper part two arms with the testicles... like the scrotum... a common body in the middle... a collum1 with a canale in it like the shaft... and the vulva is like glans and preputium."

1"Collum" usually means the vagina.

cited in Speert (1973)
particularly as the penis held such a positive, powerful position. Whereas Aristotle believed that the key to life lay in male sperm, the wandering womb was the root of hysteria.

Centuries later, Charcot, Breuer, Freud and Berheim considered the uterus in the aetiology of hysteria (Ananth, 1978). Briefly exploring hysteria and the "wandering womb" from antiquity to the present day, can offer some insight regarding the psychological aspects of hysterectomy. For example, much of the literature of nineteenth century America examining the medical and biological view of a woman and her role suggests that physicians' diagnostic and treatment practices were aimed at reinforcing traditional sex role definitions, and establishing masculine control over the female sex (Nathanson, 1977). Often this took the form of attributing a large proportion of illness in women to disorders of the reproductive system - primarily hysteria. Accordingly, 'physicians saw a woman as a prisoner of her reproductive system' (Smith-Rosenberg & Rosenberg, 1973). Her uterus and ovaries controlled her body, behaviour, personality, social role, intellectual abilities and limitations from puberty through to menopause (Smith-Rosenberg, 1972). Many physicians even connected the woman's central nervous system with her uterus (op. cit). Others credit the uterus with more power:

It was "as if the almighty, in creating the female sex, had taken the uterus and built up a woman around it."

Hofbrook (1882)

In the nineteenth century hysteria among women was widespread. It often came in the form of fits, paralysis, nervous depression and loss of speech. Physicians
unable to detect its cause frequently associated it with personality factors, masturbation or uterine origins (Dixon, 1846).

At the turn of the last century, the frequency of operations performed on patients suffering from hysteria prompted Janet (1907) to state:

"Do not try to count the number of arms cut off, of muscles of the neck incised for cricks, of bones broken for mere cramps, of bellies cut open for phantom tumours, and especially of women made barren for pretended ovarian tumours."

Despite such protestations coupled with the knowledge that no conclusive evidence advocated the benefits of these operations, these procedures for hysteria continued. More recently, Cohen et. al. (1953) noted that hysteria patients undergo more major and minor operations, than control subjects. Furthermore, among the hysteria patients gynaecological operations were seven times commoner than the control group. These findings suggest to some observers that hysteria patients desire to suffer by being cut, or mutilated and this attention-seeking behaviour contributes to them getting more non-surgical hospitalizations and receiving more sedative drugs and opiates than the general population (see Cohen et al). This argument could be taken further by postulating that some patients who desire hysterectomy when no pathology is indicated, could be suffering from a sense of guilt associated with the reproductive organs. For example, Menninger (1939) says ‘... we think first of all those disturbances of menstruation which have been traced to a direct connection with the unconscious repudiation of femininity..... amenorrhea is the most logical, dysmenorrhoea probably the most frequent. But menorrhagia, metrorrhagia and even leucorrhoea have also been identified as psychologically determined and, by
removal or correction of the psychopathology, cured.' Menninger (1939) went on to suggest that women with the above conditions may wish to destroy or to have destroyed - the femaleness within them. He believed that rejection of the uterus is dependent upon deep-lying hostility which is directly outwardly against men and inwardly against the feminine part of themselves because of their sense of inferiority. In association with these hostilities, comes a sense of guilt and this is directed upon that part of the body where a repudiation of femininity has been made concrete. Menninger (1939) saw such complaints as amenorrhoea, dysmenorrhoea, leucorrhoea, acting simultaneously as a rejection of the feminine role, an aggression against the male and a local self-punishment (see Chapter 4).

The Uterus and Femininity

For many centuries the womb has been personified as an integral part of femininity. Its often seen as the organ of conservation of feminine shape or sphincter control (Turpin & Heath, 1979). More recently it has been realised that the role of the uterus is instrumental in a woman’s general well-being. For example, it often plays a part in sexual lubrication, orgasmic contraction and hormone production. Furthermore, the hormones and nerve impulses it produces influence hormone and neurochemical production in the spinal cord, the brain, the ovaries, and other glands (Cutler, 1988).

Almost universally femininity is synonymous with fertility and motherhood; the uterus symbolizes biological vitality and its extirpation, the ultimate loss of womanhood (Deutsch, 1945; Chapman, 1967). The loss of childbearing ability
is a major concern for pre-operative hysterectomy patients, particularly in younger women without children and the personal sense of gratification, a child to love and the possibility to please a partner are denied (Turpin & Heath, 1979). In psychotherapy sessions Turpin & Heath found that this sense of loss affected these patients’ self-concept and self-esteem. The significance of the uterus to the feminine self-image is recognized by many researchers (e.g. Deutsch, 1945, Kroger, 1957, Drellich & Bieber, 1958 and Hollender, 1960). Wolf (1970) and Raphael (1972) have proposed that hysterectomy for some women could mean a ‘surgical disruption’ of the self-concept of ‘femininity’ and after the operation may see themselves as having lost a major physical component of the self and a vital psychological one as well (cited in Kincey & McFarlane, 1984). If the idea of femininity evolves around the functions of uterus, then adaptation to its loss could signal a large number of psychopathological sequelae to hysterectomy (Dennerstein et al, 1977). This problem has already been addressed in the literature (e.g. Barker 1968 and Richards, 1973) - although many of the findings are open to criticism (see Chapter 2). However, when many patients envisage themselves as being "one-half a woman," "desexed," "a shell," "neuter," and "an empty woman," (Sloan, 1978) after hysterectomy, there is a need to dispel these negative associations between loss of the uterus and loss of femininity.

**Menstruation**

Menstruation is a monthly cycle of hormone production and ovarian activity that prepares the female body for pregnancy, culminating in shedding of the uterine lining and bleeding if conception has not occurred (Jovanovic & Sharpe, 1990).
Probably a large part of the menstrual flow is an endometrial fluid transudate (Fraser, McCarron, Markham, Resta & Watts, 1986). Menstruation begins in puberty and ends in menopause. The beginning of the menstrual cycle is counted as the first day of the menstrual flow and normally bleeding lasts from two to eight days (Goldfarb & Greif, 1990).

For such a natural bodily occurrence, menstruation has been linked with numerous psychological factors from depression, personality, anxiety, irritability and mood swings to violent crimes and suicide (Awaritefe, Awaritefe, Diejomaoh & Ebie, 1980). For example, in 1980, Sandie Smith, a 29-year-old London barmaid, who had a background of violence, killed a work colleague. Smith was put on probation under medical supervision on the grounds that the premenstrual syndrome \( (PMS) \) was responsible for her violent behaviour. Christine English, killed her husband by running him down in a car. Like Smith, on appeal English was not guilty of murder, but guilty of manslaughter. It was argued that her behaviour was due to \( PMS \). The same claim was made successfully for a 24-year-old New York mother her beat her four-year-old daughter (Parlee, 1982b). The implication of the outcome of these cases is that all women who menstruate have the propensity to commit violent crimes because of diminished responsibility due to hormonal fluctuations. Dalton (1977; 1983) who has investigated female suicides, women criminals and women in mental institutions, proposed that during the menstrual and premenstrual stage of their cycle, women are more likely to manifest anti-social behaviour or commit crimes because of their hormonal levels. Parlee (1982b) suggests that the reverse could be true, that behaviour influences hormones, not the hormones affecting behaviour. In other words, the stress of criminal or antisocial behaviour could influence the production of hormones.
Menstruation, Menstrual Problems and Hysterectomy

The exact nature of the above associations is not entirely understood, however, various religions, philosophical notions, anthropological, sociological and psychological research findings all offer some insight into the possible roots of these psychological manifestations.

Historically, a lot of interest has focused on menstruation. For example, Aristotle (384-322 B.C.) believed that menstruation was the loss of bad humours. Roman scholar, Pliny II believed menstrual blood had malevolent properties and described them in his *Natural History*:

Contact with it (menstrual blood) turns new wine sour, crops touched by it become barren, grafts die, seeds in gardens are dried up, the fruit of trees falls off, the edge of steel and the gleam of ivory are dulled, hives of bees die, even bronze and iron are at once seized by rust, and a horrible smell fills the air; to taste it drives dogs mad and infects their livers with an incurable poison... Even that very tiny creature the ant is said to be sensitive to it and throws away grains of corn that taste of it and does not touch them again.

Generally a negative connotation of the menstrual flow survives almost globally and, in many societies it is considered polluting and perhaps dangerous (Brooks-Gunn, 1985). It features in rituals, magic, myths and folklore.

Menstruation imposes restrictions on sexuality, food preparation, personal habits and social activities (Brooks-Gunn, 1985). For example, in the Bible, in Leviticus, the third book of Moses (1515 B.C.), menstruation is described as polluting. Menstruation is also termed as a sickness, and having sex with a menstruating woman is seen as a crime much like incest (cited in Williams & Echols, 1994). Some clergy believed that witch and devil worshippers used menstrual blood in their magic ointments, but the most popular belief was that menstruation was a punishment inflicted on womankind because of Eve’s sin. For orthodox Jews, a menstruating woman sleeps separately from her husband to avoid intercourse.
Afterwards it is obligatory for her to cleanse herself by taking a ritual bath (Mikvah). The Koran, the holy book of Islam, calls the menstruating woman a "pollution." This notion of menstruation as polluting is held among Hindu women, and as such, affects their social relations. When menstruating they are prohibited from preparing food; marriages are cancelled if future mother-in-laws are menstruating; and menstruating widows are excluded from mounting their husband's funeral pyre (Dumont, 1979). Adult male Oriya Brahmans\(^1\) believe that menstrual blood is poisonous, able to obliterate trees and plants, shrink testicles, and pollute the environment (Shweder, 1985). Melanesian Ifaluk men avoid social or sexual contact with menstruating women for fear of death. They also fear 'if a drop of menstrual blood falls on them, they will lose their hair, have a constant stomach-ache and will go insane' (Paige & Paige, 1981). The Rom gypsies - who originated from India some 5,000 years ago, consider the lower half of the female body as polluted. The genital-anal area of the body is particularly shameful and all excretions from this area are highly polluting (Sutherland, 1975) and once a women starts menstruating her top and bottom clothes are washed separately. During menstruation she sleeps alone facing a wall - sometimes with her legs tied together.

Menstrual myths and taboos also persist among New Guinea society. For example, it is reported that a tribesman divorced his wife because she slept on his blanket while menstruating. Convinced he could still be affected by her evil influence, later he killed her with an axe (Meggitt, 1964 cited in Delaney, Lupton & Toth, 1988). Among some modern day Mexican-Americans the belief exists

\(^1\)Brahman is a member of the highest or priestly caste among Hindus.
that during menstruation the *chirionera* and the *ajolote*, lizard-like animals, prey on women smelling of menstrual blood. Should an unsuspecting woman urinate outside, these creatures may enter the vagina and build a nest in the womb, resulting in the woman giving birth to these beings, or the woman may have her insides eaten by lizards, resulting in the woman's death (Snow & Johnson, 1977). Researchers (Snow & Johnson, 1977) claim that in some cultures, women fear menstruation because they associate it with witchcraft which can injure them during this vulnerable time.

In western society, menstruation also governs many women's lives. For example, one quarter of American women reorganise their physical and social activities because of it and fifty per cent refrain from sexual intercourse (Brooks-Gunn, 1985). During menstruation, Jewish and Catholic women are more likely to practice sexual abstinence.

Snow & Johnson (1977) testing ideas about intercourse to women in a Michigan public clinic found that 62 percent of the women thought that intercourse during menstruation would increase the menstrual flow, cause haemorrhaging, infections and uterine cancer (Matlin, 1987).

Evidently there is a wealth of published material on the negative aspects of menstruation, but infrequent regard for the positive aspects of it. Some studies, however, have redressed the balance. Drellich & Bieber (1958), for example, found that the majority of the hysterectomy patients they investigated had positive feelings towards menstruation and regretted the loss of this important activity. If positively viewed, menstruation has a cleansing function, and is
Menstruation, Menstrual Problems and Hysterectomy

instrumental for the conservation of health and well-being. In some societies (e.g. Somali) it represents power. ‘Since military power and political power depend on the continual expansion of the numbers of males in the clans, strong fraternal interest groups place an overwhelming value on fecundity’ (Paige & Paige, 1981). Cessation of menstruation not only signifies loss of fertility, but a disruption to a woman’s whole sense of womanhood and bodily equilibrium and loss of power. In 1983 the World Health Organisation (WHO) studied attitudes towards menstruation in all socioeconomic classes in Egypt, India, Indonesia, Jamaica, Mexico, Pakistan, Philippines, Republic of Korea, the United Kingdom, and latter day Yugoslavia. The research focused on patterns of menstrual attitudes by collecting data on birth control practices, since it has been universally established by population and health workers that disturbances in the menstrual cycle often affect the way a woman selects and uses birth control (Snowden & Christian, 1983 cited in Delaney, Lupton & Toth, 1988). They found that despite the physical and emotional problems women suffer during menstruation, and negative cultural taboos regarding this monthly event, some women saw it as a positive event. This was apparent in parts of India where religion, caste and notions of pollution induce many women to avoid chores at this time. The majority of these Indian women would not voluntarily submit to induced amenorrhea, such as might result from the pill.

Clearly throughout history menstruation has been described as having negative properties, and, as a result, beliefs and attitudes towards it may adversely affect women’s body image and perception of disease causation (Snow et al, 1977). Therefore, medical practitioners might want to focus more on the psychological ramifications of these belief systems, particularly when historically medical
theories of the nature of the female body and temperament emphasized the weakness and unstable emotions created by hormonal imbalances, and to the nineteenth-century physician, the womb and ovaries were the most significant organs in a woman’s body (Owen, 1993).

**Disorders of Menstruation: Menorrhagia and Dysmenorrhoea**

‘No man, (who is but never so little versed in such matters) is ignorant, what grievous Symptomæs, the Rising, Bearing down, and Perversion, and Convulsion of the Womb do excite: what horrid extravagancies of the minde, what Phrenses, Melancholy Distempers, and Outrages, the præternatural Disease of the Womb do inducæ, as if the affected Persons were incantæd: as also how many difficult Diseases, the deprave effusion of the Terms, or the use of Venus much intermitted, and long desired do foment.’  

Harvey (1653)

Twentieth century medical and psychological journals have amassed much material on the pathophysiology of menstrual disorders, though progress in understanding the psychological aspects involved, appears to be limited and controversial.

Several studies have shown that there is a recognized association between emotional illness and gynaecological symptomatology (Stott, Teague & Walker, 1983). This has been demonstrated in the UK (e.g. Bryne, 1984; Ballinger, 1977) and Australia (Worsley, Walters & Wood, 1977) who used the General Health Questionnaire [GHQ] (Goldberg, 1972) to detect such morbidity. It has prompted such comments as: ‘of all the medical specialities, there is perhaps none so closely allied to psychiatry as gynaecology’ (Rogers, 1950).

Ballinger (1977) reported that women attending gynaecology outpatient clinics manifest higher levels of psychiatric morbidity than women in the general
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population (cited in Iles and Gath, 1989). Sainsbury (1960) compared patients with dysmenorrhoea, menorrhagia, irregular menstruation, asthma, psoriasis, acne vulgaris) to patients with other complaints: appendicitis, cholecystitis, fractures, hernia, injuries, varicose veins - where the psychological factor was not usually considered important - to see whether there were any differences on personality factors. He found high levels of neuroticism among gynaecological patients.

**Menorrhagia**

The origins of menorrhagia come from the Greek *men*, meaning month and *rhegyai*, meaning to burst forth. Menorrhagia is excessive or irregular bleeding (*blood loss over 80 ml monthly*) from the vagina, a common menstrual disorder (Lewis & Chamberlain, 1990) which accounts for nearly one million GP consultations a year in the United Kingdom (Parke-Davis, 1983). A MORI survey showed that 31% of fertile women in the UK complain of heavy menstrual bleeding. Iles & Gath (1989) suggest that menorrhagia is ‘one of the commonest presenting complaints amongst women approaching the menopause.’ The mean age at menopause is about 50 years (Coope, 1993) but it can occur between the ages of 45 to 55. In a survey of a gynaecological outpatient clinic, Ballinger (1977) reported that 39% of patients between 40 to 44, and 62% of patients aged between 45-49 complained of long or heavy menstrual blood loss.

There are a number of reasons for the occurrence of menorrhagia. It could be caused by endometrial polyps, fibroids, malignancy, pregnancy (Smith, 1985),
endometriosis, pelvic inflammatory disease (Rees, 1989) and intrauterine contraceptive devices (Lewis & Chamberlain, 1990). Psychosomatic disturbances often account for excessive or frequent menstrual bleeding which often subsides when the problem disappears - pituitary function is responsible for this irregularity (Lewis & Chamberlain, 1990). When no evident pathology can be established, these cases are referred to as dysfunctional uterine bleeding (Novak & Woodruff, 1974).

Of major concern to gynaecologists and psychologists is that 60% of hysterectomies in England and Wales are for menorrhagia (McPherson, 1983). Only 40% of those undergoing hysterectomy for this problem actually have objective menorrhagia (Fraser, McCarron, Markham, Resta & Watts, 1986).

One of the main problems concerning menorrhagia is that it is a subjective complaint which is seldom confirmed clinically (Fraser, McCarron, Markham, Resta & Watts, 1986). For example, in gynaecological practice, the patient’s self-statement of her heavy menstrual blood loss is enough for initiating medical or surgical treatment (Chimbira, Anderson, & Turnbull, 1980). Since treatment for menorrhagia frequently results in hysterectomy, serious considerations should be given to reappraising the assessment of this complaint. This is particularly significant when studies (e.g. Hallberg, Hägdahl, Nilsson & Rybo, 1966) have reported that women often make poor judgements of the volume of their menstrual blood loss. Hallberg et al (1966) reported that 40% of women with menstrual blood loss exceeding 80 ml regarded their menstruation only moderately heavy or light, but 14% of those with a measured loss of less than 20ml considered their periods to be heavy (Chimbira et al). However, it is
important to understand why women's perceptions of menstrual blood loss are often inaccurate. Fraser, McCarron & Markham (1985) report that 'many women lose their menstrual discharge in small gushes which lead to 'accidents', soiling or soaking of clothes, and that the total volume of menstrual discharge is more than double the blood content,' (cited in Fraser, 1989).

Objective measurement of menstrual blood loss ($MBL$) is based on results from a Swedish population study with 476 women (Hallberg, 1966) and 348 women in Northumberland (Cole, Billewicz & Thomson, 1971). This technique uses the alkaline method of Hallberg & Nilsson (1964) - where blood is extracted from sanitary towels using a sodium hydroxide (NaOH) solution, then its optical density is measured and compared with a venous blood control. Objective measurement of blood loss has a skewed distribution with a mean of 35 ml and the 90th percentile of 80 ml (Rees, 1989). Menstrual blood loss exceeding 80 ml per month causes iron deficiency anaemia in 20% to 25% of fertile females in the United Kingdom (Smith, 1985).

Several researchers (Granleese, 1990; Fraser, McCarron & Markham, 1984; Chimbira, Anderson & Turnbull, 1980) have found significant discrepancies exist between women's subjective estimation of their $MBL$ and an objective measurement of it. Some researchers have also included other factors with these measurements. For example, Chimbira et al (1980) examined the relation between measured menstrual blood loss and patient's subjective assessment of loss (during two consecutive menstrual periods), duration of bleeding, number of sanitary towels used, uterine weight and endometrial surface area. In 44% of the women, who subsequently had a hysterectomy because of their complaint of
menorrhagia, the uterus was weighed and the endometrial surface area measured. There was no evidence to support the notion that menorrhagia is associated with a large uterus or large endometrial surface. Interestingly, Chimbira et al (1980) suggest that even if women were informed that their MBL was normal, they may not believe it. However, this assertion was not tested.

Granleese (1990) argued that 'diagnosis of menorrhagia should not be made on the self-statement of patients alone nor on reported menstrual symptomatology but only on the basis of objective measurement of menstrual blood loss' (MBL). There are nonetheless problems with this procedure. She reported that both tampons and sanitary towels were found to have a mean recovery rate ranging from 80.5 to 86.5% and 81.3 to 84.4%, respectively. How these figures are arrived at is questionable. For example, women notoriously lose their tampons and sanitary towels down the toilet. Furthermore, even when 'going to the toilet' women lose menstrual blood (including blood clots). Remembering to collect soiled sanitary protection in public conveniences and keep them on one's person poses obvious problems. Therefore how accurate is objective MBL? Certainly objective MBL can be an important factor in identifying menorrhagia in medical terms, but the methods presently used for measuring it are inadequate. Other factors have to be considered when examining women presenting with menorrhagia.

Many studies investigating patients presenting with menorrhagia (e.g. Granleese, 1990) fail to establish whether the respondents were using, or if they have ever used a contraceptive device. The 'pill' is known to lessen menstrual blood loss (it can also cause 'spotting' [blood] in between menstruation) whereas an
intrauterine device often increases menstrual blood loss (Lewis & Chamberlain, 1990). Women presenting with menorrhagia could have been on the ‘pill’ for several years. When these patients then experience ‘normal’ menstruation after stopping the pill, it may appear ‘abnormal’ to them since their menstrual blood loss could have increased in quantity. Since menstrual blood loss varies from woman to woman, normality (of menstrual blood loss) could be interpreted as: an individual’s experience of menstruation and what is acceptable or unacceptable to her. In other words, if it impinged on her quality of life, then it could be perceived unacceptable. Perhaps this might be a more valid basis for medical intervention than objective MBL.

Psychological Aspects of Menorrhagia

Dutton (1965) diagnosed psychological illness (e.g. anxiety, psychoneurosis, depression and hysteria) in 82.6% patients with dysfunctional uterine bleeding (e.g. heavy menstrual bleeding, prolonged menstrual bleeding, frequent menstruation or inter-menstrual bleeding). Although no objective measurement was made of the volume of bleeding or standardized measures of psychiatric disorder, several empirical studies have supported Dutton’s findings. For example, it has been estimated that 58% of women who are scheduled for hysterectomy are suffering from depression (Ross & Tyrer, 1974; Martin, Roberts, Clapton & Wetzel, 1977; Gath, Cooper & Day, 1982). In the Gath, Osborn, Bungay et al (1987) Oxford community survey a connection was found between menstrual symptoms and psychiatric disorder. Psychiatric disorder was measured by the General Health Questionnaire (GHQ) and the Present State
Examination (PSE) and women's recent menstrual symptoms were also evaluated. Women's menstrual loss, blood clots and flooding was found to be associated with psychiatric disorder. Other studies (e.g. Watts, Dennerstein & de la Horne, 1980) have linked personality factors with menstrual symptomatology. Greenberg (1983) suggested that 62% of women complaining of menorrhagia were suffering from mild to moderate neurotic depression (measured by the (GHQ), manifested less severe menstrual bleeding, greater psychosocial vulnerability (e.g. divorce/separation, unemployment, three or more children, termination/miscarriage) and had higher neuroticism scores than women with heavy blood loss who did not manifest these psychological tendencies. Since Greenberg did not objectively measure MBL - apart from measuring blood haemoglobin (Hb) and serum iron (Fe) which yielded no significant findings - it is difficult to determine the differences between patients with objective menorrhagia and those with subjective menorrhagia. However, the findings of Greenberg have been supported by other studies which suggest that women presenting with menorrhagia have recently experienced losses of some kind (e.g. death of a partner; marital separation or divorce) (Blaikley, 1949; Ballinger, 1977).

If this is the case, are physical means being used to cure a predominately psychological problem? If so, were the patients cured - insomuch that their pelvic symptoms and psychological problems have been relieved? Perhaps those complaining of menorrhagia should be offered psychological rather than gynaecological management (Greenberg, 1983). If counselling is given over a long period of time some of these candidates for hysterectomy may decide against having an operation. Counselling could help women evaluate their health and offer them a choice of how to tackle their health/psychological problem(s).
Research findings have suggested an association between menorrhagia and depression. But the nature of the link needs further investigation. Greenberg (1983) has proposed that: (1) excessive menstrual bleeding could cause depression because of anaemia, consistent discomfort and debility (2) that depressed women may experience increased menstrual blood loss, via some hormonal mediator (3) some primary underlying pathology (e.g. large fibroid(s)) could cause both depression and menorrhagia and (4) menorrhagia could be symptomatic of depression.

**Treatment for Menorrhagia**

Mention of menorrhagia can be traced back to about 1400 BC to the early Hindu sacred books (*the four vedas of Brahma*). Since then all manner of treatments have been suggested for its relief. For example, Pliny (AD c23-79) advised the application of beaver oil and onyx, calves gall, or dried snake; Soranus (AD c100) suggested pessaries soaked with the yolks of roasted eggs or burnt cork to be applied to the vagina; Oribasius of Pergamum (325-403) recommended tight limb bandaging together with the application of sponges soaked in various medications which were inserted vaginally and rectally (O'Dowd & Philipp, 1994). More recently treatment ranges from on the one hand, hormones, antioestrogens, prostaglandin inhibitors, antifibrinolytics, drugs to stabilise capillary vessel walls, ergot preparations and on the other to surgery (dilatation and curettage [D&C]⁴, endometrial resection⁵ or hysterectomy⁵ (Noble, 1985). Occasionally these

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⁴ See glossary.
⁵ See page 32.
treatments have side effects (e.g. acne, weight gain, loss of libido, deepening of the voice) (Phipps, Lewis, Robert, Prior, Hand, Elder & Field, 1990). Increasingly, hysterectomy is offered as an alternative and effective way to treat menorrhagia when medical treatment has been unsuccessful (Macdonald, 1990).

**Dilatation and Curettage (D&C)**

This procedure involves dilating (widening the opening of) the cervix and gently scraping (by using a curette) away the lining of the uterus (Cutler, 1988). This minor operation only takes 10 to 15 minutes and can be carried out on a day-patient basis or can require an overnight stay in hospital (Coltart & Smart, 1992). A D&C allows for pelvic assessment and exclusion of intrauterine disease (e.g. endometrial cancer or endometrial polyps) (Fraser, 1989). It can also remove polyps and the remains of a miscarriage or a placenta after childbirth (Coltart & Smart, 1992).

Many clinicians use this procedure more as a diagnostic tool than a therapeutic technique. Evaluation of the therapeutic benefits of curettage for women with menstrual problems has produced mixed findings. For example, Jeffcoate (1975) reported no symptomatic relief for patients whereas other studies have reported a 40%-50% improvement (Israel, 1967) while Haynes, Hodgson, Anderson, & Turnbull, 1977) found no longterm reduction in menstrual blood-loss. The therapeutic properties of D&C regarding dysfunctional menstrual bleeding (e.g reducing menstrual blood loss) could lie in the fact that removal of the
endometrial lining somehow allows for a new buildup of a healthier lining (Parsons & Sommers, 1962), but this does not fully explain why this occurs in some cases and not in others. McKenzie & Bibby (1973) reported that unsuspected pelvic or endometrial lesions were found in 34/160 patients who had a hysterectomy after the curettage. They state that 'some of these previously undetected lesions may have arisen since the curettage, a 10% rate of missed endometrial lesions has been quoted by others' (Word, Gravell & Wideman, 1958). Because pieces of endometrial tissue are randomly removed from the uterus it is not surprising that some diseased tissue could remain undiscovered (Valle, 1981) though this can easily be resolved by carrying out a hysteroscopy and laparoscopy at the same time as the D&C (Cutler, 1988).

In an hysteroscopic evaluation of patients with abnormal uterine bleeding Valle (1981) performed a hysteroscopy prior to D&C, and directed biopsies were obtained under hysteroscopic view when abnormal lesions were discovered. Valle reported that in 352 patients, such pathology as: endometrial polyps, submucous leiomyomas, intrauterine adhesions and focal lesions compatible with adenomatous hyperplasia or endometrial carcinoma, several of which were not detected at the subsequent D&C. Other studies in this area, have produced similar results. For example, after comparing hysteroscopic directed biopsies to D&C in a sample of 66 patients, Gimpelson (1984) reported that hysteroscopy provided more information in 16 cases whereas D&C was only superior in two cases. In the remaining 28 cases, the results of two investigations were similar. A more recent study concerning 29 patients showed that hysteroscopy was a more accurate technique in identifying abnormalities that were discovered in 24 patients which were not detected at D&C (Brooks & Serdan, 1988).
Complications

About 1.7% of women who undergo a D&C experience significant complications from it (MacKenzie & Bibby, 1978). The risks of uterine curettage include: splitting the cervix, perforation of the uterus (Govan, Hodge & Callander, 1985) haemorrhage and sepsis (Grimes, 1982).

Endometrial biopsy

This is a minor procedure lasting a few minutes which can take place in a doctor’s surgery or an outpatients clinic. Endometrial biopsy is less traumatic than a D&C as it does not necessitate a general anaesthetic, although it can cause some physical discomfort to the patient. A small plastic cylinder containing a suction device is placed within the cervix and a section of the endometrial lining is removed for histological examination (Goldfarb & Greif, 1990). Like D&C the endometrial biopsy is limited as a diagnostic procedure since it involves randomly removing a portion of the endometrial lining (see above), but unlike a D&C, endometrial biopsy cannot reduce abnormal menstrual bleeding.

Hysteroscopy

Hysteroscopy can either be carried out under local or general anaesthetic. It is a low-risk procedure in which a hysteroscope (a small fibreoptic telescope) is passed through the cervix into the uterine cavity, which is distended with fluid or gas (Lewis & Chamberlain, 1990; Coltart & Smart, 1992). This procedure can enable a gynaecologist to identify endometrial polyps or carcinoma, uterine septa
and submucous fibroids (Lewis & Chamberlain, 1990). It can enable operators to pass surgical instruments down a channel in the hysteroscope to collect samples of the endometrium for laboratory examination (Cutler, 1988). In endometrial ablation or resection a hysteroscopy is also used (Coltart & Smart, 1992).

Compared to D&C, hysteroscopy is a more sensitive and accurate procedure. For example, Goldrath & Sherman (1985) detected numerous polyps and fibroids that had previously been overlooked by D&C because less than 50% of the uterine cavity had been curetted on 60% of patients and less than 25% of the cavity in 16% of patients (cited in Goldfarb & Greif, 1990). Similar findings were found by Goldfarb (1989) who examined the efficacy of D&C by hysteroscopy in a retrospective study concerning nearly 300 patients. One-hundred and eighty-five patients were identified with such complaints as polyps. It was found that most patients had retained their polyps following curettage and the majority required several attempts at removal (see also Goldfarb & Grief 1990). Goldfarb concluded that hysteroscopy allows gynaecologists to tell that the pathology has been totally removed. It saved patients from having repeated curettages while still suffering from their symptoms because an examination of the entire uterus was able to be conducted at once (Goldfarb & Grief, 1990).

**Complications**

This procedure involves very few risks. The main risk is that the operator punctures the uterine wall (Cutler, 1988).
Laparoscopy

Laparoscopy, a procedure which is performed either under local or general anaesthesia, allows inspection of the pelvic organs (*uterus, ovaries and fallopian tubes*) through an endoscope with a light cable and small telescope through the anterior abdominal wall (Lewis & Chamberlain, 1990) via a small incision within the navel (Goldfarb & Greif, 1990). Gas (*carbon dioxide*) is blown into the abdomen, inflating the middle region of the body so that the gynaecological organs may be clearly examined and separated from each other in order to avoid puncturing healthy tissue (Cutler, 1988).

As a diagnostic technique, laparoscopy is important in the investigation of pelvic pain and is useful when identifying such conditions as salpingitis, endometriosis and early tubal pregnancy (Govan, Hodge & Callander, 1985).

Complications

Inserting the laparoscope too deeply can accidentally puncture the uterine wall, bowel or blood vessels (Goldfarb & Grief, 1990). Infection is rare and usually the result of unnoticed bowel damage (Govan, Hodge & Callander, 1985).

Endometrial destruction (*laser ablation, resection, rollerball*)

Endometrial destruction can be approached by several methods for example, endometrial ablation, in which a heat induction technique permanently destroys the endometrium; either by laser, or by radiofrequency-induced endometrial
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ablation (here a 'microwave' tube is inserted into the uterus) (Coltart & Smart, 1992). The main disadvantage of this approach is the lack of tissue for histopathology (Pyper & Haeri, 1991). Moreover, hysteroscopic resection of the endometrium is quicker method than laser ablation and allows gynaecologists adequate tissue for histological examination. A transcervical resection\(^6\) of the endometrium (TCRE) is a method whereby the endometrium is removed using a cutting loop. A partial or complete resection of the endometrium can be carried out. In a partial resection a 1 cm \((1/2 \text{ in.})\) ring of the endometrium is left just above the cervix, this results in a reduction in menstruation. The intention of a complete resection is to produce amenorrhoea \((\text{absence of periods})\).

Compared to a hysterectomy the endometrial resection has several advantages. First, it is a minor operation lasting approximately 20 to 25 minutes which can be carried out under a general or local anaesthetic and patients can return home the same or the following day. There is no scar after this procedure and the patient retains her womb which psychologically could be important to her. After endometrial resection a patient can return to work within a matter of days (Magos, Baumann, Lockwood & Turnbull, 1991). Hysterectomy patients' hospital stay varies from 5 to 8 days with a long recovery period (see page 38).

Pyper & Haeri (1991) examined the efficacy of endometrial resection by hysteroscopic electro-diathermy in treating 80 patients with menorrhagia. Seventy-five of these patients were followed up a year later. Forty-five (60\%) had a successful outcome in terms of subjective assessment of the alteration in

\(^6\)Information supplied by Watford General Hospital.
their menstrual blood loss; nine (12%) patients reported ‘some improvement.’
The operation failed in 21 cases; 14 had ‘no improvement’ initially and seven
were late failures after a good result at 6 months; 15 had a repeated procedure
with a 83% success rate at 6 months; 4 women went on to have a hysterectomy.
These results indicate that in some cases endometrial resection is an effective
treatment for menorrhagia, but they also imply that there is room for
improvement in the technique.

Dwyer, Hutton & Stirrat (1993) conducted a randomised control trial comparing
endometrial resection with abdominal hysterectomy for the treatment of
menorrhagia in which 97 patients underwent hysterectomy and 99 patients
underwent endometrial resection. Assessment of patient satisfaction 4 months
after surgery showed that 89/95 hysterectomy patients were statistically
significantly more satisfied with their operation compared to 84/95 endometrial
resection patients. Dwyer et al (1993) reported that post-operative morbidity,
length of hospital stay and time taken to return to work, normal daily activities
and sexual intercourse were significantly less in the endometrial resection group,
but among the hysterectomy patients, premenstrual symptoms of dysmenorrhoea,
bloating and breast tenderness were less apparent. Although endometrial
resection patients had less morbidity than the hysterectomized patients, there was
a failure rate of least 10% among ER patients. These results indicate that more
investigation needs to be applied to ER before it can be regarded as an
alternative to hysterectomy, particularly when the following study is considered.

Slade, Ahmed & Gillmer (1991) followed up 228 women 10 and 30 months after
a transcervical endometrial resection (TCRE). Patients were sent a questionnaire
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asking them for their long-term views of TCRE and about their menstrual patterns. Two-hundred and twenty patients responded to the questionnaire with 72 (32.7%) reporting their disappointment with the outcome. During the follow-up period 25 patients had a hysterectomy and another 10 were scheduled to have one which overall accounted for 15.9% of the sample; and 6 patients had a repeat TCRE. Patients dissatisfaction mainly related to persistent dysmenorrhea and failure to achieve amenorrhea. There could be several reasons for the poor results of this study since many of the endometrial resection operations were carried out by inexperienced operators. Furthermore, the researchers did not distinguish between total and partial endometrial resection which is a major consideration when comparing rates of amenorrhea and treatment failure (Magos, 1991). For example, a patient who has a total resection would become amenorrhoeic and if she has a partial resection she would still experience menstrual blood loss afterwards (see above).

In a later study Pinion, Parkin, Abramovich, Naji, Alexander, Russell & Kitchener (1994) conducted a randomised trial of hysterectomy (N=99), endometrial laser ablation (N=53) and transcervical resection (N=52) for dysfunctional uterine bleeding among 204 women under the age of fifty. Patient satisfaction which was assessed 6 and 12 months after surgery, indicated that patients in the hysterectomy group were significantly more satisfied with their operation than those in the hysteroscopic endometrial ablation group. Between 70% to 90% of the patients were satisfied with the results of hysteroscopic surgery, even though a significant number needed a second procedure. In the hysterectomy group, five women experienced major complications (e.g. resulting from the anaesthetic, intra-abdominal bleeding and pelvic abscesses). The only
major complication was in the laser ablation group where a patient had a small bowel obstruction.

Although such procedures as selective endometrial destruction and hysteroscopic surgery are still in their infancy, they offer great possibilities for hospital managers - reduced bed occupancy, better cost effectiveness\(^7\) (Macdonald, 1990) and, for those suffering from menorrhagia, presumably less surgical and psychological trauma.

The advantage of endometrial destruction is that it rules out some of the side-effects associated with hysterectomy including the possibility of premature menopausal symptoms. For example, Siddle, Sarrel & Whitehead (1987) assert that hysterectomy for menorrhagia on average hastens the onset of menopausal symptoms, due to oestrogen deficiency, by about 4 years. These symptoms may occur earlier in younger women.

**Complications**

Although endometrial ablation is perhaps preferable to hysterectomy, there is little available information on the incidence and severity of complications attached to this operation. Those which do occur appear to be most likely through inexperienced and unsupervised surgeons (Macdonald et al, 1992). In the Macdonald et al survey on endometrial ablation concerning 4038 procedures 123 (3\%) were associated with complications. The complications included:

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\(^7\)Estimates for hysterectomy are £1,462 and endometrial resection £296.
uterine perforations during endometrial resection, endomyometritis, peritonitis and one death.

**Dysmenorrhoea**

The origins of dysmenorrhoea come from the Greek *dys* meaning difficult and *men* meaning month and *rrhoea* meaning excessive flow of fluid.

Dysmenorrhoea (*painful menstruation*), a common menstrual problem, affecting approximately 50% of women of reproductive age, accounts for 13 per 1,000 GP consultations in England and Wales (Rees, 1990). Costs to the NHS arising from chronic pelvic pain has been estimated roughly at £150m per annum (Davis, Gangar, Drummond et al, 1992). However, about 80% of patients who have undergone laparoscopic investigation for chronic pelvic pain have no apparent underlying pathology, and Guirgis (1988) reported that only 13% of patients had symptomatic improvement after gynaecological referral (see Stones, 1995).

In American 140 million working hours are lost annually because of dysmenorrhoea (Ylikokola & Dawood, 1978). Dysmenorrhoea is a separate complaint from pre-menstrual syndrome (Lewis & Chamberlain, 1990) and it is not unusual for women to experience both dysmenorrhoea and menorrhagia (Rees, 1990).

There are two types of dysmenorrhoea, primary and secondary. The commoner disorder, primary dysmenorrhoea, is experienced after the menarche (*the onset*
of menstruation) once the periods have become ovulatory (Lewis & Chamberlain, 1990) and occurs in the absence of pelvic pathology (Rees, 1988). The pain, usually central in the lower abdomen, is colicky, spreading to the back and upper thighs (Rees, 1988) and is often accompanied by gastrointestinal disturbances - diarrhoea and vomiting (Rees, 1990). These symptoms usually occur a few hours preceding the menstrual flow and last for one to two days (Rees, 1989).

Only a century ago old spinsters and widows suffering from dysmenorrhoea were labelled as suffering from colica scortorum, ovaralgia or hysteralgia, because of an unsatisfied sexual appetite (Graham, 1950). Two decades ago, primary dysmenorrhoea sufferers were considered neurotic, however, most researchers believe that dysmenorrhoea results from excessive muscular contractions in the uterus, specifically in the myometrium (Jollie, 1981) mediated by prostaglandin biochemistry (Pickles, Hall, Best & Smith, 1965) which results in pelvic pain. Some researchers report that vasopressin may play a role in the aetiology of dysmenorrhoea. For example, Äkerlund, Strömberg & Forsling (1979) reported higher plasma vasopressin levels in dysmenorrhoeic women, than in controls. Demers, Hahn & McGuire (1984) indicated that high levels of leukotrienes could also be involved in primary dysmenorrhoea. Rees (1989) states that: ‘although excessive levels of prostaglandins, leukotrienes and vasopressin have been found in primary dysmenorrhoea, the primary stimulus for their production remains unknown.’

Secondary dysmenorrhoea is usually associated with organic disease such as endometriosis, adenomyosis or pelvic inflammatory disease (PID) (Lewis & Chamberlain, 1990) submucous myomas, endometrial or endocervical polyps,
cervical stenosis or the presence of an intrauterine device (IUD) (Friederich, 1983). The pain occurs only when ovulation has occurred and sometimes continues throughout the period (Lewis & Chamberlain, 1990). It is usually associated with a heavy feeling of discomfort which is often relieved when menstruation occurs. Generally patients presenting with secondary dysmenorrhea are older than those with primary dysmenorrhea. However, it can occur in women in their teens and twenties (Lewis & Chamberlain, 1990). The pain is usually progressive with age whereas with primary dysmenorrhea it decreases with age (Friederich, 1983).

**Psychological Aspects of Dysmenorrhea**

Once a woman has experienced menstrual pain, it is likely that she will anticipate a recurrence of it as the next period approaches (Friederich, 1983). Thus the expectation of pain, may in fact, produce more pain. Like severity of menstrual blood loss, a patient’s estimation of pain during menstruation may be grossly exaggerated. Psychoanalytic interpretation may see painful cramps as the female’s fantasy punishment for sexual desires (Lamb, 1981). Others may see this as a rejection of adulthood, a similar attitude often attributed to the anorexic who starves herself apparently to avoid puberty and which often results in amenorrhea\(^5\). Painful menstruation could be through a mother’s negative conditioning based on her own experience of dysmenorrhea. Several studies (Miller, 1977; Whitehead, 1979) have proposed that pathophysiological changes as well as overt illness behaviours could be inadvertently learned when somatic

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\(^5\)See glossary.
complaints are rewarded (cited in Whitehead, Winget, Fedoravicius, Wooley & Blackwell, 1982). For example, it is possible that a mother may unintentionally reinforce abnormal physiological responses by caring for a child and letting her off school work when she complains of menstrual pain but not when she grumbles about an ear-ache or headache. A mother (or other female carer) modelling menstrual pain symptoms may also be relevant.

In a telephone survey of 832 people (440 men and 392 women), Whitehead et al (1982) examined learned illness behaviour in patients with irritable bowel syndrome (IBS) and peptic ulcer disease (PUD). Compared to patients with PUD (10% of the sample), and the general population, patients with IBS (8% of the sample) were more likely to have multiple somatic complaints and see such illnesses as colds and flus as more serious than other people, to consult their doctor for minor illnesses. There were no significant differences between those with peptic ulcers and the general population. Whitehead et al (1982) reported that patients with IBS (45%) were significantly more likely than those with PUD (29%) to recount that their parents gave them gifts or special food when they had colds or flu during childhood. Yet, neither IBS patients nor PUD patients claimed to be excused from school when they suffered from cold or flu in childhood any more frequently than the general population. The results of this study have to be treated with some caution since it relies on retrospective material which could be inaccurate. Its classification of IBS and PUD people is also open to question. For example, those having IBS were classified on the basis of their subjective answering to questions relating to this complaint. PUD people were judged on the basis of having this complaint simply because a doctor or nurse had stated they had an ulcer, but no differential was made as to the type
of ulcer they had. However, these results can offer researchers some insight as to how certain conditions can come about through faulty conditioning in childhood.

Although a number of psychological factors have been related to dysmenorrhoea, no conclusive picture has emerged to identify the main components. Upbringing can affect perceptions of menstrual pain which can eventually lead to fears of sex and pregnancy. Some researchers have suggested that dysmenorrhoea could also be associated with sexual abuse (see Chapter 4).

**Treatment for Dysmenorrhoea**

Throughout history the treatment for dysmenorrhoea has been extremely varied. For example, Pliny II’s remedy for extreme menstrual pain was calf’s gall, dried snake, beaver oil and onyx which were either administered transdermally, orally, vaginally in pessary form or by fumigation (Rees, 1990). Even in Victorian times primitive devices were applied to relieve women with this ailment. For example, the cervix was either pierced with a tiny knife or leeches were attached there. Often leeches were counted after removal from the vagina as on occasion they had entered the uterine cavity, producing severe distress (Ricci, 1945). Scanzoni (1861) in *Diseases of Women* stated:

In all cases when it is desirable to produce a complete and durable depletion of the organ, leeches should be preferred to scarifications. They should be applied in the following manner: A solid cylindrical speculum, Ferguson’s for instance, is to be introduced into the vagina. The neck exposed, is to be carefully cleaned of any mucus which adheres to it by means of a pledge of lint. After having introduced into the speculum the desired number of leeches (six or eight are most always sufficient) they are to be pushed up to the neck by a pledge of lint. If they are greedy and the vaginal part is carefully cleaned, they will have bitten after a few moments.  

Translated by A.K. Gardner
Fortunately, this method of treatment is no longer advocated in western medicine.

**Drugs**

Today, prostaglandin synthetase inhibitors such as mefenamic acid, naproxen, ibuprofen and the combined oestrogen progestogen oral contraceptive pill have been effective in reducing dysmenorrhoea in 80 to 90% of patients (Rees, 1990). Those 10% to 20% of women who fail to respond to treatment could be suffering from secondary dysmenorrhoea (Rees, 1988).

**Exercise Programmes**

More recently exercise programmes (e.g. aerobic exercise) appear to offer some obvious benefits to dysmenorrhoeic patients. Sutton (1983) showed that the exercise group showed a significant decrease in symptoms as training advanced (see Giampapa, 1983) as compared to the controls. The premise was that exercise may reduce peri-menstrual symptoms by suppressing prostaglandin release and therefore dampening uterine contractions or by promoting an analgesic effect by releasing beta-endorphins. However, Hamilton et al (1983) found no support for these assumptions among healthy young women.

Some investigators have implemented self-control procedures to help women with dysmenorrhoea or pre-menstrual tension (Moos, 1985). Quillen & Denney (1982)
adapted an anxiety management training programme and taught dysmenorrheic college women to use relaxation to control menstrual pain and discomfort. During the training programme no significant differences in improvement were found between treated and untreated women. Yet following treatment, women who received pain management training reported significantly less pain as measured by the MDQ\textsuperscript{10} and fewer autonomic reactions associated with menstruation than the women in the control group.

**Hysterectomy**

The first recorded hysterectomy was performed by Soranus of Ephesus (AD 120) on a gangrenous uterus. Hysterectomy, the surgical removal of the uterus, is a major surgical procedure which is performed either vaginally or abdominally, depending on the nature of the problem, parity and age (Wijma, Kauer & Janssens, 1984).

Vaginal hysterectomy involves the removal of the uterus and cervix through the vagina. Vaginal hysterectomy is usually carried out when there are no indications of any underlying pathology in the abdominal cavity and therefore avoids the need to expose other pelvic organs to the trauma of surgery. It has the advantage of less postoperative pain and no abdominal scar; and is associated with lower morbidity than abdominal hysterectomy (Lewis & Chamberlain, 1990).

\textsuperscript{10} See Menstrual Distress Questionnaire (Moos, 1977).
Abdominal hysterectomy entails removal of the uterus via an incision in the abdominal wall and is a longer surgical procedure than vaginal hysterectomy, often involving the removal of several organs (uterus, cervix, ovaries, fallopian tubes).

In addition to the surgical route used, the extent of the surgical removal may also vary.

**Total hysterectomy** which involves the removal of the uterus and cervix, accounts for 95% of all procedures. A subtotal hysterectomy is where the cervix remains in situ. Another type of hysterectomy is a hystero-oöphorectomy in which the uterus and ovaries are removed. A more radical hysterectomy is known as hystero salpingo-oöphorectomy (unilateral or bilateral) which refers to the removal of the uterus and one or both the fallopian tubes and ovaries. There is also Wertheim's hysterectomy which involves removal of the uterus with the fallopian tubes, ovaries, pelvic cellular tissues, pelvic lymph glands and upper part of the vagina.

Because the last three procedures involve removal of both ovaries, patients go through *surgical menopause* as the ovaries virtually cease producing hormones. However, if one ovary remains menopause should occur naturally. But removal of the ovaries often triggers such menopausal symptoms as hot flushes, insomnia, and mood swings, crying spells, depression and irritability (Jovanovic & Sharpe, 1990).

If a women is over 40 years-old, gynaecologists often suggest removal of both
ovaries as a prophylactic procedure against cancer (Jovanovic & Sharpe, 1990). Whether removal of the ovaries is necessary is debatable since the risk of ovarian cancer relatively low and is estimated as 1% for women of 40 and the mortality rate of uterine cancer is 1.5% for women of 35 years-old (Selwood & Wood, 1978). Long-term effects of surgical menopause are associated with the onset of osteoporosis and an increased incidence of heart attacks. Some researchers (Centerwall, 1981) claim a threefold increase in the incidence of coronary heart disease from the time of the hysterectomy to the age of 50. However, Studd, Anderson & Montgomery (1986) maintain that hormone replacement therapy could help overcome these problems. Some researchers suggest an increased risk of cancer after possible oestrogen replacement therapy (Antune, Stolley, Rosenhein, Davies, Tonascia, Brown, Burnett, Rutledge, Pokempe

Physical complications
Physical complications associated with hysterectomy vary from 25% to 50% (Coulter & McPherson, 1986). Of 85 women, nearly a year after hysterectomy, 50% suffered from critical physical symptoms (e.g. secondary haemorrhage and urinary tract infection) Gould (1986). A Canadian study reported that there was a significant risk (40 per 1,000) of complications requiring hospital readmission within two years following hysterectomy and associated repair procedures (Ehrenreich & English cited in Hufnagel & Golant, 1988). Other researchers have estimated the risk of complications as high as 80% (Easterday, Grimes & Riggs, 1983).
Physical and psychological problems differ between women who have undergone vaginal and abdominal hysterectomies (Dicker, Greenspan, Strauss, Cowart, Scally, Peterson, DeStefano, Rubin & Ory, 1982). Those who had undergone abdominal hysterectomy had more complications than those who underwent vaginal hysterectomy. Dicker et al, 1982, indicate that these differences are probably due to the prevalence and efficacy of prophylactic antibiotic use among vaginal hysterectomy patients. Vaginal hysterectomy was connected with more unexpected major surgical operations, but less febrile morbidity, bleeding necessitating transfusion, hospitalization, and convalescence than abdominal hysterectomy.

**Mortality**

The mortality rates from hysterectomy range from 6 (Dickie et al, 1982) to 12 per 10,000 procedures (Wingo, Huezo, Rubin, Ory & Peterson, 1985). They increase with age - particularly after the age of 54 and are twice as high among black women in the U.S.A. (Dickie et al, 1982). Mortality rates from hysterectomy in the UK are not routinely collected by the Office of Population Consensus and Surveys (OPCS). However, recent estimates show a mortality rate of 6/10,000 (MacDonald, 1990). Over 50% of the specimens removed from these women were normal.

Wingo et al, 1985 examined the risk of mortality by matching patients for age, race, and surgical procedure for non-radical hysterectomies. Out of 317,389 women having abdominal hysterectomy, there were 477 deaths, and 46 deaths
among 119,972 women having vaginal hysterectomy. Mortality rates for hysterectomy were much higher for procedures connected with pregnancy or cancer, than for procedures not associated with these conditions (29.2, 37.8, and 6.0 per 10,000 procedures, respectively). Only 8% of all hysterectomies were connected with pregnancy and cancer, but 61% of all deaths occurred in these areas.

**Indications for Hysterectomy**

According to the Department of Health, Hospital Episode Statistics (1992-1993) approximately 74,000 hysterectomies are performed in England annually. Over the last decade these operations have increased by 14,000. In 1983 in England and Wales over 60,000 were performed (DHSS/OPCS 1985). In England during 1990-1991 and 1991-1992 - 70,675 and 71,630 hysterectomies were performed, respectively (Dept. of Health Hospital Episode Statistics). However, these figures exclude the private sector. In a survey of common surgical operations experienced among a random sample of 6000 general practice patients aged 40-64 years resident in the Oxford area, Coulter, McPherson & Vessey (1988) reported that 14% of hysterectomies had been performed in the private sector. Nicholl, Thomas, William & Knowelden, 1984) reported that by 1980/81 21% of non-emergency hysterectomies in England and Wales were carried out in the private sector (cited in Coulter, McPherson & Vessey, 1988). Therefore the rising number of hysterectomies is likely to be higher than would appear from an examination of the NHS alone.
Although hysterectomy is one of the most frequently performed surgical operations in England and Wales (DHSS/OPCS, 1985), only 10% of these operations are performed for life-threatening conditions (Amirikia & Evans, 1979; Grant & Hussein, 1984). For example, some hysterectomies are performed for cancer of the uterus, ovary or fallopian tubes, pelvic inflammatory disease and endometriosis. However, the majority are performed for benign conditions such as menstrual problems (pain and bleeding), fibroids and genital prolapse and sterilization. Therefore, how necessary is hysterectomy for non-benign conditions? Are these operations increasing because the indication for surgery have expanded to unnecessary hysterectomies (Coulter & McPherson, 1986)?

Blais (1988) stated that "It is not whether there are too many or too few [hysterectomies], it is, is it indicated?"

International and regional variations in the frequency of hysterectomy and of the most common surgical procedures (Wennberg, Freeman and Culp, 1987; McPherson, Wennberg, Hovind, 1982; McPherson, Strong, Jones & Britton, 1986; Wennberg, 1986) could be explained by factors such as medical and surgical bed density, insurance and payment systems (Bunker, 1970; Lewis, 1969), professional uncertainty (Wennberg, Barnes, Zubkoff, 1982), surgeon’s sex (Domenighetti, Luraschi, Marazzi, 1985), control and review of surgical indications (Wenneberg, Blowers, Parker & Gittelsohn, 1977; Dick, Murphy, Murphy, et al, 1977), medical auditing (Gruer, Gordon, Gunn & Ruckley, 1986), and second opinion programmes (Grafe, 1982) rather than differences in morbidity, and other sociodemographics characteristics of the population studied (cited in Domenighetti, Luraschi, Casabianca, Gutzwiller, Spinelli, Pedrinis & Repetto, 1988). Although the above may explain regional variations in the frequency of
hysterectomy and other common surgical procedures, other important factors also have to be considered regarding hysterectomy, namely examining what the patient desires (e.g. does she want a hysterectomy?), what she expects from this operation and will she be satisfied? The majority of hysterectomies are not for life-threatening conditions, rather for improving a patient’s quality of life.

Pratt (1980) in a speech discussing his personal series of 1000 vaginal hysterectomies stated: ‘I firmly believe that of all operations no surgical procedure offers more to the quality of life for a woman than the carefully considered and evaluated but often maligned hysterectomy’.

**The Hysterectomy Debate**

How necessary is hysterectomy for menstrual problems (*heavy menstrual bleeding and pain*) when no pathology is apparent? Does this surgical procedure attempt to cure a problem which could be psychological in nature?

Hysterectomy is a major operation and can be life-saving for cancer sufferers and therapeutic for women suffering from enervating uterine disorders. It can also be dangerous and involve additional medical complications (Dicker, Greenspan, Strauss, Cowart, Scally, Peterson, DeStefano, Rubin & Ory, 1982). It has been argued that it could negatively affect a woman’s psychological wellbeing (see Chapter 2).

Coulter & McPherson (1986) state that trying to calculate the magnitude of
unnecessary surgery is fraught with problems mainly because there is no basic criterion of evaluation available. This is further thwarted by there being no general consensus on the indications for many operations (Rutnow, 1982c). Evaluation of hysterectomy is further compounded by difficulties in measuring the outcome of elective surgery, specifically in the assessment of effects on quality of life (Bunker, McPherson, & Henneman, 1977). Not only does it pose problems for medical researchers, but it also emphasizes the need to evaluate the psychological aspects involved, particularly when a healthy organ may have been removed unnecessarily.

Many feminists view the rise in hysterectomies as a male conspiracy to exercise power over women (Coulter & McPherson, 1986): "Sadistic surgery is targeted at that which symbolizes the female to the fetishist. It keeps women pure, that is, terrified, victimized, docile" (Daly, 1979). With such assertions from Wright: "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)

the feminists could be right. But if this is true, why do so many women wish to have a hysterectomy particularly when there is no evidence of underlying pathology for their symptomatology?

There could be several reasons why women wish to have a hysterectomy for menstrual complaints which are not life-threatening. They may have unrealistic expectations of hysterectomy (see Chapter 3) which go beyond the aim of the operation. For example, they may expect improvement in the following domains: marital problems, sexual problems, depression and social life, simply because the
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burden of heavy and painful menstruation has impinged on these areas of their life. It is quite probable that there could be improvement in these areas, but it depends on the extent and the root of these difficulties and if they are directly related to a woman's menstrual problems. Since hysterectomy is a major operation a woman electing to have this operation must evaluate the consequences for such a decision. She must ask herself - at what risk or at what benefit? She needs to be informed of the physical effects it will have on her body (e.g. dry vagina, menopause) and the possible morbidity connected with it.

Expectations of hysterectomy alone may not be the only reason why a woman seeks a hysterectomy, there could be other influences such as a background of physical and/or sexual abuse, depression, hypochondriasis, and somatization. The link between physical and/or sexual abuse and the desire for hysterectomy has not been established (see Chapter 4). It has been established that women who have a history of sexual abuse in childhood suffer more psychopathology in later life (Browne & Finkelhor, 1986; Tong & Oates, 1990; Mullen, 1990; Mullen, Martin, Anderson, Romans & Herbision, 1993; Beitchman, Zucker, Hood, et al (1992a) and in view of these characteristics, it is feasible to speculate that a desire for hysterectomy may symbolize women purging their body of an offensive organ (the uterus) which is the root of their depression. Thus, in effect, they could believe that by getting rid of the offending organ may negate the possibility of being abused again because they have stripped their body of its femininity, womanhood and fertility, thus ensuring that they are no longer attractive and as a result, they will not have to endure anymore physical or mental damage.
Another way of exploring why many women succumb to hysterectomy when no pathology is indicated is to examine the negotiation of treatment between doctor and patient. What transpires in a doctor-patient relationship is a unique experience and outcome may depend on how a woman describes her physical symptoms and the impact they have on her quality of life (see Chapter 5).

Over a three-year period, Stott, Teague & Walker (1983) explored menorrhagia and the doctor-patient relationship to see whether the complaint, treatment and outcome was related to this interaction. Patients presenting with menorrhagia were discussed at weekly seminars consisting of between seven to twelve general practitioners led by a psychoanalyst. The discussion centred upon the feelings of the doctor and with emphasis on how s/he gave insight into the patient's problem. The researchers findings suggested that the 'character of the doctor-patient relationship was related to outcome, particularly to likelihood of gynaecological referral and subsequent hysterectomy'. For example, consider the following case study:

A 50 year-old patient wrote to her doctor for a oral contraceptive pill for her holiday. The doctor requested that the patient see him. Their first interaction was described as confused with the patient presenting with heavy, irregular periods and vague menopausal symptoms, and her desire for contraception. Within 4 months the patient returned to her G.P. with a letter from a well-woman clinic suggesting a hysterectomy. At this stage the G.P. saw it fit to discuss the patient's 'changing sexuality and functions, her fears and her fantasies' along with her marriage and other physical problems (vaginal dryness and soreness, fluid retention, bloating and flatus). The patient was referred to a gynaecologist which resulted in a D&C and as the patient's menorrhagia had returned, a hysterectomy was advised. After a discussion with her G.P. the operation was deferred while the patient accepted the menorrhagia. A year later her periods ceased.

Stott, Teague & Walker (1983)

The above case illustrates how an operation is avoided through a caring, empathetic doctor. Stott, Teague & Walker (1983) found that these group meetings comprised four out of 50 cases studied (8%), and in these 4 cases there were no hysterectomies and all ceased to complain of menorrhagia.
However, there are situations within the doctor-patient relationship were a doctor is overpowered by 'powerful, dominating women, often angry and contemptuous; scornful of weakness and passivity which they nevertheless induced in their doctor'. Stott et al (1983) reported that this group of patients were likely to pursue and indeed get hysterectomies on their own without their G.P.'s involvement. For example, consider the following case:

A large, 47-year-old woman often stands during her consultation with her G.P. who is seated. Mrs. X is used to getting her own way. She gesticulates and makes her points forcibly. The doctor has his hands folded on his lap and agrees with the patient's verbalizations. When Mrs. X presented with menorrhagia, the doctor examined her and discovered a cervical polyp and suggested a referral for a polypectomy. But Mrs. X suggested to the doctor that a hysterectomy would be better for her. Since the G.P. knew he had to discuss the case at a seminar he tried to ascertain why the patient was keen to have a hysterectomy. But the doctor's attempts were rebuffed and as a result he felt intimidated and unable to function professionally.

Mrs. X was referred to a gynaecologist which resulted in her having a D&C and polypectomy. However, three months later the G.P. was informed that Mrs. X had been admitted for a hysterectomy.

Stott, Teague & Walker (1983)

Who is the victim of this conspiracy - the patient or the doctor? To answer this question it is necessary explore further the dynamics of the doctor-patient relationship (see Chapter 5).

Conclusion

The etiology of menstrual problems (heavy bleeding and/or pain) is still poorly understood. Several psychological explanations have been proposed to explain these conditions when no apparent organic cause can be found. When medicine fails to help women with menstrual problems, women often elect to have a hysterectomy, although other procedures such as endometrial destruction are now available. 'The widespread prevalence of these disorders is one of the key
arguments of those who advocate that hysterectomy should be used on a wide scale' (Open University, 1985). This operation could have a major impact on a woman’s physical and psychological well-being, but these costs must be weighed against the benefits such as an improved quality of life. Since many researchers have claimed that hysterectomy has serious psychological effects on some women, it is necessary to investigate this claim. Chapter two examines the psychological sequelae of hysterectomy.
We should look upon the female state as being, as it were, a deformity, though one which occurs in the natural course of nature.

Aristotle (384-322 B.C.)
CHAPTER TWO

PSYCHOLOGICAL SEQUELAE OF HYSTERECTOMY

'Hysterectomy injures the patient psychologically only in proportion to her ignorance. If she clearly understands that she only loses her reproductive capacity but remains absolutely normal in other respects, the injury is minimal.'

Gallo (1969)

Introduction

For over a century researchers have pondered over the psychological sequelae of hysterectomy. Keith (1889) was opposed to hysterectomy with removal of the ovaries, as he assumed that 10 per cent of patients 'became insane' (cited in...
Broome & Wall, 1984). Others echoed this assumption (Krafft-Ebing, 1890; Kelly, 1909) by stating that gynaecological patients were predisposed to post-operative psychosis and later Picque (1912) suggested an association between mental illness and gynaecological surgery (see Broom & Wall, 1984). Several decades later the association between psychopathology and hysterectomy still remains an enigma. Of concern for gynaecologists and psychologists is the increasing rise of hysterectomies performed in the UK and the possibility of an association with adverse psychological sequelae. Research findings in this area, however, are often contradictory (Dennerstein & van Hall, 1986) because they are based on methodological inconsistencies.

This chapter will examine the methodological issues involved with this kind of research, retrospective and prospective studies, expectations and satisfaction, and women’s knowledge of the reproductive system, the uterus and sexuality.

**Methodological Issues**

One difficulty in trying to identify the range of psychological problems associated with psychological sequelae of hysterectomy lies in methodological differences in both retrospective and prospective studies. Examples of these differences are: unreliably defined psychopathology, lack of control for pre-existing psychopathology (Kav-Venaki & Zakham, 1983), and varying types of assessment used for evaluating psychological status (Ryan, Lorraine, Dennerstein & Pepperell, 1989); studies also vary in whether the hysterectomy surgery was performed vaginally or abdominally and if it was total, sub-total, radical, or a
Wertheim's hysterectomy, whether surgery involved unilateral or bilateral salpingo-oophorectomy, whether it was performed for benign or malignant conditions and if the operation was elective. Often patients are not matched for age, parity, cultural factors (which might entail different attitudes towards menstruation and the womb); partners' attitudes towards hysterectomy are not noted or considered; there may be differences in sample size and methods of data collection (Ryan et al, 1989); and the sex and professional status of data collectors are not reported. For example, it is important to know how women subjects respond to male versus female data collectors, or a psychiatrist versus other professionals. Some women might respond more honestly to a woman than to a man about sexuality and hysterectomy or vice versa. This is particularly relevant when issues surrounding the symbolism of the uterus involve women's femininity and self-concept (Drellich & Bieber, 1958). Furthermore, few studies mention whether women or their partners have already been sterilized before hysterectomy. Richards (1978) [USA] found that over 40% of his total group of patients had hysterectomies without regard to sterilization; 16.4% had tubal ligations and 24.4% vasectomies, that is 40.8% of the women survey reported permanent sterilization preceding hysterectomy.

Difficulties often arise when comparing different countries and the influence of cultural factors on a woman’s perceptions of her uterus. Differences in psychiatric criteria and in health systems between countries, may be factors which determine the woman’s pathway to surgery and her experience of hysterectomy (Dennerstein & van Hall, 1986). For example, many French gynaecologists report that there are only two reasons to perform hysterectomy in young women; cancer, and abnormal uterine bleeding that cannot be controlled
in any other way, while many U.S. gynaecologists offer a broad range of reasons to perform hysterectomy (Payer, 1988). Over twenty years ago Easley (1971) described several common American reasons for hysterectomy: "In many ways hysterectomy fits women's present needs. It is an excellent procedure for sterilization. A woman is a more reliable worker after she's had one. It is advantageous at the menopause if only to simplify estrogen therapy. For some time I've been telling women that in another twenty years I expect hysterectomy to have become almost routine at menopause." Perhaps this explains Bunker & Brown's (1974) findings that in parts of North America women are three times more likely to have a hysterectomy than women living in England and Wales.

Retrospective studies

Many retrospective studies have investigated the notion that 'because of the symbolic significance of the uterus, hysterectomy could be followed by a higher incidence of psychological and sexual disorders' (Dennerstein & van Hall, 1986). For example, higher psychiatric-hospital admission rates compared with other surgery or with expected community rates (mainly depression); an increased occurrence of treatment with antidepressants in a general-practitioner setting; and sexual dysfunction of many hysterectomized patients.

Barker (1968) examined the case histories of 729 Dundee women who underwent hysterectomy from 1960 to 1964. Fifty-three of the hysterectomy patients (7%) received psychiatric treatment five years post-operatively, 45 (85%) were diagnosed as depressed. Barker also found that psychiatric referral was more
common among patients who had no significant underlying pathological abnormality compared to those who had significant pelvic disease. Marital problems were shown to be more clearly related to psychiatric referral than was a stable marital background. In his control group consisting of 780 cholecystectomy patients, only 9 (3%) received psychiatric treatment following their operation. There could be several reasons to account for the variance of depression between the hysterectomized patients and cholecystectomy patients. The mean age of the hysterectomy group was much younger (44 years-old) compared to the cholecystectomy group (55 years-old) and considering the mean age for menopause is 50 years-old, it could be assumed that the latter group would have gone through menopause. Furthermore whether or not the hysterectomized women in this study had their ovaries removed, after hysterectomy menopause is speeded up by three years (Siddle, 1987) and it is not uncommon to experience depression at the perimenopausal stage or at menopause which could account for these women's depressive symptoms. Ballinger (1975) showed that there was a peak of mild depressive illness and anxiety among women who were perimenopausal. It is also highly probable that marital problems and a background of psychiatric disorder would increase the chances of depression after hysterectomy. However, this study illustrates the importance of considering a patient's and her partner's expectations of hysterectomy and to note that the psychological significance of the operation was not realized until a while after the patient had recovered from surgery (Turpin & Heath, 1979).

Steiner & Aleksandrowicz (1970) investigated the 'emotional' response in 133 women who had undergone gynaecological operations. Their control group consisted of 41 cholecystectomy patients. Neither of the groups of patients had
any malignancies. Over thirty-four per cent of the gynaecological patients manifested depression, anxiety, loss of libido, or physical symptoms. Nearly half (48.8%) of those adversely affected postoperatively were hysterectomy patients. In the control group only 16.2% of patients showed psychiatric sequelae. Steiner & Aleksandrowicz (1970) suggested that losing the uterus could cause a patient to go through a mourning process.

Although most of these studies reflect a general state of depression in hysterectomy patients, some researchers believe in a existence of a hysterectomy syndrome. Richards (1973, 1974) describes the frequent occurrence of a ‘post hysterectomy syndrome’ (headaches, dizziness, insomnia, tiredness, hot flushes, and urinary symptoms) with depression as its most salient feature. Other researchers claim there is no specific psychological hysterectomy syndrome and that Richards' findings on post-operative depression may have been influenced by his methodology (Gitlin & Pasnau, 1989). For example, several women suffered from malignancy (Kav-Venaki & Zakham, 1983) and it is not unreasonable to expect different psychiatric sequelae following surgery for cancer compared with surgery for benign conditions.

Kav-Venaki & Zakham (1983) examined the psychological effects of hysterectomy in premenopausal women. The study included three groups of patients: 19 post-hysterectomy patients; 24 post-hystero-oophorectomy; and 14 post-cholecystectomy. No malignancy was found among these patients. A questionnaire included: pre- and post-operative complaints, the woman’s attitude to the operation; the husband’s attitude to the operation and to his wife; a couple’s sex life before and after the operation; the woman’s knowledge about the
operation she had undergone. The results showed that both groups of hysterectomy patients saw themselves as less feminine after the operation than the cholecystectomy group. There were no differences in levels of depression between the three groups of patients, however, depression was found to be associated with the degree of pre-operative complaints; women who suffered more symptoms pre-surgery, reported more depression post-surgery. Roeske (1969) also found that women who had more physical complaints prior to surgery were more depressed post-surgery. Both Kav-Venaki & Zakham (1983) and Roeske (1969) suggest that these findings imply that the ‘complaints related to the uterus increased the women’s awareness of it, and this salience of the uterus make its loss more traumatic’ (Kav-Venaki & Zakham, 1983) It is also possible that the physical complaints gave rise to depression before the operation.

Kav-Venaki & Zakham (1983) also reported a negative correlation between depression and education, for example the higher the patient’s educational level, the less depression reported; and between depression and the influence of the operation on sex-life, the more positive the influence of the operation on sexual satisfaction, the less depression was reported (Kav-Venaki & Zakham, 1983). The results of the study thus suggest that hysterectomy per se does not necessarily cause depression.

Because the above studies were retrospective they cannot offer conclusive evidence as to whether there are adverse sequelae of hysterectomy, as details about the patients psychological profile before the operation is not available (Dennerstein & van Hall, 1986).
Prospective studies

Fifty years ago prospective studies on the psychological sequelae of hysterectomy were basically exploratory and descriptive, with little attention given to quantitative data or statistical analyses in the reports (Dennerstein & van Hall, 1986). Lindemann (1941) noted that women who had pelvic operations had a higher incidence of depressive symptoms immediately postoperatively than patients who had surgery on the upper abdomen (e.g. cholecystectomy). After conducting further interviews 12 to 18 months after surgery, Lindemann suggested that pelvic surgery patients frequently experienced a depressive syndrome consisting of mild agitation, insomnia and a preoccupation with depressive thoughts and that there was an increased risk of these symptoms occurring if patients had a background of depression. Unfortunately, it is difficult to draw any concrete conclusions from this study as Lindemann neglected to indicate how many women had a hysterectomy and also his findings were not supported by any statistics.

A more satisfactory study was carried out by Barglow, Gunter, Meyer, Johnson & Meltzer (1965) in which twenty-two patients were randomly assigned to either a hysterectomy or a tubal ligation group. One week prior to surgery and one year following surgery a psychological profile was taken of the sample. The hysterectomy group emerged as being less satisfied with their operation and experienced high anxiety compared to the tubal ligation patients. Those suffering from high anxiety prior to surgery were worse off after surgery and considering that two-thirds of the hysterectomy patients had high anxiety it is difficult to conclude whether it was the operation itself or the pre-existing anxiety that was
responsible for the poor outcome. Furthermore, there are many other facts that need considering with regard this study: (1) that there was no underlying pathological reason for having a hysterectomy as it was carried out as a form of contraception (2) hysterectomy is a major operation whereas tubal ligation is a minor operation (3) recovery from hysterectomy takes 6 to 8 weeks compared to a matter of days regarding tubal ligation.

Martin, Roberts & Clayton (1980) examined 44 patients 3 days prior to surgery and one year after their hysterectomy and concluded that hysterectomy was not associated with adverse sequelae. They reported that the patients were less symptomatic than before the operation. Most complaints came from women who were symptomatic prior to surgery, with a greater number of these patients (27%) suffering from hysteria (Briquet’s somatization syndrome). Martin et al suggests that patients suffering from hysteria should be assessed objectively rather than on complaints before being ‘placed at risk of hysterectomy on the basis of psychiatric rather than gynaecological illness.’

A more recent prospective study of Ryan, Dennerstein & Pepperell (1989) demonstrated that there was no evidence to indicate that morbidity increased after hysterectomy. Pre-operatively there was a high prevalence of psychological morbidity (55%) but, it markedly reduced to 31% post-operatively.

Vyas, Bathore, Sharma, Singhal (1989) compared 30 patients women who were hysterectomized for non-malignant pathologies with 30 patients who underwent

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1 Hysteria, defined by Frighner, Robins & Gaze (1972) is a polysymptomatic disorder, with a dramatic, vague, or complicated medical history and multiple, medically unexplained symptoms in many organ systems, as well as psychological complaints such as recurrent nervousness and depression.
other gynaecological operations. The majority of patients were interviewed immediately after their gynaecological consultation, before their operation and at the time of discharge from hospital. Patients were subjected to a battery of psychological measures (e.g. Hindi version of the General Health Questionnaire [GHQ] (Goldberg, 1978); Beck's Depression Rating Inventory [BDRI] (Beck & Ward, 1961). The results suggested a significant increase in psychiatric morbidity after hysterectomy (e.g. reactive depression, 20%; neurotic depression, 10%; anxiety neurosis, 26%; and phobic neurosis, 3%). Such adverse reactions to hysterectomy have been reported by other researchers (e.g. Ackner, 1960; Barker, 1968; Stengel & Zeitlyn, 1958). However, the study discussed took place in India, therefore it is possible that 'hysterectomy constitutes a stressful experience for the patient in India due to misbelief and mystical properties attributed to the functions of the uterus' (Chaudhury, Bhattacharyya & Augustine, 1992).

Many studies have used short durations of follow-up to assess post-operative change due to the problems of patient availability and the fact that most physical consequences of hysterectomy are thought to have resolved within several months of the operation. For some psychological considerations, such as immediate post-operative anxiety or satisfaction with the effects of the operation, short-term follow-ups would appear adequate. Where, however, the psychological variables examined include longer term perceptions of health, self-esteem, psychosexual functioning or dissatisfaction with health care, lengthy follow-up of the order of years may be appropriate.

Most of the studies reported here reflect contradictory findings concerning hysterectomy and psychological sequelae - particularly in relation to depression.
However, it is necessary to also investigate such factors as social support and satisfaction.

**Social support**

Increasingly, research has shown that social support, particularly from a partner, is important to hysterectomized patients (Raphael, 1978) and that the attitude of a woman’s partner (or close companion) is essential in the woman’s psychological recovery from hysterectomy (Roeske, 1978). If the partner is remote, lacks interest in a woman’s feelings or emotions she is more liable to become depressed than if the partner is emotionally supportive and if she still enjoys sexual relations (D’Esopo, 1962; Dennerstein et al, 1977). Dennerstein (1977) found that hysterectomized women "altered sexually" as a reaction to the attitude of their partner. Indeed negative comments by partners "....you can’t have any more children" (Williams, 1977) can appear to the hysterectomized woman as an assault on her motherhood and womanhood which could induce additional anxiety.

If a hysterectomized woman is consistently defined as being ‘castrated,’ ‘desexed,’ ‘female eunuch’ by her partner or significant others it is possible that in time she may come to believe these definitions and as Melody (1962) speculates ‘....among other aspects of the clinical response, the syndrome of depression may evolve.’ However, this supposition may not apply to women who elect to have a hysterectomy.
Webb & Wilson-Barnett (1983) found that lack of social support from partner, family and friends were associated with poor outcome and support was also related to an improved sex life. Melody (1962) describes woman as a tribal creature ‘the acceptance, approval, and support of significant members of the social group of which she herself is a member are critical factors in the prevention of adverse reactions to hysterectomy, especially in women who preoperatively have shown the proclivity for reacting to threat with the syndrome of depression as their particular adaptive pattern.’

Social support need not only relate to friends and partners it can also involve workers in a healthcare setting. For example, research in this area has shown that when health advisers offered patients information about hysterectomy, the incidence of sexual dysfunction after surgery was lower (Dennerstein et al, 1977). Webb & Wilson-Barnett (1983) found that out of a sample of 150 hysterectomized women that the majority (77%) had heard old wives’ tales about hysterectomy. The most common comments were: "you get depressed," "you put on weight," "it takes a long time to get over it" and to a lesser degree some patients had heard they would lose their femininity, they would age prematurely, their sex life would deteriorate and that they might even grow facial hair. However, these researchers suggest that by offering social support (e.g. counselling) to women before a hysterectomy "old wives’ tales" and lay theories on the negative effects of hysterectomy can be corrected by explaining what effects the operation should and should not be expected to have.
Satisfaction

Schofield, Bennett, Redman, Walters & Sanson-Fisher (1991) in a retrospective study looked at women's perceptions of, and satisfaction with, long-term outcomes of hysterectomy performed 2 and 10 years ago. They found that benefits included relief from heavy periods and painful periods and an improved emotional well-being, 57%, 12% and 4%, respectively. Satisfaction with treatment was related to age and parity. Women under 50 years-old with less than three children were more contented with their recovery than older women who had more than three children.

Although women were generally satisfied with outcome of hysterectomy (96%), self-reported morbidity was high, 59% admitted having symptoms that had been caused or worsened by the operation (Schofield et al, 1991). This contradiction seems to imply either that women were averse to complaining about medical treatment (Nehring & Geach, 1973) or possibly that the positive effects of treatment outweighed the negative ones. Similar findings were reported by Taylor (1983) who looked at adjustment among cancer patients. After being diagnosed as having cancer, patients were asked how they regarded changes to their life. Fifty-three per cent reported positive changes against 17% who reported negative changes. Moreover, the majority of these patients considered themselves better adjusted since having cancer. Greenwald (1980) proposes that 'individuals attempt to construe benefit from difficult or threatening situations and these positive biases have been linked to positive adjustment.'

For many women the removal of the uterus may signify the relief from
malignancy, from menorrhagia and dysmenorrhoea, yet psychological maladjustment and further physical complications following surgery may override the initial satisfaction gained.

Other research has found that satisfaction with a hysterectomy was significantly related to marital status. For example, van Keep, Wildemeersch & Lehert (1983) reported that married women (84%) were more satisfied with the result of their operation than single, divorced and widowed women (67%).

Research in this area thus suggests that a patient’s satisfaction with a hysterectomy is dependent on many factors: first a hysterectomized woman may see the loss of her uterus as the loss of femininity, fertility and the start of the ageing process which in western youth-oriented culture might make a woman feel less sexually attractive. It also seems likely that women who have been denied motherhood because of a hysterectomy would be less satisfied with the removal of her uterus than a hysterectomized woman who has a ready-made family. As noted previously the quality of support a hysterectomized woman receives can influence her recovery level and with this presumably her satisfaction with the operation.

**Expectations**

There are several important reasons for measuring women’s expectations of hysterectomy since this operation can lead to a number of negative psychological effects which do not necessarily relate to other operations. For example, some
women equate losing their womb to loss of identity, loss of femininity and feelings of mutilation (Patterson & Craig, 1953; Nathorst-Boos, Fuchs & von Schoultz, 1992) and loss of childbearing possibilities.

Although the negative effects of hysterectomy are all too apparent, little research has attempted to measure the positive effects such as improvement in wellbeing, improved psychosexual adjustment and loss of pain and discomfort. Richards (1978) asked an American sample of patients \((N=340)\) who had hysterectomies 3 years previously if they thought their surgery was beneficial. Of this sample approximately 76% of patients claimed they had elective hysterectomy and 92.8% of these patients considered it necessary. The majority of the patients reported feeling better after the operation (77.7%); 4% felt worse; 12.8% felt both better and worse; 4.7% felt the same and 0.7% gave no comment. They felt better for the following reasons: (in order of priority ranging from 69.7% to 0.4%): less inconvenience, more energy, better sex life; no more/less pain; better emotionally; better generally; no dyspareunia; no more fear of pregnancy; no fear of cancer; less discharge; saved my life; bowels better; no more fear of contraceptives. On the negative side, patients reported: weight gain; worse sex life; depression; weight loss; tired, less energy; bladder problems; menopause symptoms; loss of muscle control; still have pain. Ninety per cent of the patients claimed that they knew the risk involved in surgery and despite an overall positive response, many patients considered a second opinion was necessary. The main problem with Richards’ (1978) findings is that it has not been subjected to any statistical analysis. They are also contradictory to Richards (1974) U.K. findings where he suggested that 70% of the hysterectomy patients complained of postoperative depression with a similar number complaining of hot flushes, urinary symptoms
and severe exhaustion. It could be that English patients should not be compared with those in America. Findings in countries such as Sweden (e.g. Nathorst-Boos et al, 1992) suggest that, as in Richards’ (1978) American sample, hysterectomy patients were generally positive about the effects of the operation. The most common benefit reported was the termination of heavy menstrual bleeding and irregular bleeding followed by freedom from pain and pressure.

Knowledge of the reproductive system

It might be expected that a woman’s knowledge of her reproductive system could influence both the psychological sequelae of hysterectomy and a woman’s expectations of this operation. Yet, few studies examining the psychological aspects of hysterectomy have focused on this area.

Tsoi, Poon and Ho (1983) examined 80 gynaecological patients’ knowledge of the shape, size and function of their reproductive organs and found that the ovaries were the least understood organs in terms of shape and size and the vagina in terms of functions. The relationship between gynaecological knowledge and preoperative anxiety in 20 hysterectomy patients indicated that although gynaecological information was not associated with the number of expected postoperative changes, women who understood less about their body tended to believe that hysterectomy would have certain effects which had no medical basis (Tsoi et al, 1983). Singh, Raphael, Gyaneshwar & Johnson (1983) reported that when hysterectomy patients were asked about their understanding of the function of their uterus and ovaries, those whose knowledge was poor had poorer health
outcomes than patients whose knowledge was better.

If a woman has enough knowledge about her reproductive system perhaps negative reactions to a hysterectomy would be minimal. Gallo (1969) illustrates this point by stating: 'Hysterectomy injures the patient psychologically only in proportion to her ignorance. If she clearly understands that she only loses her reproductive capacity but remains absolutely normal in other respects, the injury is minimal.'

**The uterus and sexuality**

A popular belief that often surrounds removal of the uterus is that there is "better sex" afterwards (Sloan, 1978). Little evidence exists to support this idea and much of the earlier research into the uterus and sexuality produced inconsistent results. Bernhard (1986) examined 18 studies concerning hysterectomy and female sexuality, published between 1950 to 1982 and reported mixed findings mainly due to 'methodological and measurement problems, definition of terms, data collection instruments and procedures and sampling approaches...'. Cutler (1988) reported that for approximately 50% of premenopausal hysterectomized women the sexual response almost disappears. There could be several reasons for this occurrence. After hysterectomy and oophorectomy, decreased estrogen causes physical changes in the genitalia; the vagina is drier and becomes shorter and less flexible; removal of the cervix can cause painful sex as there is no lubrication present (Goldfarb & Greif, 1990). Many women claim the importance of the uterus for orgasm (Haspels, 1979;
Rubin, 1980) and for general female sexuality (Zussman, Zussman, Sunley & Bjornson, 1981). The Textbook of Sexual Medicine states that contractions occur in the uterus during orgasm (Kolodny, Masters & Johnson, 1979). However, it has been shown that hormonal treatment improves coitus and orgasm for hysterectomy and bilateral salpingo-oophorectomy women (Sherwin & Gelfand, 1987).

On the psychological side, Dennerstein, Wood & Burrows (1977) in a retrospective study of patients who had undergone hystero-oophorectomy showed that negative, pre-operative expectations of sexual changes were significantly correlated with post-operative sexual dysfunction. Craig & Jackson (1975) reported that almost three quarters of their patients with a mean age of 40 had sexual dysfunction after vaginal hysterectomy (e.g. dryness of vagina, dyspareunia, lack of libido and bleeding). One study reported that sexual desire had decreased post-hysterectomy in 32% of cases, was unaltered in 22%, and improved in 32% (Ananth, 1983). Kornacki, Broldzinsli, Wilczynski (1971) reported dyspareunia had doubled following hysterectomy. Studies in the United Kingdom have reported that between 33% to 46% of women complain of decreased sexual response after hysterectomy-oophorectomy (Zussman, Zussman, Sunley & Bjornson, 1981; Nathorst-Boos, Fuchs & Schoultz, 1992). In Japan other studies have produced similar findings among hysterectomy patients (Sakai, Yamamoto & Kamiya, 1983). The incidence of sexual dysfunction following hysterectomy can vary from 10% to 46% (Ananth, 1983; Dodds et al, 1961; Huffman, 1950; Patterson & Craig, 1963; Richards, 1973; Zussman et al, 1981).

"For some women, the quality of the orgasm is related to the movement of cervix and uterus... the intensity of the orgasm is thus diminished when these structures are removed. For other women, orgasm is achieved mainly by clitoral stimulation so that the loss of the internal structures does not have a comparable effect."
Some researchers suggest that 'depression after the operation may manifest in sexual symptoms and many of these patients find a simultaneous improvement in depression as well as sexual function with antidepressant therapy' (Ananth, 1983). Bachmann (1990) has suggested that postoperative psychosexual problems emerge predominantly in hysterectomy patients with: (1) a history of preoperative depression, sexual dysfunction, or other psychological disturbances (Lindemann, 1941; Ackner, 1960; Moore & Tolley, 1976); (2) ages below 35-40 years, limited educational achievement, or conflict regarding future pregnancy (Richards, 1974; Ackner, 1960; Barker, 1968; Hampton & Tarnasky, 1974; Moore & Tolley, 1976; Domenighetti, Luraschi, Casabianca, 1988); (3) an inadequate preoperative comprehension of suggested surgery and what changes to expect postoperatively (Sloan, 1978; Ananth, 1983; Zussman, Zussman, Sunley & Bjornson, 1981); (4) a view that the uterus is of a unique psychological and sexual importance (Ananth, 1983; Marbach, 1967; Zussman et al, 1981; Dennerstein, Wood & Burrows, 1977; Drummond & Field, 1984); and (5) an absence of pelvic pathology (Barker, 1968; Richards, 1973).

However negative attitudes towards sexuality and loss of a uterus can also come from male partners. For example, some men view their partners as "neutered" (Goldfarb & Greif, 1990) and therefore no longer desirable. Nevertheless, loss of the uterus can have positive effects for some women. It can mean a better sexual life as the fears of pregnancy and disease have gone.

'Theoretically, removal of the uterus should increase sexual pleasure because it frees those patients who do not want children from the fear of pregnancy, does away with the fear of uterine disease, particularly cancer, relieves dysmenorrhoea
and dyspareunia due to intrapelvic disease, and eliminates the sexual abstinence some patients practice during menstruation' (Huffman, 1985).

Conclusion

Investigations into the positive and negative effects of hysterectomy are often contradictory and can be explained largely in terms of research design and method (Vyas, Rathore, Sharma & Singhal, 1989). Prospective studies on hysterectomy patients often show that they suffer from post-operation depression which later disappears while other studies show depression/psychiatric problems associated with the operation often emerge within a two-year period.

Since many researchers suggest that depression is a negative psychological consequence of hysterectomy, gynaecologists should consider patients’ the long-term effects it has on the patients’ quality of life. In other words, do the benefits outweigh the risks? Hysterectomy is a major, irreversible operation which has implications for women in the areas of procreation, womanhood and sexuality. Disharmony in any of these areas might be expected to affect women’s mental and physical wellbeing.

The main emphasis of the studies discussed above is that depression and sexual dysfunction are seen as negative aspects of hysterectomy. These features of hysterectomy may be ameliorated if psychological preparation (guidance, reassurance and measuring patients expectations of treatment) are considered before surgery. The data in many of these studies indicate that depression seen
Psychological Sequelae of Hysterectomy

post-operatively existed in many of the patients before they underwent a hysterectomy. Marital problems, partners' reactions to hysterectomy, lack of knowledge of the reproductive system can also lead to negative reactions to this operation. In the case of sexual dysfunction after hysterectomy, hormonal replacement therapy can frequently rectify the problem.

In order to make causal inferences about post-hysterectomy psychological changes it is important that studies are prospective (e.g. Barglow et al, 1965; Martin et al, 1980; Ryan et al, 1989) rather than retrospective (e.g. Barker, 1968; Steiner & Aleksandrowicz, 1970). Pre-operative measures can then be compared with their post-operative equivalents although problems still exist in obtaining pre-operative data early enough to avoid 'contamination' by the effects of illness or by anticipation of the hysterectomy (Broome & Wallace, 1984, p.146).

This chapter has examined the issues surrounding hysterectomy. The question whether hysterectomy triggers depression remains unresolved, however, the background of retrospective and prospective studies provides researchers with a guide as to the areas to focus on regarding what patients expect from hysterectomy. These include: relief from menstrual pain and menstrual blood loss, birth control, improvement in bowel and sexual function, negative expectations of harm such as ageing, loss of femininity and reduced sexual interest which are investigated in study 1 and study 2.
The surgeon and the diagnostician must be one and the same, so often the diagnosis cannot be complete or procedure fully determined until the operation is under way. And to be a good diagnostician in the diseases of women one must know as much about women as about disease; as much about environmental and social and domestic conditions as about pelvic lesions; as much about cases as results.

*Newman (1896)*
CHAPTER THREE

THE MEASUREMENT OF WOMEN'S EXPECTATIONS OF HYSTERECTOMY AND ALTERNATIVE TREATMENTS

Abstract

Two studies looked at women complaining of menstrual pain and/or bleeding attending gynaecology outpatient clinics in six general hospitals in the U.K. In study 1 (N=200) women's expectations of hysterectomy and alternative treatments (drugs, dilatation and curettage and endometrial resection) were measured on a 58-item Expectations of Treatment Questionnaire (ETQ) based on a survey of women's (N=26) spontaneous descriptions. Principal components analysis of the ratings identified seven independent dimensions: wellbeing, harm, menstruation, sensitivity to physical symptoms, sex, womb and bowels. These components were then compared in patients who expected a gynaecological operation or drugs. The results revealed that hysterectomy was seen as the most 'powerful' treatment which brought with it the expectancy of improving patients' quality of life. In study 2 the ETQ was reformed to 46 items on the basis of the principal component analysis and then given to another sample of gynaecological patients (N=100). Patients were asked to read one descriptive paragraph on one of the above treatments and then asked to imagine they were going to receive such a treatment before completing the ETQ. The results confirmed the findings of study 1 - outcome expectations of hysterectomy were that it would have more powerful positive and negative effects than other treatments.
Introduction

If the health care providers’ goal is to improve the effectiveness of care, increase the efficiency with which it is delivered, and improve their reputation locally with both patients and purchasers (HMSO, 1993) they must recognize that patients have consumer-type expectations. With the development of consumerism, patients can no longer be regarded as passive recipients of medical care or of the information provided about that care. Patients’ and consumers’ groups are becoming increasingly active about perceived shortcomings in standards of communication in clinical services (HMSO, 1993). With the introduction of The Patient’s Charter, patients, as consumers, should also have more influence in the decision-making process, enabling them to decide if procedures such as hysterectomy would be an effective treatment of their symptoms.

Considering the increasing incidence of hysterectomies in the last decade in England (see Chapter 1), it is important to clarify what patients expect from this costly (financially and healthwise) procedure. Compared to other types of operation, hysterectomy is in many ways unique. It has a greater potential than most operations to evoke fear and other negative expectations. It can induce or speed up menopause and therefore hastens aspects of the ageing process. It is often associated with depression, other psychiatric disorders or psychosexual difficulties (Richards, 1973; Ballinger, 1975, 1977; Ryan, Dennerstein & Pepperell, 1989; Wijma, Boake & Janssens, 1982). However, there are a number of reasons why patients could have positive expectations of hysterectomy; it can relieve prolonged heavy menstrual bleeding and pain, it can alleviate premenstrual tension (if the ovaries are removed) and can also remove the threat
of malignancy. In some cases it may give women more interest in sex and/or make it more enjoyable since the worry of pregnancy is removed. And, most importantly, it can also improve women’s quality of life (e.g. Richards, 1978).

Since the majority of hysterectomies are performed for benign conditions, removal of the uterus could be seen as the ‘target of the surgical abuse’ (Wolfe & Jones, 1991) or a subject of women’s desires/expectations. Therefore, one way of addressing this question is to measure patients’ expectations of treatment. The process of formalizing their expectations could make patients more aware of the different factors to consider concerning hysterectomy (e.g. risks and benefits). It may prompt them to ask more questions about the procedure and give them more control in the decision-making process regarding their treatment. As a result it could help relieve some patients of unwarranted negative expectancies of outcome. It can also give doctors an indication of what changes patients expect or desire from certain treatments. In the long-term this can save time and resources by avoiding mistakes which could be the result of administering an inappropriate treatment because a patient’s expectations of treatment was not fully understood.

Finally, analyzing patients’ expectations can also aid clinicians in designing educative programmes for medical students and health care workers. If medical workers are expected to be skilled information providers they should recognise the extent to which patients’ expectations can be used as a predictive tool in treatment outcome. If the aim of health care is to offer patients a better quality of life, it is vital for clinicians to understand patients’ expectations of treatment.
This is particularly important with regard to hysterectomy operations where often objective indications for this operation are absent.

**Expectations of general surgery**

With *all* operations patients have certain psychological or physical expectations ranging from enhancement of appearance, relief from life-threatening symptoms, relief from pain, greater physical mobility to improvement of the quality of life. Despite this research into patients' treatment expectations has been generally neglected in the literature.

There have however been some studies which have looked at patients' expectations and some have been reported in a range of surgical procedures. For example, Kiyak, Vitaliano and Crinean (1988) focused on the measurement of presurgical expectations of postsurgical problems, mood states and satisfaction with outcomes. One-hundred and fourteen orthognathic patients (with a mean age of 26 years-old and a range of 14 to 43 years-old) were asked to complete a 15-item questionnaire designed to assess their expectations of short-term changes associated with surgery - such as pain, paraesthesia, and problems with speech and eating. Patients responses were measured on a 7-point response scale ranging from (1) *no discomfort expected* to (7) *much discomfort expected* which was completed six to twelve months before surgery. The items on the questionnaire were based on a previous longitudinal study of surgical patients (Kiyak, McNeill, West, Hohl, Bucher & Sherrick, 1982; Kiyak, West, Hohl, McNeill, 1982; Kiyak, Hohl, West & McNeill, 1984) in which open-ended
questions and rationally derived checklists were used to assess patients' motives for, expectations from, and concerns about orthognathic surgery (Kiyak, Vitaliano & Crinean, 1988).

Kiyak, Vitaliano & Crinean (1988) predicted that orthognathic patients expecting numerous problems postsurgically would have better outcomes than patients who anticipated fewer problems with surgery. However, the results did not support this notion. Patients who expected few problems with surgery reported better psychological outcomes than those who expected numerous problems. One explanation for this result is that those expecting many problems may have caused themselves unnecessary anxiety by focusing on the negative aspects of surgery. Patients who expected fewer problems may not have denied the threatening aspects of surgery, but instead may have been quite realistic about the risks attached to orthognathic surgery. As Kiyak, Vitaliano & Crinean (1988) note 'Perhaps the definition of "unrealistic expectations" should be modified for this type of surgery; it may be that the individual who expects serious problems from surgery is more unrealistic than one who expects few problems'.

Barbosa, Marcantonio, Barbosa, Gabrielli & Gabrielli (1993) approached the measurement of orthognathic patients expectations of treatment from a different perspective than Kiyak et al (1988). Patients expectations of surgery were assessed through carefully structured interviews (based on the guide-lines of Peterson & Topazian, 1980) where the patient indicated to the surgeon what he/she expected from surgery. In response to the patient's expectations, the
surgeon explained what he/she was attempting to achieve. Peterson & Topazian (1980) comment that 'a patient who has been given a realistic idea of how much improvement in jaw function and physical appearance could be expected would probably react favourably to the outcome. The patient who has vague, nonspecific expectations usually has unrealistic expectations. The interview was designed to produce an objective evaluation, but the surgeon's intuitive feeling could strengthen the more objective findings.' The study involved forty-one patients (with an age range of 17 to 42 years-old) undergoing various surgical procedures (mandibular advancement, mandibular retrusion, maxillary surgery and maxillary and mandibular surgery). Patients' expectations in relation to surgery were rated by the researcher on a 3-point scale from: realistic, not clear to unrealistic. Additionally, evaluations of treatment outcome were assessed by the same researcher on 3-point scale: satisfactory, reasonable, or poor.

Most of the patients (80%) presented realistic expectations of surgery. However, some patients (7.2%) presented poorly defined expectations and others (2.44%) had totally unrealistic expectations. Long-term evaluations of treatment showed that 92.7% considered the treatment as satisfactory.

Another area of surgical procedures that has attracted some interest in measuring women's expectations of treatment, concerns augmentation mammoplasty (AM). Elective surgery for this operation is 'often associated with underlying psychopathology and high expectations of a positive psychological outcome' (Schlesbusch & Marhrt, 1993). AM patients and orthognathic patients expectations of treatment might be quite similar. Both groups of patients might
see themselves with a deformity and anticipate it would be rectified through surgery. As a result they might expect to gain more confidence, a better self-image and an increase interpersonal skills. However, measurements of expectations of treatment differed considerably between orthognathic surgery and AM. In their study Schlebusch & Mahrt chose to investigate the long-term psychological effects of AM in a group of 20 patients (with a mean age 34.5 years-old and a range of 20 to 40 years-old) who were reassessed 3 years or more post-operatively. They conducted comparative analysis between preoperative and postoperative data from a semi-structured clinical interview which evaluated patients expectations in terms of: interpersonal skills and relationship; body and breast perception in relation to body image; intrapsychic factors; marital adjustment and self image.

Most patients expected positive psychological changes as a result of surgery in such areas as: personality characteristics (40%) self-confidence (90%), interpersonal skills (85%), social relationships (50%), social acceptability (40%), sexual relationships (80%), and improved self-image by altering their clothing style (80%) (Schlesbush & Mahrt, 1993). After AM 80% of patients reported that some of these expectations had been fulfilled. However this might not have been the case if surgical complications and/or post-operative problems had arisen since many patients (60%) had not considered surgical failure, and a higher proportion (80%) admitted they had not considered postoperative complications. It is somewhat surprising that few patients had considered surgical failure or postoperative complications since many American and British plastic surgeons are now increasingly concerned about silicone leakage.
Whilst it would be reasonable to assume that certain parallels exist between orthognathic and AM surgery the expectations of oncology patients may be very different. For example, though perceptions of body image could change in all three groups of patients (orthognathic, AM and oncology), the direction of that change may vary in predictable ways. Orthognathic and AM patients would expect an improvement aesthetically, whereas oncology patients might expect treatment to have a negative affect on their appearance. For example, possible mutilation and altered bodily functioning often results when some malignant tumours require extensive removal of surrounding tissue or extirpation of an organ or limb (Fallowfield, 1990). Maguire, Brooke, Tait, Thomas & Sellwood (1983) reported that 'at least one in five patients who undergo mastectomy develop body image problems' (cited in Maguire, 1985). Chemotherapeutic agents destroy cancer cells, but also normal cells of the body: cells within the hair follicles, bone marrow and lining of the gastrointestinal tract are particularly vulnerable, therefore, the well-known side-effects of alopecia, bleeding, anaemia, lowered resistance to infection, vomiting and diarrhoea (Fallowfield, 1990). Additionally, oncology patients' expectations of treatment could also be linked to a poor prognosis.

With most surgical treatments patients experience an element of pain. But the studies reviewed so far, do not appear to have included this measure. Moreover, when measurements of patients' expectations of pain are assessed, they are often over a short-term period and frequently include patients' past experience of pain. This was demonstrated by Walmsley, Brockopp and Brockopp (1992) who examined previous pain experiences and expectations of post-operative pain in
101 patients (with an age range of 55 to 87-years-old) undergoing elective surgery. A structured interview was constructed to assess expectation of pain post-surgically (e.g. *Thinking about this operation, show me on this scale how much pain you expect to have, [VAS 1-10 cm]*). Also attitudes about pain (e.g. *If I know what pain to expect I can handle it*) were measured using a 5-point scale with disagree at one end and agree at the other end.

Walmsley, Brockopp and Brockopp (1992) found that the two factors that correlated significantly with pain expected postoperatively were: (a) agreement with the statement: "pain is to be expected post-surgery even with medicine" from the "general attitude questions" and (b) the total of the global ratings of past pain experiences (the sum of global surgical pain, global trauma pain, global childbirth pain, chronic pain, and other pain). The total of the global pain ratings of past pain experiences was the single strongest partial correlate of expected pain. Presurgical pain, five of the six attitudes about pain, and pain related to specific surgeries were not correlated with patients' expectations of postsurgical pain. The researchers concluded that "expectations that can include both overestimates and underestimates of postsurgical pain may be the result of prior experiences and attitude toward the effectiveness of pain medication." It is also possible that some people complain of a lot of pain.

**Conclusion**

There are two main problems which emerge from the majority of these studies
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concerning patients’ expectations of general surgery. First, there is a widespread tendency for them to focus on the negative aspects of surgery. Apart from this, there appears to be very little consistency between the studies in how expectations have been measured, which makes comparisons of expectations of treatment a complex task. However, there is a tendency for patients who expect few problems with surgery, or have realistic expectations of surgery, to be more satisfied with treatment than those without such expectations.

The second problem is that many of these studies focus on short-term changes associated with surgery. It is important also to examine the long-term effects of surgery - particularly if researchers are to consider the effects of surgery on patients’ quality of life.

Gynaecological surgery

Exploring patients’ expectations of treatment in general surgery may not be a straightforward exercise. For example, how researchers interpret patients realistic or unrealistic expectations may be open to ambiguity. Where gynaecological surgery is concerned, one might expect a measurements of patient’s expectations of treatment to bear some resemblance to those in general surgery. However, this does not necessarily follow as factors such as culture may affect expectations of the two types of surgery differently.

The influence of culture on patients’ expectations of treatment has received little coverage in the gynaecology literature. The studies of Tsoi et al (1983, 1984)
clearly show the value of examining the affects of culture on patients perceptions of hysterectomy. Tsoi, Poon & Ho (1983) examined whether patients knowledge about their reproductive organs was related to their expectations of outcome of surgery. Twenty Chinese hysterectomy patients (with an age range of 28 to 52 years-old) were asked presurgically about the shape, size and function of the uterus, ovaries, vagina and fallopian tubes. Additionally patients were asked by the researchers "What do you know about menstruation?" and the patients responses were rated: accurate, near accurate, wrong, and don't know.

When assessing expectations, twelve items (which were derived from the results of a pilot study based on interviews with a sample of pre- and post-hysterectomy patients) were suggested to the patients: (1) loss of menstruation, (2) loss of childbearing capacity, (3) a hole in the body, (4) prolapse/bundling of other organs, (5) loss of sexual functions, (6) lowered sexual interests, (7) no longer a woman, (8) irritable moods (9) ageing, (10) weakened health (11) loss of blood (anaemia) and breathlessness, (12) rejection by husband. The number of expected post-operative changes was recorded for each patient (range 0-12) and from this list seven items were selected (items 1 to 7 listed above). If a patient expected the loss of menstruation and the loss of childbearing capacity, this was judged as a justifiable concern ie. one with a realistic basis. Also a negative response to the other items was also considered as justifiable. This yielded a scoring for 'Justifiable expectation.'

The majority of patients expected loss of menstruation and childbearing, although 85% did not anticipate sexual dysfunction (45% answered 'don't know') while
35% expected a decrease in sexual interests. Seventy per cent of the patients expected a hole being left in their body; 50% were anxious about the prolapse or bundling of the other organs; and 60% expected premature ageing (Tsoi et al, 1983). No correlation was found between the scores relating to patients knowledge of the female reproductive organs and the number of preoperatively expected changes. However, there was an association between gynaecological knowledge and justifiable expectations, which implies that knowledge concerning the reproductive organs is related to the degree of realistic concern about the outcome of hysterectomy. Tsoi et al (1983) demonstrated that a woman’s knowledge of her reproductive system has an important role in determining the significance a patient attributes to an organ. It can affect her concern/ expectations about its removal and can lead to fear and distress.

In a later study Tsoi, Ho & Poon (1984) took their research on patients’ expectations of treatment a step further. They investigated the association between sex-role stereotype, mental health status and patients’ expectation of outcome and postoperation adjustment. Twenty Chinese gynaecology patients (with an age range of 40 to 50 years) were given a battery of questionnaires (e.g. the 30-item General Health Questionnaire (GHQ; Goldberg, 1972), the hypochondriasis Scale of the MMPI, and the Chinese Sex-Role Inventory (CSRI; Keyes, 1980). In the semi-structured presurgery interview a list of 12 items describing the post-hysterectomy changes expected by patients (loss of childbearing ability, ageing, irritable moods, hole in the body, prolapse or adhesion of other organs, impaired physical health, and impaired sexual functioning and interest) was used. From this interview two indices were obtained (1) listed
changes (the number of changes patients indicated on the 12-item list) and (2) total changes (the sum of listed changes and the spontaneous report of any items not on the original list). Post-surgery measures (administered to 18/20 patients who returned for a follow-up) included an interview to assess if the patients reported any changes they had expected pre-operatively and if patients now complained about them (the original 12-item list used listing complaints). Other spontaneous complaints reported were combined with the listed items to form a total complaints measure. Additional measures given to these 18 patients were the 30-item GHQ and the HS (hypochondriasis scale) scale.

Preoperation expectations (interpreted by listed changes and total changes') correlated significantly with all the post-hysterectomy outcome variables. For example, the greater number of changes expected by patients presurgery (total changes), the higher their responses on HS post-surgery, and the poorer their adjustment on the GHQ, and the greater number of complaints they reported on the supplied list as well as total complaints (Tsoi et al, 1984). Patients expectations of treatment varied and often had no medical foundation. For example 70% patients expected that a hole would be left in their body; 50% believed the adhesion of other organs would result; and 60% were concerned about ageing. Prior to surgery several patients did not anticipate having many post-hysterectomy complaints. But at follow-up, more patients (56%) complained of weakened health (identified through dizziness, numbness at various parts of the body, vaginal dryness) than those who expected it to occur (35%) (Tsoi et al, 1984). Patients also reported hot flushes, pain and sleeping problems. HS

'The sum of listed changes and the spontaneous report of any item not on the original list' (Tsoi et al, 1984).
responses during this period were not significantly increased. Yet the most common pre-surgery concern, prolapse or adhesion of the other organs, was not reported.

It appears that patients who expected many changes to be brought about by hysterectomy were more likely to complain at follow-up, but the complaints registered had not been expected by them. For example, common physical symptoms - hot flushes and vaginal dryness - often related to ovarian removal were not expected by patients. From this Tsoi et al (1984) concluded that patients lack of knowledge about their reproductive organs could affect their expectations of treatment. These two studies conducted by Tsoi et al (1983, 1984) also demonstrate how culture affects the way women regard their body. For example, Chinese women, are assigned a passive role in their traditional culture, as a result they are both disinclined and ashamed to discuss their body. As in Africa, in China and other cultures, myths and taboos are associated with the woman's reproductive system (see Chapter 1). As in Judaism and Christianity, Chinese women refrain from sexual intercourse during menstruation. In essence, women in China and indeed in other cultures, view intercourse as a way of satisfying their husbands' sexual appetite, and deriving little pleasure from it themselves (Tseng & McDermott, 1981, cited in Tsoi et al, 1983). When measuring gynaecology patients' expectations of treatment, the effects of culture should be considered as it could explain why some women's expectations of hysterectomy could be negative or unrealistic.

Few investigations feature black gynaecology patients' expectations of treatment,
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however, Bernhard (1985) conducted a study on 37 black American women (with a mean age 35.5 years). They were interviewed about the effect of hysterectomy on their sexuality and on the sexual outcomes they experience. Patients were interviewed preoperatively, at their first postoperative checkup, and three months after surgery about their feelings, expectations, and experiences with the hysterectomy. These interviews were tape-recorded and transcribed verbatim for qualitative analysis. Patients’ expectations lay in four main areas: personal attractiveness (related to their surgical incision scar, gaining weight, becoming ‘masculine’, or experiencing menopause or ageing), loss of womanhood (sense of loss and regret about menstrual periods), ability to engage in sexual activity (lack of sexual desire or orgasm, "sex life would change", or experience different feelings during sex, or a dry vagina) and partner’s response ("men would think women who have hysterectomies are different, not complete and can’t function sexually").

Some women (15/34) in this sample with a regular sexual partner did not inform their partners that they were having a hysterectomy. Instead they claimed that their operation was for either tubal ligation, cholecystectomy, or tumour removal. However, following surgery 4/15 told their partner about their hysterectomy, and one partner was notified by the surgeon. Several women claimed that were not going to "take the chance of telling him," with the possible result of losing him (Bernhard, 1985). Many of these women were apprehensive about recommencing sexual intercourse because they feared: "tearing on the inside" or that it would be painful because "they did so much cutting and taking out". The fact that many women withheld information from their partners about the nature of their operation implies their fears of rejection. Rejection insomuch that the site of
womanhood (the uterus) is removed, denying them of any chance procreation. Considering that the womb symbolizes 'power' in some societies (see Chapter 1) removal of this source of fertility could have negative affects on both females and their partners. Thus 'the sources of expectations are not only from within the person' but are greatly influenced by the perceptions of other women and men (Bernhard, 1985).

Wolf (1970) considered how hysterectomy could also affect patients' partners. He found that husbands were concerned about the operation and the effects it would have on their own sexuality and believed that after the operation their partner would not be a woman. Daly (1976 cited in Bernhard, 1985) showed that men could be physically affected by their partners' hysterectomy. He reported that 18% of men in his study became impotent with their partners after hysterectomy. Yet when they had sex with other women with wombs their impotence disappeared.

It is possible that cultural differences may also influence the attitudes and expectations of patients and their partners, however, little investigation has been done in this area. Williams (1979) suggested that Mexican-American women are more concerned than Anglo women about their husband's reactions to hysterectomy and that these women often equate fertility with femininity and appeal (cited in Keith, 1980).

Culture and partners reactions have been seen to affect patients' perceptions of hysterectomy. In other gynaecological surgery researchers have focused on the
relationship of expectancies of pain and symptoms to the experience of postoperative pain, symptoms and distress. For example, this was investigated in two studies (Wallace 1985a; 1985b) of female patients undergoing laparoscopic surgery for either sterilization or infertility investigation. In the first study, 118 patients completed a 20-item multi-choice questionnaire which assessed expectations about surgery of which 4 items referred to commonly experienced symptoms (incisional pain, shoulder tip pain, sore throat and discomfort in the rib area). Measures of patients expected intensity and severity of pain was rated on a 10-point scale ranging from 'no pain' to 'extreme pain'. State anxiety, upset and fear ratings were also assessed presurgically and postsurgically. The resulting evidence showed that greater expected pain was associated with more distress and more reported pain at return from surgery. There was no indication that patients who expected symptoms to occur reported experiencing more symptoms.

Following this investigation, Wallace (1985b) conducted a second study, which considered the effect of accurate information on expected and experienced pain and symptoms in 63 female patients undergoing laparoscopy surgery for sterilization or infertility investigation. There were three conditions: (1) patients received routine care only or (2) routine care together with a minimal information booklet (about hospital procedures) or (3) routine care plus a maximal information booklet (information about surgery on expected and reported pain accuracy). As in the first study patients completed the state anxiety measure, fear and pain expectancy measures. In addition they completed a more detailed expected symptoms relate to abdominal surgery under general anaesthesia.
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symptoms questionnaire which asked them to identify symptoms expected to occur after surgery from a list of 19 items. Included on this list was eleven of the most commonly reported items. Patients completed psychological measures before and after surgery.

There was no evidence to suggest that the provision of maximal information about surgery influenced the level of pain expected by patients. However, those who received maximal information reported significantly less pain postoperatively than those in the other two conditions. The fact that the patients in the maximal information group were given a booklet which also included details about cognitive and behavioural strategies for coping with pain and discomfort could have helped ease the pain. Or the impact of pain might have appeared less simply because patients had expected it. It is possible in other words that offering patients coping techniques may have helped them to deal with the effects of surgery or altered their expectations regarding the emotional response to it.

These studies involved sterilization and infertility and a decision to have surgery for these conditions is a highly emotive one. To simply investigate dimensions of pain, anxiety, fear and mood concerning surgery in these studies, might thus deprive researchers of a full insight into the psychological processes women usually go through when undergoing such procedures. If measurements of patients' expectations of treatment included such dimensions as depression, femininity and long-term effects, it would add richness to this research area.

Other studies that have attempted to evaluate patients' expectations of
hysterectomy have often failed to encompass a full-range of patients perceptions of the long-term outcomes of treatment. Often researchers have not reported whether patients were undergoing vaginal or abdominal hysterectomy. They also have neglected to mention what the operation involved (e.g. removal of the cervix, ovaries, fallopian tubes). These data are important to include in any evaluation of the long-term effects/expectations of treatment since removal of certain organs could have different physical and psychological effects on the patient.

A prospective German study (Schulze, Florin, Matschin, Sougioutzi & Schulze, 1988) approached the subject of womens' expectations of hysterectomy by using a wide range of questionnaires. The aim of the study was to examine psychological distress two months after surgery in 52 women (with a mean age 41.8 years-old with a range of 31 to 55 years-old) undergoing hysterectomy. The pre-surgery measures included a 21-item questionnaire relating to the expected effects of removal of the uterus (a measure of cognitive appraisal of hysterectomy). These expectations were marked on a 7-point scale from very negative effect to very positive effect. For example: Removal of the uterus will have a very negative/positive effect on my attractiveness, femininity, libido, self-esteem, health, process of ageing, well-being of body, interest of male partner. (iv) three rating scales from very, clearly to more like of ten pairs of words (e.g. depressed and relieved; confident and helpless; sad and happy), with each scale measuring attitudes toward removal of the uterus, cessation of menstruation, and definitive infertility. (v) knowledge about the uterus which was measured by 15 questions (e.g. the ovaries are located inside the uterus/the uterus is a hormone producing organ/the uterus is an essential prerequisite for an orgasm) on a 3-point scale yes,
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no, don’t know. Post-surgery measures consisted of the Impact of Life Event Scale (Horowitz, Wilmer & Alvarez, 1979) which consisted of 15 items measuring "unbidden thoughts and images, troubled dreams, strong pangs or waves of feelings and repetitive behaviour" and "avoidance behaviour including ideational constriction, denial of the meanings and consequences of the event, blunted sensation, behavioural inhibition or counterphobic activity, and awareness of emotional numbness.

Pre-surgery psychosocial factors predicted women’s subjective distress following hysterectomy. Patients with positive attitudes toward loss of the uterus experienced low postoperative distress as did those who had positive expectations of hysterectomy.

An interesting survey in Australia was conducted at two hospitals, one central (study A) and one suburban hospital (study B), on women who had hysterectomies (Singh, Raphael, Gyaneshwar & Johnston, 1983). The first study (Study A) was conducted by a psychiatrist (Raphael) and involved two hundred and sixteen patients (mean age of 38.1 years; age range 22 to 45 years) who had a hysterectomy for non-malignant conditions. These patients were interviewed within 10 days of surgery and followed up 13 months later by a postal questionnaire. Study A involved similar measurements of women’s expectations of treatment to those used in Tsoi et al’s 1983 and 1984 studies. Furthermore, the findings of this survey confirmed Tsoi et al’s observation that patients with high expectations about future health as a result of the hysterectomy were more liable to experience poor health at follow-up. This outcome is, however, is in
contrast with the results of Schulze et al (1988) mentioned above.

The second study (Study B), conducted two years later by a gynaecologist (Gyaneshwar), involved one hundred and forty-six women (mean age 42 years; age range 22 to 45 years). All the patients having hysterectomies during a 12-month period were sent follow-up questionnaires a year after the operation, this was to determine whether the results of Study A which involved a selected sample, could be generalized to a broader, less selected sample. Seven of the patients in Study B were operated on for cancer.

The measures used in Study A were obtained in a semi-structured interview which included: an evaluation of the social support network as this related to the perceived helpful and unhelpful interventions from their environment prior to the crises of surgery (e.g. from husband or mother) including the patients' feeling about how well their emotional needs were satisfied. Also rated was the perceived helpfulness of doctors following surgery. Measurements of patients knowledge of the functions of the uterus and ovaries was assessed by 7 questions and by asking them to draw on a diagram the position of these organs. Expectations of surgery consisted of women's expectations of sexual function, general health and psychological function. These responses were measured on a 4-point scale consisting of: no change, better, worse and don't know.

Generally patients expectations were not high. For example, no change was expected concerning sex (68%), health (70%) and psychological function (55%). Thirteen months later 194 patients (out of 216) returned a follow-up
questionnaire (General Health Score; Maddison & Viola, 1968) comprising of 57 items which was based on physical and psychiatric complaints and symptoms experienced in the past year. Forty-five per cent of patients reported a good health outcome whereas only 15% reported a poor outcome. Most women (87%) were not aware of any mood change since their operation, but those who did complained of depression. Patients reported sexual function as either much better (30%), a little better (18%), unchanged (34%) a little worse (14%) or much worse (3%).

As already noted patients with high expectations of their future health (in comparison with those with moderate expectations and low expectations) as a result of hysterectomy were more likely to have poor health at follow-up. Singh, Raphael, Gyaneshwar & Johnson, (1983) suggested that a poor health outcome on the health questionnaire at 13 months was related to previous psychiatric illness, many unhelpful interventions and high expectations assessed one week post-operatively. These three factors were highly intercorrelated insomuch that there are associations between past psychiatric symptomatology and many unhelpful interventions and high health expectations. This implies that there could be an association between patients with higher expectations of hysterectomy and high levels of morbidity (e.g. Tsoi et al, 1984) and therefore a valid reason for including a morbidity dimension in a expectations of treatment questionnaire. Also, the fact that less than half of the patients reported a good health outcome, emphasizes why researchers need to examine factors relating to patients perceptions of wellbeing following surgery.
Although Study B did not concern patients' expectations of treatment, comparison of the two follow-up studies (Study A [with a response rate of 70%] and Study B [with a response rate of 90%]) at thirteen months on a total of 294 patients revealed that approximately the same proportion deteriorated following hysterectomy (15% versus 19%). Factors that were associated with poor outcome included: previous psychiatric illness (Study A and Study B), many unhelpful interventions and high health expectations (Study A).

Conclusion

Scrutiny of the literature has shown that there is no appropriate assessment tool available in gynaecological outpatient/inpatient units to analyze patients' specific expectations of treatment. Gynaecological surgery involves a greater range of expectations from patients with regard to treatment compared to patients undergoing general surgery. For example, hysterectomy can affect a woman's body image, feelings of femininity and sexuality (see Chapter 1 and Chapter 2).

A number of methodological problems exist in several studies attempting to measure patients' expectations of treatment such as: concentration on immediate, short-term, negative effects of treatment instead of including long-term positive effects; questionable formulation of questionnaires and lack of validation of questionnaires. For example, many have been formulated from semi-structured questionnaires which have been based on the findings of other researchers where intuition tends to play a role (see Peterson & Topazian, 1980), or based on little or no background. Furthermore, many studies have neglected to mention how
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interviews with patients were organized and how much the patients had been prompted to answer questions. Several researchers have used qualitative analysis in their studies but they failed to explain how the analyses of the patients' conversations were performed.

Often patients' expectations of treatment have not clearly defined and therefore are open to ambiguity in interpretation, thus making interpretation of the data unreliable. Some of these expectations come in the form of fears or beliefs. They have been mainly confined to patients' preoperatively measured expectations, namely fear of surgery and postoperative recovery problems: pain, general physical discomfort, weakness, anxiety, depression and irritability (Jamison, Parris & Maxson, 1987; Friedlander, Steinhart, Daly & Snyder, 1982; George, Scott, Scott, Turner & Gregg, 1980; Kent, 1984; Scott, Clum & Peoples, 1983). Some questionnaires examining patients' expectations of treatment have placed more emphasis on pharmacological expectations, rather than physiological and psychological effects.

Several studies have used small samples of patients which could limit generality and increase risks of sampling bias, especially if many patients dropped out of the study (Broome & Wallace, 1984). Using small samples can be restrictive when analyzing data, particularly if the sample falls into different sub-divisions of treatment. This would make it difficult to compare groups receiving different treatments.
Basis of research

It has been described how patients' expectations have been conceptualized and measured. Because of the apparent scarcity of available and reliable measures and associated problems, the Expectations of Treatment Questionnaire (ETQ) was devised to measure gynaecological patients' beliefs about outcome of gynaecological treatments (e.g. outcome of hysterectomy, endometrial resection, dilatation and curettage). The ETQ incorporates expectations that would be expected in general surgery. It also uses more specific expectations that relate to other gynaecological treatments that have not been considered in previous studies in this area. It builds on previous work in this area (e.g. Tsoi et al 1983, 1984; Schulze et al, 1988; Singh et al, 1983) and addresses the methodological difficulties encountered in previous studies. The approach used is similar to previous attempts to measure expectations in primary care (Salmon & Quine, 1989).

Study 1 and Study 2 are aimed at measuring women's expectations of outcome of hysterectomy and alternative treatments. It is essential to examine if those patients who anticipate being offered hysterectomy have expectations of treatment outcome that differ from patients who anticipate other forms of treatment. It is important to explore whether outcome expectations vary according to type of gynaecological treatment. To answer these questions, Study 1 and Study 2 used dilatation and curettage (D&C) and (in Study 1) other exploratory techniques as a baseline treatment on which to compare other gynaecological treatments (e.g. endometrial resection and hysterectomy). D&C was selected as a baseline as it is usually the first line of diagnostic investigation used by clinicians investigating
dysmenorrhoea and menorrhagia.

For the present study it was necessary to conduct semi-structured interviews asking patients their reason for attending the outpatient clinic, their expectations of, or desires for, change as a result of treatment. If necessary, patients were prompted to consider a range of factors: menstrual, psychosocial, employment and recreation. These responses formed the basis for the ETQ. In order to validate the questionnaire, it was then given to a larger sample of patients.

In Study 1 the experimenter asked patients (N=200): (1) what treatment do you expect to be offered today? and (2) what are your outcome expectations of this treatment?

In Study 2 the experimenter allocated gynaecology patients (N=100) randomly to four different groups to obtain their expectations of specific procedures (exploratory, drugs, endometrial resection and hysterectomy). These patients were newly referred for menstrual bleeding and/or pain to outpatient gynaecology clinics and their expectations of treatment were measured on the day of their consultation. There was a restriction on the age of patients (16-50 years). As the study was dealing with menstrual disorders it would have been inappropriate to include patients over the age of fifty since they could have been perimenopausal which could account for their menstrual problems. Other patients may have been post-menopausal in which case they would have been unsuitable for the study.
The aim of the ETQ was to allow us to explore the expectations of different treatments and to test hypotheses about these expectations. By knowing more about women’s attitudes to treatment, health workers should be able to improve patient care and therefore meet the needs of patients more effectively.

Method

Design

This study had four aims. The first aim was to design a questionnaire for measuring expectations of treatment in gynaecological patients’ who have been referred for menstrual bleeding and/or pain. The second aim was to give the resulting Expectations of Treatment Questionnaire (ETQ) to another sample of patients and subject their responses to principal component analysis to identify groups of items which shared common variance and which therefore could be regarded as indicators of a single underlying dimension. The third aim was to use these results to select a reduced set of items to form subscales for future studies. The final aim was to compare patients’ expectations of hysterectomy and alternative treatments.

Preliminary study

Subjects

Twenty-six patients newly referred to routine gynaecology clinics were recruited if they had been referred for menstrual bleeding and/or pain to one of three
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general hospitals: City Hospital, Nottingham (N=6; 23.7%); Queen Elizabeth II Hospital, Welwyn Garden City (N=6; 23.7%); Hillingdon Hospital, Uxbridge (N=14; 52.6%). The mean age of the patients was 36 years (range 17 to 50, standard deviation 9.35). Patients with confirmed or provisional diagnoses of gynaecological cancer, endometriosis, fibroids, prolapse, cysts and history of psychiatric illness were excluded. All patients agreed to participate in the preliminary study.

Procedure

Consecutive patients were approached individually at either morning or afternoon gynaecology clinics before their first consultation with a gynaecologist in response to the referral, by the experimenter who introduced herself as a research worker independent of the hospital. In a private area of each clinic, patients were asked if they would like to participate in a study which assessed "gynaecological patients' expectations of treatment." No patient refused. Patients were informed that the study was looking at women who sought medical advice for menstrual problems (heavy bleeding and/or pain). It was emphasized that all the information that the patients gave would be strictly confidential and that no member of the hospital (i.e. the doctors and nurses) would be privy to it. Patients were assured that whether or not they chose to take part in the study would not affect their own treatment. However, those who agreed to participate in the study were obliged to sign a consent form. Altogether five to ten minutes was spent with each patient for recruitment.
Devising Expectations of Treatment Questionnaire

Semi-structured interviews were carried out by the experimenter. Each patient was asked to describe their main reason for attending (e.g. bleeding and/or pain). They were then asked for their expectations of or desires for change in their lives as a result of treatment. Where necessary they were prompted to consider the following areas: discomfort and pain, excessive bleeding, threat to health, wellbeing, social and psychosexual function, employment and recreation (see Appendix A). The interviewer recorded all terms used. After elimination of idiosyncratic, redundant or ambiguous terms, the remainder resulted in the list in Table 8, page 115. These items had been sorted by the experimenter and another psychologist so as to identify groups of items with common meaning. One item was chosen and modified to represent each group resulting in a 58-item Expectations of Treatment Questionnaire (see Appendix A) in which the terms were to be rated on a five point scale (definitely won't happen------definitely will happen). The position of items on the questionnaire was randomly assigned. Positive answers were allocated to the right side of the questionnaire. The instruction for each statement was to ‘tick a box to show the extent to which you expect that outcome to follow your treatment.’ They were reminded that there were no right or wrong answers to the questions, but what was required was their own views.
Measurement of Women’s Expectations of Hysterectomy and Alternative Treatments

Validation Study

Subjects

The Expectations of Treatment Questionnaire (ETQ) was given to a larger sample of women (N=200) who had been newly referred for menstrual bleeding and/or pain to outpatient gynaecology clinics at one of six general hospitals: City Hospital, Nottingham (N=31; 15.5%); Hillingdon Hospital, Uxbridge (N=85; 42.5%); Queen Elizabeth II Hospital, Welwyn Garden City (N=4; 2%); Mount Vernon Hospital, Northwood (N=11; 5.5%); Watford General Hospital, Watford (N=27; 13.5%); Whittington Hospital, London (N=42; 21%)\(^1\). The mean age of patients was 37 years (range 16 to 50, standard deviation 8.37). Seventy-nine (N=79; 39.5%) of the patients were aged between 16 to 35 years and one-hundred and one (N=121; 60.5%) were aged 36 to 50 years. Patients with confirmed or provisional diagnoses of gynaecological cancer, endometriosis, fibroids, prolapse, cysts or history of psychiatric illness were excluded.

Of the patients approached, 100% (N=200) completed questionnaires.

Questionnaires

Attached to the Expectations of Treatment Questionnaire (ETQ) was a front sheet giving a brief explanation of the study. This was followed by questions which sought information about the woman’s age, marital status, number of children, occupation and religion. A health questionnaire asked five general questions: (1)
the main reason for attending the clinic (e.g. menstrual bleeding and/or pain), (2) the length of time they had experienced these symptoms, (3) if the symptoms had worsened whilst waiting for their appointment with a gynaecologist (4) type of contraception used, and (5) what treatment they expected as a continuation of their course of investigation and treatment. See Appendix A.

Procedure

Consecutive patients attending routine gynaecology clinics for the first time were approached individually in either the morning or afternoon before their consultation with a gynaecologist in response to the referral, by the experimenter who introduced herself as a research worker independent of the hospital. In a private area of each clinic, patients were asked if they would like to participate in a study which assessed "gynaecological patients' expectations of treatment." They were informed that the study was looking at women who sought medical advice for menstrual problems. They were told that they would be required to answer some questionnaires. At the same time it was emphasized that they would remain anonymous and they were under no obligation to take part in the study, and that whether or not they did would not affect their own treatment.

Sample questions contained in the ETQ were read to patients by the experimenter to ensure they understood the instructions. Each patient then recorded their answers on the questionnaire. The questionnaires took approximately 5 to 10 minutes to complete.
When the experimenter asked patients (1) 'what sort of treatment do you expect you will get today (e.g. has your GP suggested what course of treatment you might expect from the gynaecologist? and (2) what do you expect this treatment will do for you?' - all women had an idea of what treatment to expect. The majority readily answered this question since their GP had informed them of what to expect. Others saw an investigative procedure as part of the treatment process. The experimenter noted the patients’ answers and later categorized them into the following groups: (1) D&C (2) hysteroscopy (3) drugs (patients saw these as some form of ‘pill’ without a predominantly hormonal component), (4) hormones (5) the ‘pill’ (6) laparoscopy, (7) laser (patients described their womb as being ‘lasered’ to lessen their menstrual blood loss, but did not realize they were describing endometrial resection) (8) hysterectomy.

Statistical Analyses

Statistical analyses were computed by the Genstat statistical programme (Lawes Agricultural Trust, 1980) and the SPSS/PC+ computer package:-

Results

Sample - Type of treatment patients expected

Originally the types of treatment patients said they expected were divided into eight categories: drugs, D&C, hysterectomy, endometrial resection (ER), laparoscopy, hormone treatment, laser and the ‘pill’ which for practical reasons were collapsed into the following four main groups: (1) drugs, hormone treatment
and the ‘pill’ (N=42; 21%); (2) D&C and laparoscopy (N=115; 57.5%); (3) endometrial resection and laser (N=13; 6.5%); (4) hysterectomy (N=30; 15%).

First, it seemed reasonable to assume treatment classified under ‘drugs’ would constitute some form of medication. Secondly, since D&C and laparoscopy are mainly diagnostic procedures (rather than a treatment, as compared to the other categories) they were classed under ‘exploratory’. Thirdly, endometrial resection (ER) was combined with laser as this treatment (ER) uses an electrically heated loop to remove the lining of the womb. Furthermore, some of the initial categories were small and would make little sense in terms of statistical analyses. Table 2 (see page 112) shows that the majority of patients expected some exploratory procedure.

**Demographic details**

Seventy per cent of the patients were married or living with a partner and a lesser proportion were either single, divorced, widowed or separated (see Table 3, page 112). Fifty-nine per cent of patients were multiparous (59%); 16.5% had one child; and 24.5% were nulliparous (see Table 4, page 112). A large proportion of the sample were employed (70%) and they were mainly unskilled and skilled manual workers, clerical and shopworkers (66.5%) whereas a lesser proportion of women (26%) held professional or managerial positions (see Table 5, page 112). Additionally, patients were mainly Church of England (64.5%) or Roman Catholic (18.5%) with the remainder belonging to various other

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1See glossary.
dominations (see Table 6, page 112).

Although most of the sample expected some type of exploratory investigation (57.5%), statistical analysis (Chi-square) revealed that age was significantly related to the kind of treatment patients expected (Chi-square=13.11; d.f.=3; p=<.004). Overall, patients expecting major surgery (endometrial resection and hysterectomy) were in the older age range (36 to 50 years-old). See Table 7, page 113. Interestingly, no ‘single’ patients expected endometrial resection or hysterectomy; instead they assumed they would be given drugs, (29.4%) or be offered an exploratory investigation (70.6%).

Statistical analysis by Chi-square showed that a patient’s age was not related to her complaint (Chi-square=2.93; d.f.=2; p=>.05). See Table I, Appendix A. Further analysis by Chi-square indicated that a patient’s age was not related to the length of time she had experienced her symptoms (Chi-square=4.38; d.f.=2; p=>.05). See Table I, Appendix A.

**Complaint and contraception**

Both menstrual pain and bleeding (58.5%) accounted for most patients symptomatology with fewer women just complaining of bleeding (31%) or pain (10.5%) alone (see Table II, Appendix A). However, the type of treatment patients expected was not associated with their symptomatology (Chi-square=2.84; d.f.=3; p=>.05) nor was the type of contraception they used (see Table III, Appendix A). A breakdown of the length of time patients had experienced their menstrual
Measurement of Women's Expectations of Hysterectomy and Alternative Treatments

problems and the relationship of treatment is shown in Table IV, Appendix A.

Table 1: Breakdown of Hospitals (Study 1)

<table>
<thead>
<tr>
<th>HOSPITALS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>City Hospital, Nottingham</td>
<td>31</td>
<td>15.5</td>
</tr>
<tr>
<td>Sittingbourne Hospital, Uxbridge</td>
<td>85</td>
<td>42.5</td>
</tr>
<tr>
<td>Mt. Vernon Hospital, Northwood</td>
<td>11</td>
<td>5.5</td>
</tr>
<tr>
<td>Queen Elizabeth II Hospital, Whickham Gardens City</td>
<td>4</td>
<td>2.0</td>
</tr>
<tr>
<td>North East General Hospital, Winfield</td>
<td>27</td>
<td>13.5</td>
</tr>
<tr>
<td>Whittington Hospital, London</td>
<td>42</td>
<td>21.0</td>
</tr>
</tbody>
</table>

Total: 200

Table 2: Breakdown of Patients Treatment Expectations (Study 1)

<table>
<thead>
<tr>
<th>TREATMENT EXPECTATIONS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs</td>
<td>29</td>
<td>14.5</td>
</tr>
<tr>
<td>Dilatation &amp; Curettage (D&amp;C)</td>
<td>109</td>
<td>54.5</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>30</td>
<td>15.0</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>10</td>
<td>5.0</td>
</tr>
<tr>
<td>Laparoscopy</td>
<td>6</td>
<td>3.0</td>
</tr>
<tr>
<td>Hormone treatment</td>
<td>3</td>
<td>1.5</td>
</tr>
<tr>
<td>Laser treatment</td>
<td>3</td>
<td>1.5</td>
</tr>
<tr>
<td>The &quot;pill&quot;</td>
<td>10</td>
<td>5.0</td>
</tr>
</tbody>
</table>

Total: 200

Table 3: Breakdown of Marital Status (Study 1)

<table>
<thead>
<tr>
<th>MARITAL STATUS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>34</td>
<td>17</td>
</tr>
<tr>
<td>Married</td>
<td>125</td>
<td>62.5</td>
</tr>
<tr>
<td>Living with partner</td>
<td>14</td>
<td>7.0</td>
</tr>
<tr>
<td>Divorced</td>
<td>17</td>
<td>8.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>1.0</td>
</tr>
<tr>
<td>Separated</td>
<td>8</td>
<td>4.0</td>
</tr>
</tbody>
</table>

Total: 200

Table 4: Breakdown of Parity (Study 1)

<table>
<thead>
<tr>
<th>NUMBER OF CHILDREN</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>One child</td>
<td>33</td>
<td>16.5</td>
</tr>
<tr>
<td>Two children</td>
<td>69</td>
<td>34.5</td>
</tr>
<tr>
<td>Three children</td>
<td>34</td>
<td>16.9</td>
</tr>
<tr>
<td>Four children</td>
<td>11</td>
<td>5.5</td>
</tr>
<tr>
<td>Five children</td>
<td>3</td>
<td>1.5</td>
</tr>
<tr>
<td>Six children</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>No children</td>
<td>49</td>
<td>24.5</td>
</tr>
</tbody>
</table>

Total: 200

Table 5: Breakdown of Employment (Study 1)

<table>
<thead>
<tr>
<th>EMPLOYMENT</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>137</td>
<td>68.5</td>
</tr>
<tr>
<td>Unemployed</td>
<td>20</td>
<td>10.0</td>
</tr>
<tr>
<td>Self-employed</td>
<td>4</td>
<td>2.0</td>
</tr>
<tr>
<td>Housewife</td>
<td>34</td>
<td>17.0</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Student</td>
<td>4</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Total: 200

TYPE OF EMPLOYMENT

<table>
<thead>
<tr>
<th>TYPE OF EMPLOYMENT</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unskilled manual</td>
<td>33</td>
<td>16.5</td>
</tr>
<tr>
<td>Skilled manual</td>
<td>32</td>
<td>16.0</td>
</tr>
<tr>
<td>Shopwork/secretarial work</td>
<td>68</td>
<td>34.0</td>
</tr>
<tr>
<td>Skilled technical</td>
<td>15</td>
<td>7.5</td>
</tr>
<tr>
<td>Professional/managerial</td>
<td>52</td>
<td>26.0</td>
</tr>
</tbody>
</table>

Total: 200

Table 6: Breakdown of Patient's Religion (Study 1)

<table>
<thead>
<tr>
<th>RELIGION</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church of England</td>
<td>129</td>
<td>64.5</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>37</td>
<td>18.5</td>
</tr>
<tr>
<td>Jewish</td>
<td>2</td>
<td>1.0</td>
</tr>
<tr>
<td>Hindu</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Sikh</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Jehovah's Witness</td>
<td>6</td>
<td>3.0</td>
</tr>
<tr>
<td>Others</td>
<td>6</td>
<td>3.0</td>
</tr>
<tr>
<td>Aghnostic</td>
<td>4</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Total: 200
Table 7: Age and Treatment Expectations  
(Study 1)

<table>
<thead>
<tr>
<th>AGE</th>
<th>EXPLORATORY</th>
<th>DRUGS</th>
<th>E.R.</th>
<th>HYSTERECTOMY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (16-50)</td>
<td>N = 200</td>
<td>N = 200</td>
<td>N = 200</td>
<td>N = 200</td>
</tr>
<tr>
<td></td>
<td>N = 105</td>
<td>N = 37.30 (8.73)</td>
<td>N = 115</td>
<td>N = 37.30 (8.65)</td>
</tr>
<tr>
<td></td>
<td>57.5%</td>
<td>21.0%</td>
<td>6.5%</td>
<td>15.0%</td>
</tr>
<tr>
<td>Age (16-35)</td>
<td>N = 200</td>
<td>N = 200</td>
<td>N = 200</td>
<td>N = 200</td>
</tr>
<tr>
<td></td>
<td>N = 105</td>
<td>N = 37.30 (8.73)</td>
<td>N = 115</td>
<td>N = 37.30 (8.65)</td>
</tr>
<tr>
<td></td>
<td>57.5%</td>
<td>21.0%</td>
<td>6.5%</td>
<td>15.0%</td>
</tr>
<tr>
<td>Age (36-50)</td>
<td>N = 200</td>
<td>N = 200</td>
<td>N = 200</td>
<td>N = 200</td>
</tr>
<tr>
<td></td>
<td>N = 105</td>
<td>N = 37.30 (8.73)</td>
<td>N = 115</td>
<td>N = 37.30 (8.65)</td>
</tr>
<tr>
<td></td>
<td>57.5%</td>
<td>21.0%</td>
<td>6.5%</td>
<td>15.0%</td>
</tr>
</tbody>
</table>

Principal Components Analysis

Following the preliminary analyses of the data, skewed items were eliminated (i.e. if they exceeded >85% at one point of the rating scale). This reduced the ETQ to 46 items. Ratings of the sentences describing patients’ expectations of treatment were subjected to principal components analysis. A scree test was used to select the number of components to retain before varimax rotation. This conservative measure (Zwik and Velicer, 1986) was used to minimize the risk of finding unreliable components. Seven separate components were selected with eigenvalues of 8.84, 4.86, 3.1, 2.65, 2.25, 1.97 and 1.64. Loadings above 0.40 were used to describe the components (see Table 8, page 115). The smaller loadings were ignored.

\[\text{Item: 19. Men will no longer find me attractive (skewed 94%).}\]

\[\text{5. I will have less energy (skewed 92.5%).}\]

\[\text{See glossary}\]

\[\text{See Appendix A and glossary}\]
Thirteen items loading on component 1 (‘well-being’) described patients’ positive global expectations towards treatment. By contrast, component 2 (‘harm’) consisted of eleven items which concerned patients’ negative perceptions of treatment regarding bodily function and appearance. For example question 6 referred to loss of interest in sex and question 27 referred to premature ageing. Components 3, 4, 5, 6 and 7 (‘menstruation’, ‘physical symptoms’, ‘sex’, ‘womb’ and ‘bowels’) respectively, described patients’ positive expectations of treatment. For example, component 3 labelled ‘menstruation’ contained four items which related to patients’ anticipation of reduced menstrual blood loss. Component 4 (‘physical symptoms’) was made up of eight items which concerned relief from typical pre-menstrual/menstrual symptoms. For example, question 28 referred to relief from vomiting during menstruation and question 47 referred to less painful/tender breasts. Component 5 (‘sex’) contained two items (question 39 and question 40) which described patients expecting increased pleasure and interest in their sex life. Component 6 (‘womb’) was made up of six items which related to the removal of the womb. For example, question 1 referred to relief from period pain and question 45 referred to no-more birth control problems. Component 7 (‘bowels’) contained two items (question 24 and question 25) which described less loose bowels or less constipation.

Calculations of Cronbach’s alpha confirmed that the resulting scales were all highly internally consistent indicating that patients tended to answer each item in the same way as they answered all others (see Table 8, page 116).
Table 8: Results of principal components analyses: items loading on each component at >0.40

<table>
<thead>
<tr>
<th>Item</th>
<th>Well-being</th>
<th>Harm</th>
<th>Menstruation</th>
<th>Physical</th>
<th>Sex</th>
<th>Womb</th>
<th>Bowels</th>
</tr>
</thead>
<tbody>
<tr>
<td>More energy</td>
<td>0.76</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Better quality of life</td>
<td>0.66</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Able to do housework better</td>
<td>0.65</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Improved family life</td>
<td>0.64</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More active</td>
<td>0.64</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less irritable</td>
<td>0.60</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Able to do things that had been neglected</td>
<td>0.60</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Body will feel more comfortable</td>
<td>0.57</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less depressed</td>
<td>0.55</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less tired</td>
<td>0.49</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Life less disrupted by periods</td>
<td>0.48</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Improvement in health</td>
<td>0.48</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Better social life</td>
<td>0.48</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less active socially</td>
<td>-</td>
<td>0.64</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More depressed</td>
<td>-</td>
<td>0.63</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Treatment may harm physically</td>
<td>-</td>
<td>0.63</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less active at home/ work</td>
<td>-</td>
<td>0.60</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Loss of femininity</td>
<td>-</td>
<td>0.58</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Loss of interest in sex</td>
<td>-</td>
<td>0.57</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Uncomfortable body</td>
<td>-</td>
<td>0.56</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More irritable</td>
<td>-</td>
<td>0.54</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Weight gain</td>
<td>-</td>
<td>0.53</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Body will never feel normal again</td>
<td>-</td>
<td>0.53</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Premature ageing</td>
<td>-</td>
<td>0.48</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Reduction of bleeding</td>
<td>-</td>
<td>-</td>
<td>0.86</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Use fewer tampons or sanitary pads</td>
<td>-</td>
<td>-</td>
<td>0.85</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Reduction of blood clots during periods</td>
<td>-</td>
<td>-</td>
<td>0.78</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less soiling of clothes because of periods</td>
<td>-</td>
<td>-</td>
<td>0.76</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less faint</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.68</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less dizzy</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.66</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Reduce/stop heavy bleeding after sex</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.57</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less pain/discomfort after sex</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.52</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Relief from vomiting during periods</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.47</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less tender stomach</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.45</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Free from premenstrual/period headaches</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.45</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less painful/tender breasts</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.41</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More interest in sex</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.68</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More enjoyable sex life</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.67</td>
<td>-</td>
</tr>
<tr>
<td>No-more birth control problems</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.61</td>
<td>-</td>
</tr>
<tr>
<td>Relief from period pain</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.56</td>
</tr>
<tr>
<td>Unable to have a baby</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.55</td>
</tr>
<tr>
<td>Relief from pain (other than premenstrual) during periods</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.55</td>
</tr>
<tr>
<td>My stomach will be less red/dark/bloated</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.54</td>
</tr>
<tr>
<td>Relief from pre-menstrual pain</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.49</td>
</tr>
<tr>
<td>Less loose bowel premenstrually/during periods</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.70</td>
</tr>
<tr>
<td>Less constipation</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.68</td>
</tr>
</tbody>
</table>
Measurement of Women’s Expectations of Hysterectomy and Alternative Treatments

Table 8 continued

<table>
<thead>
<tr>
<th>Item</th>
<th>Wellbeing</th>
<th>Harm</th>
<th>Menstruation</th>
<th>Physical</th>
<th>Sex</th>
<th>Womb</th>
<th>Bowel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cronbach’s Alpha</td>
<td>0.87</td>
<td>0.80</td>
<td>0.89</td>
<td>0.76</td>
<td>0.92</td>
<td>0.71</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Expected treatment and expected treatment outcome

In order to clarify the presentation of component-based scales (since the number of questions varied in each component) the scores were standardized. As explained, patients were grouped according to the treatment they most expected (drugs, exploratory investigation, endometrial resection and hysterectomy). These groups were compared on wellbeing (F=4.04; p=<.001), harm (F=8.73; p=<.0001), menstruation (F=6.99; p=<.0001), physical symptoms (F=3.42; p<.02), sex (F=5.29; p=<.001), womb (F=17.47; p=<.0001) and bowel function (F=0.26; p=>.05; d.f.=3,196) by one-way analysis of variance. The majority of F scores were significant. Only bowel function was not significant.

Where the F-ratio was significant, post hoc comparisons using the Least Significant Difference (LSD) test indicated where the differences lay between groups of patients expecting different treatment (p=<.05). Using those who were expecting an exploratory investigation as a baseline group, it can be seen that on most dimensions (wellbeing, harm, menstruation, physical symptoms, sex and womb) patients’ expectations of a exploratory investigation are significantly different to those expecting a hysterectomy. On the one hand patients expecting hysterectomy (N=30) had higher expectations of wellbeing than those expecting...

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8This means that the parametric data is transformed so that it has a mean of zero and a standard deviation of 1.00. These are created by subtracting the mean value of a variable from each case value and dividing the standard deviation of the variable. (See glossary).
Measurement of Women's Expectations of Hysterectomy and Alternative Treatments

on the other hand these patients and patients expecting drugs envisaged more harmful effects of treatment than patients in the exploratory group (see Fig. 3, page 118). Fig. 5, page 118, shows that the group of patients expecting hysterectomy differ significantly in their expectations of physical improvement from those in the exploratory and drug groups.

Further inspection of the data shows that the group of patients expecting hysterectomy were significantly different on the dimensions 'menstruation', 'sex' and 'womb' from patients anticipating other treatments (exploratory investigation, drugs and endometrial resection). See Fig. 4, Fig. 6 and Fig. 7, page 118. Fig. 5 shows that patients expecting hysterectomy are significantly different from patients either expecting drugs or an exploratory investigation. Because the four groups differed very greatly in size, it was decided to reanalyse the data, eliminating the smallest, endometrial resection, group (N=13) to see if this affected group differences. However, one-way analyses of variance revealed that there were no differences between the results of three groups and the original four groups.

In this study a comparison was made of the expectations of women who anticipated different treatments to result from their referral. The different expectations may have reflected either the treatments or other differences between the groups of women. Therefore, in study 2, patients were randomly allocated to 'treatment' groups before being asked to provide their expectations of specific treatments.
Study 1 will be discussed with study 2 (see pages 127 to 134).

Fig. 2: Group mean expectations of treatment and expected treatment outcome (N=200)

Fig. 3: Group mean expectations of treatment and expected treatment outcome (N=200)

Fig. 4: Group mean expectations of treatment and expected treatment outcome (N=200)

Fig. 5: Group mean expectations of treatment and expected treatment outcome (N=200)

Fig. 6: Group mean expectations of treatment and expected treatment outcome (N=200)

Fig. 7: Group mean expectations of treatment and expected treatment outcome (N=200)
Study 2

Subjects

The Expectations of Treatment Questionnaire (ETQ)\(^9\) was given to a sample of patients (\(N=100\)) who had been newly referred for menstrual bleeding and/or pain to outpatient gynaecology clinics at one of six general hospitals: City Hospital, Nottingham (\(N=16\)); Hillingdon Hospital, Uxbridge (\(N=10\)); Mt. Vernon Hospital, Northwood (\(N=2\)); Queen Elizabeth Hospital, Welwyn Garden City (\(N=9\)); Watford General Hospital, Watford (\(N=25\)); Whittington Hospital, London (\(N=38\))\(^{10}\). The mean age of patients was 38 years (range 17 to 50, standard deviation 8.27). Thirty-nine (35\%) of the patients were aged between 17 to 35 and sixty-five (65\%) were aged 36 to 50 years. Patients with confirmed or provisional diagnoses of gynaecological cancer, endometriosis, fibroids, prolapse,

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\(^9\) See Appendix B.

\(^{10}\) See Table 9, page 123.
cysts and history of psychiatric illness were excluded.

Patients were asked to imagine receiving one of four treatments (drugs, D&C, endometrial resection or hysterectomy). There were 25 patients in each treatment group. Of the patients approached, all completed questionnaires.

**Questionnaires**

The questionnaires used in study one were given to patients. The only difference was the patient information and consent form and the ETQ which was reformed to 46 questions on the basis of the principal component analysis. On the patients' consent form there was one descriptive paragraph on one of the four treatments (no other information was given regarding these procedures): (1) drugs/hormones, (2) D&C and hysteroscopy, (3) Endometrial resection and (4) hysterectomy (see Appendix B for instructions).

**Procedure**

Consecutive patients attending routine gynaecology clinics for the first time were approached individually in either the morning or afternoon before their consultation with a gynaecologist in response to the referral, by the experimenter who introduced herself as a research worker independent of the hospital. In a private area of each clinic, patients were asked if they would like to participate

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*The treatments were assigned to patients in the following manner: patient 1=drugs/hormones, patient 2=D&C, patient 3=TCRE and patient 4=hysterectomy. Thus every fourth patient was asked to provide their expectations of hysterectomy.*
in study which assessed "gynaecological patients’ expectations of treatment."
They were informed that the study was looking at women who sought medical
advice for menstrual problems (heavy bleeding and/or pain). They were told that
they would be required to answer some questionnaires. At the same time it was
emphasized that they would remain anonymous and they were under no
obligation to take part in the study, and that whether or not they did would not
affect their own treatment. Each patient was then asked to read a brief account
of the treatment and to imagine that she was going to receive it and to then
complete the ETQ.

Sample questions contained in the ETQ were read to patients by the experimenter
to ensure they understood the instructions. Each patient then recorded their
answers on the questionnaire. The questionnaires took approximately 5 to 10
minutes to complete.

Statistical Analyses
Statistical analyses were computed by the SPSSPC+ computer package.

Results

Demographic details
Most patients were either married (55%) or living with a partner (13%) while
14% were either divorced, widowed or separated (see Table 10, page 123). Fifty
per cent of patients were multiparous; 16% had one child; and 28% were nulliparous (see Table 11, page 123). Sixty-five per cent of the patients were employed with a higher proportion involved in clerical and shopwork (see Table 12, page 123). The majority of the patients were Church of England (58%) or Roman Catholic (18%) faith, while others belonged to various dominations (9%) or were agnostic (15%). See Table 13, page 123.

Most patients suffered from a combination of pain and bleeding (50%) or bleeding (41%) and generally fewer patients complained of pain (9%). See Table VI, Appendix B. To determine whether a patient’s age was related to her complaint statistical analysis by Chi-square was used (Chi-square=10.51; p<.005; d.f.=2). See Table 14, page 124. This showed that patients who complained of pain were younger (between 17 to 35 years-old), whereas patients complaining of bleeding, pain and bleeding, were in the older age range (36 to 50 years-old). Chi-square analysis showed that a patient’s age was not related to the length of time she had experienced her symptoms (Chi-square=1.87; d.f.=2; p>.05). See Table 14, page 124).

Three-quarters of the sample used contraceptives (see Table VII, Appendix B, for a breakdown of the contraceptives).
### Table 9: Breakdown of Hospitals
(Study 2)

<table>
<thead>
<tr>
<th>HOSPITALS</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>City Hospital, Nottingham</td>
<td>16</td>
</tr>
<tr>
<td>Hillingdon, Uxbridge Northwood</td>
<td>10</td>
</tr>
<tr>
<td>Mt. Vernon Hospital, Northwood</td>
<td>2</td>
</tr>
<tr>
<td>Queen Elizabeth Hospital II, Welwyn Garden City</td>
<td>9</td>
</tr>
<tr>
<td>Watford General Hospital, Watford</td>
<td>25</td>
</tr>
<tr>
<td>Whittington Hospital, London</td>
<td>38</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Overall response rate 100%

### Table 10: Breakdown of Marital Status
(Study 2)

<table>
<thead>
<tr>
<th>MARITAL STATUS</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>18</td>
</tr>
<tr>
<td>Married</td>
<td>55</td>
</tr>
<tr>
<td>Living with partner</td>
<td>13</td>
</tr>
<tr>
<td>Divorced</td>
<td>11</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

### Table 11: Breakdown of Parity
(Study 2)

<table>
<thead>
<tr>
<th>NUMBER OF CHILDREN</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>One child</td>
<td>16</td>
</tr>
<tr>
<td>Two children</td>
<td>36</td>
</tr>
<tr>
<td>Three children</td>
<td>17</td>
</tr>
<tr>
<td>Four children</td>
<td>1</td>
</tr>
<tr>
<td>Five children</td>
<td>2</td>
</tr>
<tr>
<td>No children</td>
<td>28</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

### Table 12: Breakdown of Patients' Employment
(Study 2)

<table>
<thead>
<tr>
<th>EMPLOYMENT</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>59</td>
</tr>
<tr>
<td>Unemployed</td>
<td>12</td>
</tr>
<tr>
<td>Self-employed</td>
<td>6</td>
</tr>
<tr>
<td>Housewife</td>
<td>19</td>
</tr>
<tr>
<td>Student</td>
<td>4</td>
</tr>
<tr>
<td><strong>TYPE OF EMPLOYMENT</strong></td>
<td></td>
</tr>
<tr>
<td>Unskilled manual</td>
<td>15</td>
</tr>
<tr>
<td>Skilled manual</td>
<td>14</td>
</tr>
<tr>
<td>Shopwork/clerical/office work</td>
<td>41</td>
</tr>
<tr>
<td>Skilled technical</td>
<td>7</td>
</tr>
<tr>
<td>Professional/managerial</td>
<td>23</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

### Table 13: Breakdown of Patients' Religion
(Study 2)

<table>
<thead>
<tr>
<th>RELIGION</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church of England</td>
<td>58</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>18</td>
</tr>
<tr>
<td>Hindu</td>
<td>2</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
</tr>
<tr>
<td>Sikh</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>Agnostic</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>
Treatment Expectations

As in study one, the scores were calculated by summing the scores for the items loading on the relevant component. The scores were also standardized (see Study 1, page 116) to clarify the results (since the number of questions varied in each component). Patients were grouped according to the treatment they had been assigned (drugs, exploratory investigation, endometrial resection and hysterectomy).

These groups were compared by one-way analysis of variance on: wellbeing (F=2.28; p>.05), harm (F=9.86; p<.0001); menstruation (F=5.88; p<.001); physical symptoms (F=4.10; p<.001; sex (F=.31; p>.05; womb (F=11.56; p<.0001 and bowel function (F=2.88; p<.05; d.f.=3,99). Most of the F scores were significant, only group comparisons on wellbeing and sex were not significant.

Where the F-ratio was significant post hoc comparisons using the Least Significant Difference (LSD) test indicated where the differences lay between these groups (p<.05). As in Study 1, the exploratory group can be taken as a
Measurement of Women's Expectations of Hysterectomy and Alternative Treatments

Baseline (see introduction, page 102). Looking at the dimensions of wellbeing and menstruation (Fig. 9 and Fig. 11, 126), patients' assigned to the hysterectomy group had higher positive expectations of treatment on these dimensions, than the patients assigned to the exploratory investigation and drug groups. Also, when looking at the dimension of menstruation, patients in the drugs group had significantly fewer positive expectations of their assigned treatment than patients assigned to the endometrial resection group. Fig. 10, page 126 shows on the dimension of harm it can be seen that, apart from the exploratory investigation group, patients assigned to the other treatment groups generally envisage harmful effects of treatments. A closer examination of these results show that patients in the hysterectomy group had much higher expectations of the harmful effects of treatment than patients in the endometrial resection group. Yet on the dimensions of physical and womb, they had the highest positive expectations of treatment compared to the patients assigned to all the other treatment groups (see Fig. 12 and Fig. 14, page 126). Fig. 15, page 127) shows that patients allotted to the endometrial resection and hysterectomy groups have higher positive perceptions of treatment than those allotted to the drugs group.

In summary, patients who were assigned to the hysterectomy group emerged as having better expectations than those assigned other treatments.
Measurement of Women's Expectations of Hysterectomy and Alternative Treatments

Fig. 9: Group mean expectations of treatment and expected treatment outcome (N=100)

Fig. 10: Group mean expectations of treatment and expected treatment outcome (N=100)

Fig. 11: Group mean expectations of treatment and expected treatment outcome (N=100)

Fig. 12: Group mean expectations of treatment and expected treatment outcome (N=100)

Fig. 13: Group mean expectations of treatment and expected treatment outcome (N=100)

Fig. 14: Group mean expectations of treatment and expected treatment outcome (N=100)
General Discussion

The first aim of study 1 was to explore the dimensional structure of women’s expectations of treatment for menstrual problems. The analysis of the questionnaire (ETQ) responses yielded 7 readily identifiable components. Expectations of improvement were clearly multidimensional; i.e. a woman would expect improvement in one or more areas of life but not necessarily expect improvement in other domains. The dimension ‘menstruation’ centred on an expectation of improvement in problems directly related to menstrual bleeding. Although this described improvement in terms of women’s direct experience of menstruation, a second dimension ‘womb’ described expectations of other effects of treatment which would either remove the womb or decrease physiological activity of the womb; these included relief from pain, bloating and birth control. Two other components identified expectations in two specific areas, although not so directly related to menstruation: improvement in bowel function and in sex. In contrast, the dimension ‘wellbeing’ was much more general and described
expectations of benefit in psychological wellbeing and social function. It also indicates that patients who attend the gynaecological clinic have expectations that go beyond the bounds of medical or surgical care.

By comparison with the highly structured expectations of benefit, expectations of harm were unidimensional: i.e. emotional and social impairment, loss of femininity and physical deterioration all represented a single expectation of harm. Often these expectations have no medical foundation.

In Study 1 patients' anticipation of being offered a particular treatment as part of the treatment process and their expectations of treatment outcome were explored. In Study 2 patients' were asked to 'imagine' they were going to have a specific treatment that had been randomly assigned to them. The results of both these studies are very similar. In both these studies women's expectations of treatment concerned an improvement in the quality of their lives, improvement in patients' quality of life is the basis on which treatment is provided for patients with menstrual symptoms. There are important implications of this pattern of results. Provided that treatment for menstrual problems (bleeding and/or pain) is intended to improve quality of life, it is important for the treatment decision to be based on an understanding of the woman's particular expectations about improvement in her life. First, expectations of different kinds might be managed by different treatments. Second, unrealistic or inaccurate expectations by the patient might lead her to seek or reject particular treatments inappropriately.
Measurement of Women’s Expectations of Hysterectomy and Alternative Treatments

The component-based scales that were constructed to measure these dimensions were highly reliable and therefore allowed comparison of the expectations of women anticipating different treatments in Study 1. The main result of this was to distinguish hysterectomy from all other treatments by its perceived greater ability to improve wellbeing. This was surprising because neither of the other treatments (drugs and endometrial resection) was expected to have any significant benefit over procedures that are essentially exploratory. Patients’ views of potential treatments were divided between surgical and non-surgical interventions, because hysterectomy was also seen as more harmful than exploration. Drugs (e.g. hormones) shared the same harmful effects of hysterectomy, but none of the benefits. Our study was not designed to identify the origin of these differing expectations. This should be the subject of further research. It is possible that, expectations of hysterectomy reflect cultural attitudes and correspond to a very biomedical model of both physical and psychosocial distress which points to removal of an troublesome organ as the treatment of choice. The experience of hysterectomy by relatives and friends may also contribute to this. By contrast, the harm associated with drug (hormone) treatment may be due adverse publicity in the media. It is doubtful that these cultural attitudes are based in scientific fact, but a result of a faulty belief system of the different forms of treatment. Perhaps some women have lay models on how drugs (hormones) effect the body. For example, weight gain, thrombosis, nausea, fluid retention and spotting (blood) between periods. Whereas women have no lay models in which to understand how endometrial resection works since it has only been in performed in the U.K. in recent years. However, patients in this group had higher expectations of a reduction in
menstrual blood loss than in the drugs group. Although the whole purpose of ER is to reduce/stop menstrual blood loss, several findings have indicated that this does not always occur and often women go on to have a hysterectomy afterwards (see Dwyer, Hutton & Stirrat, 1993). Studies (Dwyer et al, 1993) which have compared endometrial resection with abdominal hysterectomy for the surgical treatment of menorrhagia found in the short term endometrial resection was almost as satisfactory as abdominal hysterectomy, and was associated with less morbidity. But, four months following surgery, there was a failure rate of at least 10% in women in whom endometrial resection appeared complete. In a review of 75 patients who were followed up for one year after endometrial resection, 45 (60%) had a successful outcome, nine (12%) had ‘some improvement’ and 21 were failures (Pyper & Haeri, 1991). Until the results of prospective studies are available, the real clinical value of endometrial resection will not be known (Macdonald, Phipps & Singer, 1992). See Chapter 1.

In the present two studies, hysterectomy was seen as more powerful than other treatments: i.e. more benefit but also more harm. This supports the notion that surgery is seen as having greater power to change life than less invasive alternatives. In clinical settings it is likely that some patients seek surgical treatment in response to emotional or social problems. This assumption is supported in our findings that often patients’ expectations of treatment go beyond the realms of medicine or surgery (see wellbeing component). In contrast drugs are seen as having harmful effects with few benefits whereas there was little difference between endometrial resection and exploratory procedures. D&C is a straightforward technique and is mainly used as a diagnostic procedure,
however, the complications surrounding it are not widely published (see Chapter 1). But, compared to hysterectomy it presents little physical or psychological risk to patients. It seems that many patients in these studies interpreted it as a therapeutic procedure rather than a diagnostic one. Few women realize that its therapeutic effects for menstrual irregularities may be short-lived (see Chapter 1). They saw a D&C as a "scrape" or a "spring clean" - but without knowing exactly what was being scraped or cleaned. However, one of the limitations of this study was that it did not systematically record the number of patients who had previous D&Cs - although in one case a patient revealed that over a twenty-year span she had six D&Cs.

In essence study 1 demonstrated that when most women attend a gynaecological consultation they anticipate a certain course of treatment. Usually this starts with an exploratory investigation (e.g. D&C). One of the flaws of study 1 was that it did not examine patients' desire for a particular treatment. There is a considerable difference between what patients expect (as part of their treatment process) and what they actually desire. Several patients stated that they ultimately wanted a hysterectomy. Various statements conveyed their feelings towards the operation: "It will let me get on with my life"; "Best to have it all done away with as it's no use. I don't want any more children." "What do I need a womb for at my age?" There was an overall optimism from these patients regarding the outcome of hysterectomy. They simply ignored the probability that complications could occur from such a procedure which is all the

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1 Usually hospital records only reflect investigations that have been carried out in their hospital. The policy of most hospitals is to dispose of patients' records if there has been no attendance for 7-years.

Doctors letters to gynaecologists do not always mention their patients previous investigations (e.g. D&C).
more reason why patients should be forewarned of the probability of this happening.

It was also shown that a greater proportion of patients in the study had menstrual problems for years as opposed to months or weeks. Many women would have been given such medicaments (e.g. mefenamic acid, tranexamic acid) from their general practitioner/gynaecologist or had various invasive investigations (D&C, hysteroscopy, laparoscopy) over a period of years. This could explain why some women wanted a hysterectomy.

An obvious limitation of the methodology of Study 1 is the ambiguity as to the direction of cause and effect. The association between anticipating hysterectomy and expecting great improvement could be because both are natural consequences of having more severe menstrual dysfunction. This is disproved by the results of Study 2 in which women, rather than being self-selected, were assigned to provide their expectations of particular treatments. In essential respects this study replicated Study 1. It confirmed that hysterectomy is seen as the most ‘powerful’ treatment insomuch that it is perceived as having beneficial effects on patients and among the most harmful effects.

Another limitation of these studies was the absence of a ‘no-treatment’ control condition. Because of this no comment can be made on the likelihood that women saw the exploratory procedures as effective treatments. It is clear that women’s expectations often differ from gynaecological views, and clinical observation and anecdotal evidence suggests that the D&C, at least is regarded
Measurement of Women's Expectations of Hysterectomy and Alternative Treatments

as a treatment. A further study should therefore examine the range of treatments by comparison with no treatment.

No other study to date has specifically asked gynaecology patients with menstrual problems what type of treatment they expect. Most studies have selected patients who are due to have a specific type of invasive treatment and have examined their expectations relating to it. The results of study 1 and study 2 have implications for patients' acceptance of, and response to, these treatments. For doctors to be able to use these treatments effectively, patients need to be given detailed information about treatment. Harm and benefit are not just two sides of the same coin as far as patients are concerned, as drugs were seen as harmful but also having some benefit. The unsuccessful experience of drugs might have led to the women's low expectations of drugs.

Study 1 and Study 2 showed the importance of having a wide range of dimensions if researchers are to fully understand the psychological and physiological influences involved in measuring patients' expectations of treatment. Previous studies (e.g. Tsoi et al, 1983, 1984) in this area have mainly focused on patients' negative expectations of treatment. In comparison with these and other studies, the ETQ not only covers similar categories of expectations, but offers a wider range of positive and negative expectations of treatment.

In summary, two studies have indicated what gynaecology patients expect from treatment. This has been accomplished by developing a standardized measurement (ETQ). Such an approach is pertinent to patients expectations of
treatment and can be used as a model for other surgical procedures. Its usefulness is plain among gynaecology patients who often expect a treatment for a condition which has no obvious underlying pathology. Future investigations could use the seven dimensions that have been identified on the ETQ to establish whether these expectations are fulfilled after hysterectomy. They could also be used to predict outcome and to assess patients' knowledge of this and other gynaecological procedures. It could be used to examine whether patients' expectations affect postsurgical reports of problems and anxiety states. Additionally, it could also be employed to predict patients' dissatisfaction with treatment or to explore the influences and beliefs surrounding hysterectomy. Although patients expectations of treatment have been measured between different groups of patients, we still need to know what they want and why they want it. In the next study, evidence will be sought about gynaecology patients' background that might reveal why they desire hysterectomy and why they expect certain effects from it.
'If a disease of unknown nature and hidden origin appears in a woman in such a manner that its cause escapes us, and that the therapeutic course is uncertain, we immediately blame the bad influence of the uterus, which, for the most part, is not responsible....'

Dr. Thomas Willis (1621-1675)
quoted in Foucault (1973)
CHAPTER FOUR

INFLUENCES ON PATIENTS' EXPECTATIONS OF TREATMENT AND DESIRE FOR HYSTERECTOMY

Abstract

This study looked at women (N=156) with menstrual problems attending gynaecology clinics in five general hospitals in the U.K. The aim was to explore the factors that may influence patients to desire certain gynaecological treatments and expectations of these procedures. It was predicted that patients who have experienced sexual, physical or psychological abuse would desire hysterectomy more than non-abused patients and that abused patients would have higher outcome expectations of gynaecological treatment in general. It was also predicted that such factors as depression, anxiety, somatization, hypochondriasis, negative feelings towards the womb, past and present menstrual problems, would influence these patients to desire hysterectomy and have high expectations of effects of treatment for menstrual problems. It was found that patients who had experienced sexual and physical abuse reported higher levels of anxiety, depression and somatization and had more negative feelings towards their womb than non-abused patients. Their expectations of the effects of treatment only differed on sexual function. Abused patients did not desire hysterectomy more than non-abused patients. In general, the more depressed and somatizing patients had the higher expectations of treatment. Generally menstrual pain was a stronger influence on patients' outcome expectations of treatment than menstrual blood loss and depression. Patients who desired hysterectomy had higher expectations of harm and benefit than those who desired other treatments.
Introduction

Traditionally, hysterectomy has been ascribed adverse psychiatric sequelae. Krafft-Ebing (1890) stated that psychoses were more frequently caused by hysterectomy than by any other surgical procedure (Raphael, 1972). Other researchers have claimed this procedure carries a significant mortality (0.6%; Dickie et al, 1982), and is followed by a high level (70%) of psychiatric morbidity, including depression and psychosexual difficulties (Richards, 1974; Ryan et al, 1989). However, other studies have concluded that hysterectomy seldom leads to psychiatric disorder (Meikle & Brody, 1977; Martin & Roberts, 1977; Gath & Cooper, 1981, 1981a; Gath et al, 1982; Coppen & Bishop, 1981). There are several reasons for these discrepant findings. For example, in many of the studies patients were assessed only after hysterectomy. Therefore it is not clear whether any psychiatric morbidity detected after the operation was due to the operation itself or to the patient’s preoperative condition. Furthermore, only a few studies have used standardized psychiatric measures (Hampton & Tarnasky, 1974; Meike & Brody, 1977; Martin & Roberts, 1980) and many studies have used mixed gynaecological samples (e.g. patients hysterectomized for menorrhagia, prolapse, cancer or in combination with abortion or child birth, with or without removal of both ovaries).

Because of the serious implications of hysterectomy for patients, it is important to ask why women often request this operation and what expectations they have of it. In Chapter 3 it was found that women who expected hysterectomy recognize the positive effects of it, but at the same time acknowledge that it could have harmful effects.
Most studies examining patients scheduled to undergo hysterectomy have focused on a narrow range of factors (e.g. depression, sexual dysfunction and satisfaction) and have tended to neglect such factors as abuse, somatization, hypochondriasis and patients' feelings towards their womb that could account for patients desiring this operation. These additional potential influences as well as the more traditionally identified ones are examined in more detail below.

**Depression**

Clinical experience has led some gynaecologists and psychiatrists to conclude that gynaecological symptoms are associated with psychiatric disorder (Rogers, 1950; Smith, 1979; Munro, 1969; Gath et al, 1987; Hunter, 1990). Greenberg (1983) found that sixty-two per cent of women referred to a gynaecology clinic were suffering from mild to moderate depression (see Chapter 1). At the same time it could be argued that an emotional disorder may lead a woman to seek a hysterectomy (e.g. Dennerstein et al, 1986). For example, psychological state can affect the hormone levels produced by the ovary through the intermediary action of the pituitary gland (Dennerstein, 1986). ‘Changes in the production of hormones by the ovary will alter the endometrium and the muscles of the uterus. This in turn may affect menstruation by changing either the severity of contractions or the amount of blood loss’ (op.cit). Thus, treatment of psychological problems may solve a menstrual complaint (Dennerstein). Therefore hysterectomy might be an inappropriate, somatic treatment for an emotional problem. See Chapter 1.
Abuse

Depression has been cited as the commonest symptom among adults with a history of child sexual abuse (Mullen, Roman-Clarkson, Walton & Herbison, 1988; Herman, 1981; Briere & Runtz, 1988; Draijer, 1989). Sedney & Brooks (1984) found among 301 college students significant differences between a control group and a group of 51 female students who claimed to be abused as children. With regard to physical manifestations, females who had been abused were twice as likely to attend a doctor and one and a half times as likely to be hospitalized than the females in the control group (Sedney & Brooks, 1984 cited in Bachmann, Moeller & Benett, 1988). The abused females tended to manifest more severe symptoms of anxiety and depression; 26% had visited a doctor or been hospitalized for severe anxiety, compared to 9% of the control group (op. cit).

A greater number of abused females (18%) had either attended a doctor or been hospitalized for depression compared to those in the control group (4%). A similar pattern of results was reported by Muenzenmaier, Meyer, Struening & Ferber (1993) who examined the prevalence of childhood sexual abuse and physical abuse among female outpatients with severe and persistent mental illness. Forty-five percent of the patients had been sexually abused, and 51% had been physically abused. There were higher rates of depressive and psychotic symptoms and higher rates of sexual victimization in adulthood than those who had not experienced abuse (op. cit.). In support of these findings a recent plethora of studies suggest an association between sexual abuse and the development of major medical, psychiatric, and criminal behaviours (Glod, 1993). However, it is not always easy to separate antecedents and consequences of abuse.
Since there is a problem of definition of what constitutes sexual abuse (Fry, 1993), for the purpose of the present study, sexual abuse will be interpreted as: sexual assault (rape), exposure of sexual organs, unwanted touching and fondling, whether committed by relatives, acquaintances, or strangers. In 1988 in the U.K. there were 516 prosecutions for incest (Cohen, 1990). Official statistics report 4,600 instances of rape and 17,400 of indecent assault against females in England and Wales in 1993 (Home Office, 1994). However, such figures on sexual abuse and rape are widely accepted as just the tip of the iceberg. A MORI survey in Britain reported that 12% of females and 8% of males have been sexually abused before the age of 16 (Baker & Duncan, 1985). Here abuse had been defined as 'exposure' (showing sexual organs), 'touching' and showing pornographic material or talking about sexual things in an erotic way. A New Zealand study reported a rate of 20% for sexual and physical abuse before the age of 12, and a rate of 13% for genital contact or greater (Mullen, Romans-Clarkson, Walton, et al, 1988). West (1988) reports it is likely that as much 98% of childhood abuse is unreported. However, it is important to remember that rates of abuse vary considerably according to how it has been defined (e.g. the age ranges designated "child" or "adult"), and whether non-contact cases are included (e.g. confrontations with an exposor, involvement in erotic talk or viewing pornography. For example, prevalence rates of 54% were shown for any sexual abuse and 38% for abuse involving contact (Russell, 1984), and Badgley, Allard & McCormack (1984) reported 39% and 22% respectively (cited in Bifulco, Brown & Adler, 1991). In America it has been shown in retrospective studies that adults have recalled sexual abuse as a child, revealing a prevalence from 6% to 62% of all females (Finkelhor, 1986). Alarmingly, other American reports
claim that one in four women are survivors of sexual abuse, yet rarely is this spontaneously revealed to doctors, although they are more likely than non-abused patients to report multisystemic medical complaints (Lechner, Vogel, Garcia-Shelton, Leichter & Steibel, 1993). This can lead to misdiagnosis and misuse of medical services (op.cit).

Arnold, Rogers & Cook (1990) examined the case histories of seven female patients between the age of 22 to 39 years of age. All these patients had experienced child sexual abuse and were receiving psychiatric treatment, and had a history of medical and surgical procedures. They had a mean of 18 contacts with non-psychiatric consultant teams and a mean of eight operations of which 66% to 70% revealed normal findings (Arnold et al, 1990). Further, all the patients experienced several somatic symptoms, which eventually led to investigations and interventions in gynaecology (in 6 of 7 patients), obstetrics, gastroenterology, urology, rheumatology, orthopaedics, neurology, and neuropsychiatry. The researchers reported that the ‘history of sexual abuse was recognized only in the later stages of medical and surgical intervention. The possibility of childhood sexual abuse should be considered earlier in such cases to prevent further unnecessary intervention.’

**Somatization & Hypochondriasis**

It is possible that abuse increases the desire for hysterectomy by increasing a tendency to somatization. Somatization is often associated with hypochondriasis
Influences on Patients’ Expectations of Treatment and Desire for Hysterectomy

and is seen as the presentation of emotional problems manifesting in the form of physical or bodily symptoms (Lipowski, 1986).

Katon, Kleinman & Rosen (1982) identified it as:

‘Presentation of physical symptoms in the absence of organic pathology, or the amplification of physical complaints accompanying organic disease beyond what can be accounted for physiology.’

Others have described somatization in terms of abnormal illness behaviour.

Pilowsky’s (1971) notion of ‘abnormal illness behaviour’ was defined as:

‘The persistence of an inappropriate mode of perceiving, evaluating and acting in relation to one’s state of health, despite the fact that a doctor has offered a reasonably lucid explanation of the nature of the illness and the appropriate course of management to be followed, based on a thorough medical examination (including special investigations where necessary).

Pilowsky (1971) emphasizes that the patient’s response to the doctor’s explanation is emphasized in this definition of abnormal illness behaviour since, in many ‘societies, individuals are expected to consult a medical practitioner in deciding the nature of the ‘sick role’ (see Parsons, 1964) to which they are entitled.’

Several investigators have suggested that a somatization disorder could be one of the underlying causes for hysterectomy. For example, Waldemar, Werdelin and Boysen (1987) reported that of 30 hysterectomized women, only six had malignant or premalignant changes in the uterus, whereas in 22 cases the removed organs were normal. Furthermore, in a prospective gynaecological-psychiatric investigation of the sequelae of hysterectomy, Bang, Dragsted and Halse et al, (1981) reported a tendency to psychosomatic symptoms in those cases in which the pathology of the uterus revealed no satisfactory explanation for the gynaecological symptoms. Similarly, Dutton (1965) studied 155 patients with
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functional uterine bleeding (e.g. heavy and long menstrual bleeding, inter-menstrual bleeding and vaginal bleeding). Over eighty-two percent of patients were diagnosed with psychological illnesses (chronic anxiety, acute anxiety, psychoneurosis, depression, hysteria and organic psychosis) and 1.3% of these patients reported they were raped. Only 17.4% of the whole sample were psychologically stable, and all but two were at puberty or approaching the menopause. Among other gynaecological patients (562) who had genital bleeding due to some recognizable organic cause (fibroids, endometriosis, cervicitis, prolapse) one third were psychologically disturbed. Patients with no apparent pathology to account for their functional uterine bleeding were diagnosed with psychological illnesses (82.6%) which far exceeded the average incidence of 33.3% reported in other gynaecological patients who had organic pathology which accounted for their symptoms. According to Dutton ‘psychotherapy alone cured 40.4% of patients’ with functional uterine bleeding. However, regardless of the method of management, the prognosis depends more on the psychological diagnosis than on the severity of bleeding.’ This suggests that health workers need to pay more attention to gynaecological patients’ subjective interpretation of their menstrual blood loss and other factors that could perhaps account for these symptoms.

Awareness that psychosomatic factors can often account for pelvic symptomatology can result in more accurate diagnoses and fewer hysterectomies. It can also help avoid unnecessary medical costs which are prevalent in medical practice. Rough estimates in America show that at least 10% of all medical services are provided for patients who have no evidence of underlying pathology,
and this figure excludes those services provided for identified psychiatric patients (Ford, 1986). Where hypochondriacs are concerned, they account for between 3% to 5% of all patients seen in general medical practice (Kenyon, 1965 cited in Ford, 1986).

Hypochondriasis has been defined as:

Excessive preoccupation about one's health and about trivial or imagined ailments.

Wingate (1976)

Among women the prevalence of somatization disorder is between 0.2 to 2 percent (Woodruff, Clayton & Guze, 1971; Smith, Monson & Livingstone, 1985), and to a lesser degree among men (cited in Smith, Monson, Debby & Ray, 1986). Therefore it is essential to look factors such as somatization that could influence women to have elective hysterectomies.

**Negative feelings towards the womb**

It could be argued that patients who have a history of abuse may have negative feelings towards their womb. Some investigators have proposed that abuse (especially childhood sexual abuse) is causally related to chronic pelvic pain by serving as a metaphor or symbol of persistent stress that relates to the original trauma (e.g. Reiter & Milburn, 1994). Menninger (1939) suggests that 'rejection of the feminine role is dependent on deep-lying hostility, a hostility which is directed outwardly against men and inwardly against the feminine part of themselves by reason of which they feel so inferior. In connection with both of
these hostilities, however, there arises a sense of guilt and a sense of guilt focused upon that part of the body where a repudiation of femininity has been made concrete. Thus the symptoms of amenorrhoea, dysmenorrhoea serves simultaneously as a rejection of the feminine role, an aggression against the male and local self-punishment. Menninger also uses this argument when it comes to menstruation - insomuch it can serve as a defense against intercourse or rejecting and disappointing the excited man. Since there is no objective way to verify such psychodynamic models, a start would be to measure gynaecology patients' feelings about their womb.

Expectations

On the bases of Study 1 and Study 2 on patients expectations of gynaecological treatment (see Chapter 3) it is likely that patients with a background of abuse, somatization, depression and hypochondriasis desire hysterectomy and would have high expectations of treatment.

Conclusion

Research findings suggest that it is likely that women with a history of sexual abuse are more likely to suffer from depression and anxiety than women who have not experienced abuse. Furthermore, it has been suggested that certain factors appear to be involved in the occurrence of hysterectomy which may cause women to want this operation and/or to expect powerful effects from it.
To approach this issue this study attempted to examine:

(i) whether patients with a history of childhood abuse desire hysterectomy more than non-abused patients.

(ii) whether abused and non-abused patients have different outcome expectations of treatment in general.

(iii) whether such factors as: emotional state, hypochondriasis and negative feelings towards the womb, influence these patients to desire hysterectomy and have high outcome expectations of treatment.
Method

Design

This study's aim was to investigate (i) whether there is an association between abuse and such factors as anxiety, depression, somatization, hypochondriasis and negative feelings towards the womb (ii) whether these factors increase the patients' desire for hysterectomy or other treatments (iii) whether such factors as anxiety, depression, somatization, hypochondriasis and negative feelings towards the womb lead patients to have high expectations of gynaecological treatments.

Subjects

One-hundred and fifty-six patients newly referred to routine gynaecology clinics were recruited if they had been referred for menstrual bleeding and/or pain to one of five general hospitals: City Hospital, Nottingham (N=10; 6.4%); Hillingdon Hospital, Uxbridge (N=47; 30.1%); Queen Elizabeth II Hospital, Welwyn Garden City (N=9; 5.8%); Watford General Hospital (N=41; 26.3%); Whittington Hospital, London (N=49; 31.4%). See Table 15, page 158.

The mean age of the patients was 37.7 years (range 16 to 50 years-old), standard deviation 8.05). See Table 16, page 158. The majority of patients were Caucasian
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(89.1%), 5.1% were African and 5.8% were Asian. Patients with confirmed or provisional diagnoses of gynaecological cancer, endometriosis, fibroids, prolapse and/or cysts were excluded.

Where possible, all patients who had follow-up appointments were tracked for approximately 6 months. Categorization of treatments was confirmed by a consultant gynaecologist who also verified all the results of diagnostic procedures (e.g. D&C and laparoscopy) and such operations as hysterectomy and endometrial resection.

Of all the patients approached (N=156) 100% completed questionnaires.

Questionnaires

The front sheet consisted of a consent form and a brief explanation of the study (see Appendix C). This was followed by questions about the woman’s age, marital status, number of children, occupation and religion. A health questionnaire (see Appendix C) asked twelve questions: (1) the main reason for attending the clinic (e.g. menstrual bleeding and/or pain), (2) the length of time they had experienced these symptoms, (3) the age they first experienced these symptoms, (4) the age their periods started, and questions: 5,6,7,8,9 asked patients to describe on a 5-point scale their menstrual pain and menstrual blood loss when their periods first

1If patients kept their appointments.

2Obviously patients who were discharged were not followed-up.

3See Appendix: C.
started; to describe these symptoms now; to rate these symptoms in comparison with other women, (10) type of contraception used, (11) what treatment ‘do you think you will be offered today?’ This question was interpreted by patients as a continuation of their course of investigation and treatment. (12) ‘how many of your relatives have had a hysterectomy?’ This was followed by Zigmond & Snaith’s (1983) Hospital Anxiety and Depression Questionnaire (HAD). This questionnaire is often used with physically sick populations and measures anxiety and depression. It does not include measures of somatic aspects of depression, such as tiredness, which could be caused by physical disease as much as by mood disturbance (Fallowfield, 1990). The scales of this questionnaire were not derived from factor analysis, but from clinical experience and are scored from 0 to 3 with the higher scores indicating the presence of problems (Bowling, 1991). Based on psychiatric diagnoses, HAD depression ratings of 11+ indicates definite cases, scores of 8 to 10 are judged to be doubtful cases and scoring of 7 or less are regarded as non-cases of depression. Zigmond and Snaith (1983) validated the scales on a sample of over 100 psychiatric out-patients and hospital staff.

The 12-item somatization scale was selected from the 58-item Hopkins Symptom Checklist [HSCL] (Derogatis, Lipman, Rickets, Uhlenhuth & Covi, 1974). This scale indicates perceptions of bodily dysfunction. ‘Complaints focused on cardiovascular, gastrointestinal, respiratory, and other systems with marked autonomic mediation are included. Headaches, pain and discomfort localized in the gross musculature plus other somatic equivalents of anxiety were also

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*See Appendix C.

*See Appendix C.
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represented' (Derogatis et al, 1974). Coefficient alpha for somatization was 0.87 (N=1435). Test-retest reliability was 0.82, based on a sample of anxious neurotic outpatients (N=425).

Patients were instructed to 'read each statement and tick one box which comes closest to how you have been feeling in the last week, including today.' Patients responses where measured using a 5-point scale from Not at all to extremely.

Illness Behaviour Questionnaire (Pilowsky & Spence, 1975): a 15-item version was selected from the 52-item questionnaire which measures illness behaviour (hypochondriasis). This shorter version assesses disease concern and disease conviction. The disease concern dimension suggests a phobic concern about one's state of health (Pilowsky & Spence, 1975). The items indicate that this obsession with the likelihood of disease is accompanied by a higher level of anxiety or arousal on the part of the patient. The disease conviction dimension is where the patient has a firm belief that he or she is seriously ill, and with such a conviction may reject the doctor's opinion. This is not to say that the patient is necessarily wrong to do so (Pilowsky & Spence). The loadings of items on disease concern showed a correlation of 0.42 to 0.73 and on disease conviction a correlation of 0.43 to 0.68.

On the IBQ patients were told: 'below are some questions about you and your thoughts about illness. Please tick either 'yes' or 'no' to each statement.

See Appendix C.
Physical and sexual abuse was measured by the Abuse Questionnaire formulated by Drossman, Lesterman, Nachman et al, (1990). The questions that Drossman et al selected were produced for the National Population Survey of Canada (Badgley, Allard, McCormack et al, 1984, cited in Drossman et al, 1990). The physical abuse questions were previously used in Briere & Runtz's (1988) survey of 251 university women. Drossman's et al (1990) definition includes: 'exposure,' 'threat' and 'contact' whereas the more rigid definition of child sexual abuse focused on 'contact.' The scoring of the abuse questionnaire was originally based on that of Drossman et al. but later in the analyses the 'rigid' definition was used. According to Drossman's definition, a patient was considered to be sexually abused if she gave a positive response to any question (1 to 5) during childhood or to any question, apart from sexual exposure (2 to 5) during adulthood. According to Drossman et al: 'a patient was considered to be physically abused if she replied "often" and "occasionally" to being kicked or beaten.' This tight definition was used to avoid ambiguity between disciplinary behaviour and abusive behaviour.

Because previous evidence has suggested that physical and sexual abuse have similar correlates they were combined for the purpose of analyses. For example, Salmon & Calderbank (in press) showed that report of childhood physical or sexual abuse in undergraduates was associated with greater health care use and somatization and hypochondriasis. By combining physical and sexual abuse it allows researchers to deal with groups with larger numbers which is more useful.

'Contact' was made up of three items: 'touched your sex organs,' 'touched their sex organs' and 'tried forcefully to have sex with you without your consent.'
The abuse questionnaire consisted of 12 main questions. The first six questions concerned physical sexual abuse (see Appendix C). Patients were first asked to ‘tick either ‘yes’ or ‘no’ for both age groups (when you were 13 years old or less, or after you were 14 years old) to such questions as: (1) ‘Has anyone ever exposed their sex organs without your consent’ (2) ‘has anyone ever threatened to have sex with you without your consent?’ Question 6 asked patients were asked if they had any other unwanted sexual experiences that were not already mentioned. If their response was positive, they were instructed to specify, if they felt able to. For question 7 patients were asked: ‘when you were a child, did an older person (a) insult or humiliate you, or try to make you feel guilty? (b) hit, kick or beat you? For each statement patients were instructed to tick one of the following boxes: ‘never—seldom—occasionally—often.’ Question 8 was the same as question 7, but patients were asked if they had the above experiences as an adult. Question 9 asked patients ‘Have you ever discussed these experiences with anyone before? Patients were instructed to ‘tick all that apply: e.g. ‘never, family member, psychologist/doctor.’ The last question asked patients: ‘Are you seeing a counsellor for these or any other emotional problems?’ Patients responded by ticking either ‘yes’ or ‘no.’

The Semantic Differential, Feeling Towards the Womb Scale (FTWS)\(^8\) was specially created for the purpose of the study. It consisted of a seven-point bipolar rating scale consisting of fourteen pairs of words which were devised as

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\(^8\)See Appendix C.
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a method of assessing gynaecological patients' feelings towards their womb (e.g. beautiful----ugly, not embarrassing----embarrassing, fertile-----sterile). The instructions were, to 'tick a box in each word pair which best shows how you feel about your womb.' Positive answers were allocated to the left side of the scale.

This questionnaire was based on Kronoff's & Landrine's (1993) hypothesis that 'people may have cognitive representations of the body's parts and that they may be relevant to illness behaviour.' The scale for the FTWS was also based on Kronoff's & Landrine's scale for their questionnaire.

The last questionnaire, the Expectations of Treatment Questionnaire ETQ (see Study 1 and Study 2) consisted of 46 statements. At the beginning of the ETQ patients were instructed to 'tick the one treatment which you feel would help you most: (1) drugs (2) hormones (3) D&C (4) endometrial resection (5) hysterectomy (6) other.' Patients were then told to 'imagine you are going to have the treatment you want. For each of the statements below, please tick a box to indicate what changes you expect to follow the treatment.' Patients were also reminded that 'there are no right or wrong answers - what we need to know are your own views.' (See Study 1 and Study 2 regarding the formulation of the ETQ).

Procedure

Patients were approached individually in either the morning or afternoon gynaecology clinic by the experimenter who introduced herself as a research
worker independent of the hospital. In a private area of each clinic, each patient was asked if she would like to participate in a study ‘designed to find out more about what patients expect from treatment.’ Patients were informed that the study was looking at women who sought medical advice for menstrual problems (heavy bleeding and/or pain). They were told that they would be required to answer some questionnaires. They were shown the content of these questionnaires. They were told if they had any problems completing the questionnaires to ask the experimenter for assistance. The experimenter informed each patient that their questionnaires should be completed and handed back to her before the consultation in the self-sealed envelope provided. Once each patient had signed the consent form it was separated from the questionnaires so that the patient’s identity was protected and no member of the hospital (i.e. doctors and nurses) would be privy to it. The number on the bottom of the consent form corresponded to an elongated postal code number on the top of the consent form which was attached to each set of questionnaires (e.g. WC1E 6BTA would correspond to patient number 1, WC1E 6BTB would correspond to patient number 2, and so on).

It was emphasized to patients that they would remain anonymous since they could only be identified by a code number known only to the experimenter. Patients were also informed that they were under no obligation to take part in the study, and that whether or not they did would not affect their own treatment. The questionnaires took approximately 15 minutes for each patient to complete.
Following each patient's consultation with a gynaecologist, the experimenter noted the clinical decision. This was categorized as: (1) no treatment (2) diagnostic (D&C, laparoscopy, scan, pipelle) (3) medical (drugs) (4) surgical: (i) endometrial resection and (ii) hysterectomy) (6) diagnostic and treatment (D&C and drugs/hysterectomy).

The results of diagnostic investigation were noted for each patient by checking each patient's medical report. If a patient went on to have surgery (hysterectomy or endometrial resection), the outcome of the operation was also noted (no pathology, fibroids, adenomyosis) and for simplification these were broken down to either 'normal' or 'abnormal'. Again, the results of an invasive procedure was obtained by checking the patient's medical report. See Appendix C and Glossary.

Statistical Analyses

Statistical analyses were computed by the SPSS/PC+ computer package:-

Results

Demographic details

The majority of patients were married (48.7%) while the remainder were either single (19.2%) or living with a partner or divorced (30.2%). See Table 17, page

\(^{9}\)Refer to page 148.
Fifty per cent of patients were multiparous, 15.4% had one child and 31.4% were nulliparous (see Table 18, page 158). Most patients (67.3%) were in employment with a higher proportion in clerical and shopwork and fewer were in professional/managerial employment (see Table 19, page 158). The sample was mainly Church of England (53.8%) or Roman Catholic (32.1%) with the remainder belonging to various dominations (15.4%) or having no religion (7.7%). See Table 20, page 158.

Menstrual Symptoms

The mean age of the menarche for patients was 12.66 years old (range 8 to 16, standard deviation 1.62). On a rating scale: none—a little—moderate—quite painful—very painful, nearly a quarter (24.4%) of the sample rated their pain as 'moderate' when their periods first started, while 23.7% saw them as 'quite painful' or 'very painful' (21.2%). Only 14.7% of patients had no pain. When asked how they now perceived their menstrual pain, most patients saw them as 'quite painful' (34.6%) or 'very painful' (28.2%). On a rating scale: very light—quite light—moderate—heavy—very heavy, many patients (47.4%) regarded their menstrual blood loss as 'moderate' when their period first started. When women were asked 'How would you describe your menstrual blood now?' a number of women perceived it as 'very heavy' (43.6%) or 'heavy' (39.7%). Only 22.4% of patients rated their menstrual symptoms the same as most women and a greater proportion of patients perceived them as either 'a little worse' (41.7%) or 'much worse' than most women (30.1%). See Table 21, page 159.
Most patients complained of menstrual pain and bleeding (49.4%) while others only complained of menstrual bleeding (25.6%) or menstrual pain (11.5%). Some women had either experienced these symptoms for over six years (17.3%) or between one to five years (42.3%). Many patients had first experienced menstrual problems *(pain and bleeding)* symptoms between the age of 31 to 40 years old (28.8%) and a lesser number between the age of 21 to 30 years old (22.4%) or 41 to 50 years old (20.5%). A breakdown of patients menstrual symptoms are contained in Table 22, page 159.

Some form of contraception was used by 53.8% of the sample *(see Table VIII, Appendix C).*

**Treatment Recommended and Pathology**

As a result of their consultation most patients had an invasive exploratory procedure *(e.g. D&C, hysteroscopy, laparoscopy)*, other patients were prescribed either drugs, endometrial resection *(ER)* or hysterectomy and some of the sample were not offered any treatment *(see Table 23, page 159).* Pathology was evident in 29.9% of patients who had exploratory or surgical *(ER and hysterectomy)* procedures and this mainly consisted of fibroids, cysts, polyps, adenomyosis.

Table 23 *(page 159)* also shows that of the 18 patients who underwent a hysterectomy 50% had some underlying pathology. Their mean age was 40.5 years (range 31 to 49 years, standard deviation 5.42) and on average they had
two children (see Table IX, Appendix C).

Table 15: Breakdown of Hospitals (Study 3)

<table>
<thead>
<tr>
<th>HOSPITALS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>City Hospital, Nottingham</td>
<td>10</td>
<td>6.4</td>
</tr>
<tr>
<td>Hillingdon Hospital, Uxbridge</td>
<td>47</td>
<td>30.1</td>
</tr>
<tr>
<td>Queen Elizabeth II Hospital,</td>
<td>9</td>
<td>5.8</td>
</tr>
<tr>
<td>Watford General Hospital, Watford</td>
<td>41</td>
<td>28.3</td>
</tr>
<tr>
<td>Whittington Hospital, London</td>
<td>49</td>
<td>31.4</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>156</td>
<td></td>
</tr>
</tbody>
</table>

Overall response rate 100%

Table 16: Age and Ethnic Origin of Patients (Study 3)

<table>
<thead>
<tr>
<th>PATIENTS</th>
<th>MEAN (years)</th>
<th>RANGE (years)</th>
<th>STANDARD DEVIATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>37.7</td>
<td>16 - 50</td>
<td>8.05</td>
</tr>
<tr>
<td>ETHNIC ORIGIN</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>139</td>
<td>89.1</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td>8</td>
<td>5.1</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>9</td>
<td>5.8</td>
<td></td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>156</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 17: Breakdown of Marital Status (Study 3)

<table>
<thead>
<tr>
<th>MARITAL STATUS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>30</td>
<td>19.2</td>
</tr>
<tr>
<td>Married</td>
<td>76</td>
<td>48.7</td>
</tr>
<tr>
<td>Living with partner</td>
<td>26</td>
<td>16.7</td>
</tr>
<tr>
<td>Divorced</td>
<td>21</td>
<td>13.5</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>156</td>
<td></td>
</tr>
</tbody>
</table>

Table 18: Breakdown of Parity (Study 3)

<table>
<thead>
<tr>
<th>NUMBER OF CHILDREN</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>One child</td>
<td>24</td>
<td>15.4</td>
</tr>
<tr>
<td>Two children</td>
<td>44</td>
<td>28.2</td>
</tr>
<tr>
<td>Three children</td>
<td>27</td>
<td>17.3</td>
</tr>
<tr>
<td>Four children</td>
<td>8</td>
<td>5.1</td>
</tr>
<tr>
<td>Five children</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Six children</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Seven children</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Nine children</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>No children</td>
<td>49</td>
<td>31.4</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>156</td>
<td></td>
</tr>
</tbody>
</table>

Table 19: Breakdown of Patients' Employment (Study 3)

<table>
<thead>
<tr>
<th>EMPLOYMENT</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>97</td>
<td>62.2</td>
</tr>
<tr>
<td>Unemployed</td>
<td>12</td>
<td>7.7</td>
</tr>
<tr>
<td>Self-employed</td>
<td>8</td>
<td>5.1</td>
</tr>
<tr>
<td>Housewife</td>
<td>28</td>
<td>17.9</td>
</tr>
<tr>
<td>Retired</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>5.8</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>156</td>
<td></td>
</tr>
</tbody>
</table>

Table 20: Breakdown of Patients' Religion (Study 3)

<table>
<thead>
<tr>
<th>RELIGION</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church of England</td>
<td>84</td>
<td>53.8</td>
</tr>
<tr>
<td>Catholic</td>
<td>36</td>
<td>23.1</td>
</tr>
<tr>
<td>Jewish</td>
<td>4</td>
<td>2.6</td>
</tr>
<tr>
<td>Hindu</td>
<td>4</td>
<td>2.6</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Sikh</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>8.3</td>
</tr>
<tr>
<td>None</td>
<td>12</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>156</td>
<td></td>
</tr>
</tbody>
</table>
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

Table 21: Breakdown of Patients' Menstrual Symptoms (Study 3)

<table>
<thead>
<tr>
<th>AGE OF MENARCHE</th>
<th>PAIN AT MENARCHE</th>
<th>PRESENT</th>
<th>PAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>None</td>
<td>23 (14.7)</td>
<td>7 (4.5)</td>
</tr>
<tr>
<td>1</td>
<td>A little</td>
<td>25 (16.0)</td>
<td>15 (9.6)</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
<td>38 (24.4)</td>
<td>36 (23.1)</td>
</tr>
<tr>
<td>3</td>
<td>Quite painful</td>
<td>37 (23.7)</td>
<td>54 (34.6)</td>
</tr>
<tr>
<td>4</td>
<td>Very painful</td>
<td>33 (21.2)</td>
<td>44 (28.2)</td>
</tr>
<tr>
<td>5</td>
<td>None</td>
<td>23 (14.7)</td>
<td>7 (4.5)</td>
</tr>
<tr>
<td>6</td>
<td>A little</td>
<td>25 (16.0)</td>
<td>15 (9.6)</td>
</tr>
<tr>
<td>7</td>
<td>Moderate</td>
<td>38 (24.4)</td>
<td>36 (23.1)</td>
</tr>
<tr>
<td>8</td>
<td>Quite painful</td>
<td>37 (23.7)</td>
<td>54 (34.6)</td>
</tr>
<tr>
<td>9</td>
<td>Very painful</td>
<td>33 (21.2)</td>
<td>44 (28.2)</td>
</tr>
</tbody>
</table>

MENSTRUAL SYMPTOMS COMPARED TO OTHER WOMEN

<table>
<thead>
<tr>
<th></th>
<th>N %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much better</td>
<td>3 (1.9)</td>
</tr>
<tr>
<td>A little better</td>
<td>6 (3.8)</td>
</tr>
<tr>
<td>The same</td>
<td>35 (22.4)</td>
</tr>
<tr>
<td>A little worse</td>
<td>65 (41.7)</td>
</tr>
<tr>
<td>Much worse</td>
<td>47 (30.1)</td>
</tr>
</tbody>
</table>

Based on 156 patients

Table 22: Breakdown of Patients' Complaint (Study 3)

<table>
<thead>
<tr>
<th>COMPLAINT</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain &amp; other problems</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td>Pain</td>
<td>18</td>
<td>11.5</td>
</tr>
<tr>
<td>Bleeding &amp; other problems</td>
<td>9</td>
<td>5.8</td>
</tr>
<tr>
<td>Bleeding</td>
<td>26</td>
<td>16.6</td>
</tr>
<tr>
<td>PMS, Bleeding, &amp; other problems</td>
<td>5</td>
<td>3.2</td>
</tr>
<tr>
<td>Pain &amp; Bleeding</td>
<td>77</td>
<td>49.4</td>
</tr>
</tbody>
</table>

TOTAL: 156

DURATION OF COMPLAINT

<table>
<thead>
<tr>
<th>Weeks</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-6</td>
<td>4</td>
<td>2.6</td>
</tr>
<tr>
<td>Months (6-12)</td>
<td>99</td>
<td>63.8</td>
</tr>
<tr>
<td>Years (13+)</td>
<td>54</td>
<td>34.6</td>
</tr>
</tbody>
</table>

TOTAL: 156

AGE AT FIRST EXPERIENCED COMPLAINT

<table>
<thead>
<tr>
<th>Years</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-10</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>11-13</td>
<td>17</td>
<td>10.9</td>
</tr>
<tr>
<td>14-16</td>
<td>14</td>
<td>9.0</td>
</tr>
<tr>
<td>17-19</td>
<td>18</td>
<td>11.6</td>
</tr>
<tr>
<td>20-29</td>
<td>21</td>
<td>13.6</td>
</tr>
<tr>
<td>30-49</td>
<td>45</td>
<td>28.8</td>
</tr>
<tr>
<td>50-59</td>
<td>32</td>
<td>20.3</td>
</tr>
</tbody>
</table>

TOTAL: 156

Table 23: Treatment recommended and results of operations (Study 3)

<table>
<thead>
<tr>
<th>Recommended treatment</th>
<th>N</th>
<th>Pathology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploratory</td>
<td>49 (44.2%)</td>
<td>49 (23.2%)</td>
</tr>
<tr>
<td>Drugs</td>
<td>25 (16%)</td>
<td>-</td>
</tr>
<tr>
<td>Endometrial Resection</td>
<td>10 (8.4%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>18 (11%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>No Treatment</td>
<td>34 (21.8%)</td>
<td>-</td>
</tr>
</tbody>
</table>

TOTAL: 156
Type of treatment expected and desired

Table 24 (page 162) gives a breakdown on the type of treatment patients expected and/or desired and it also shows the relationship between patients expected, desired and recommended treatment. Most patients expected and/or desired some kind of exploratory investigation and over a quarter of the sample desired a hysterectomy. Of the patients who expected hysterectomy, 40% were recommended it and over 32% of those who desired a hysterectomy were also recommended it. A minority (7.1%) of patients did not know what treatment to expect. Over seventy percent of women had either friends or relatives who had a hysterectomy.

Type of treatment desired and outcome expectations of treatment

Patients were grouped according to the treatment they desired (drugs, exploratory, endometrial resection, hysterectomy) and were compared on their expectations of treatment outcome (using the Expectations of Treatment Questionnaire). Patients were compared by one-way analysis of variance on: wellbeing (F=13.26; p=<.0001), harm (F=5.22; p=<.001), menstruation (F=26.26; p<.0001), physical symptoms (F=16.78; p=<.0001), sex (F=4.54; p=<.004), womb (F=59.90; p=<.0001) and bowel function (F=2.50; p>.05; d.f.=3,152).

Where the F-ratio was significant post hoc comparisons using the Least Significant Difference (LSD) test showed where the differences lay between these groups (p<.05). The results of these comparisons were very similar to those found in Study 1 and Study 2. For example, overall patients in the hysterectomy
Influences on Patients’ Expectations of Treatment and Desire for Hysterectomy

group emerged as expecting higher positive benefits on the dimensions of wellbeing, womb, menstruation, physical symptoms and sex than any of the other treatment groups. But at the same time they and patients in the drugs group had higher expectations of harm than patients in the other treatment groups. Fig. 16 to Fig. 21 (page 163) shows where these significant differences lay between groups on the above dimensions. Fig. 17, Fig. 18 and Fig. 21 indicates that patients who desired a hysterectomy had higher expectations concerning wellbeing and menstrual function and improvement in sex than patients in the drugs and exploratory groups. Patients who desired an endometrial resection had much higher positive expectations on womb function than patients in the exploratory group and higher positive expectations on wellbeing than the drugs group (Fig. 20 and Fig. 17). Additionally they had higher positive expectations regarding menstrual function than patients both the drugs and exploratory groups (Fig. 18).
**Table 24: The treatment patients ‘expected,’ ‘desired’ and treatment that was ‘recommended’**

<table>
<thead>
<tr>
<th>TREATMENT EXPECTED</th>
<th>Drugs</th>
<th>Exp</th>
<th>E.R.</th>
<th>Hyster</th>
<th>Row Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs</td>
<td>23</td>
<td>6</td>
<td>-</td>
<td>2</td>
<td>31 (19.9%)</td>
</tr>
<tr>
<td>Exploratory</td>
<td>20</td>
<td>47</td>
<td>1</td>
<td>20</td>
<td>88 (56.4%)</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>2</td>
<td>6 (3.8%)</td>
</tr>
<tr>
<td>hysterectomy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>14</td>
<td>20 (12.8%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>11 (7.1%)</td>
</tr>
<tr>
<td>Column Total:</td>
<td>48</td>
<td>59</td>
<td>9</td>
<td>40</td>
<td>N=156</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TREATMENT RECOMMENDED</th>
<th>Drugs</th>
<th>Exp</th>
<th>E.R.</th>
<th>Hyster</th>
<th>No Treat</th>
<th>Row Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs</td>
<td>7</td>
<td>14</td>
<td>1</td>
<td>-</td>
<td>9</td>
<td>31 (19.9%)</td>
</tr>
<tr>
<td>Exploratory</td>
<td>13</td>
<td>45</td>
<td>2</td>
<td>10</td>
<td>18</td>
<td>88 (56.4%)</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>-</td>
<td>2</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>6 (3.8%)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>8</td>
<td>2</td>
<td>20 (12.8%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>5</td>
<td>11 (7.1%)</td>
</tr>
<tr>
<td>Column Total:</td>
<td>25</td>
<td>69</td>
<td>10</td>
<td>18</td>
<td>34</td>
<td>N=156</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TREATMENT DESIRED</th>
<th>Drugs</th>
<th>Exp</th>
<th>E.R.</th>
<th>Hyster</th>
<th>No Treat</th>
<th>Row Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs</td>
<td>7</td>
<td>23</td>
<td>2</td>
<td>2</td>
<td>14</td>
<td>48 (30.8%)</td>
</tr>
<tr>
<td>Exploratory</td>
<td>12</td>
<td>30</td>
<td>1</td>
<td>1</td>
<td>15</td>
<td>59 (37.8%)</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>2</td>
<td>-</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>9 (5.8%)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>4</td>
<td>16</td>
<td>3</td>
<td>13</td>
<td>4</td>
<td>40 (25.6%)</td>
</tr>
<tr>
<td>Column Total:</td>
<td>25</td>
<td>69</td>
<td>10</td>
<td>18</td>
<td>34</td>
<td>N=156</td>
</tr>
</tbody>
</table>
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

Fig. 16: Type of treatment desired and expected treatment outcome (N=156)

Fig. 17: Type of treatment desired and expected treatment outcome (N=156)

Fig. 18: Type of treatment desired and expected treatment outcome (N=156)

Fig. 19: Type of treatment desired and expected treatment outcome (N=156)

Fig. 20: Type of treatment desired and expected treatment outcome (N=156)

Fig. 21: Type of treatment desired and expected treatment outcome (N=156)

*Values differ from exploratory and drug and standard error of the mean is also shown.
Influences on Patients’ Expectations of Treatment and Desire for Hysterectomy

Distribution of abuse

Table 25: Breakdown of Patients who have Experienced some form of Abuse

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>CHILDHOOD ABUSE</th>
<th>ADULT ABUSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=156</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SEXUAL ABUSE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exposure of sex organs without consent 42 (26.9%)</td>
<td>41 (26.3%)</td>
<td></td>
</tr>
<tr>
<td>Threatened to have sex without consent 18 (11.5%) 26 (16.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact (touched your sex organs) 29 (18.5%) 33 (21.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot; (tried/had sex) 13 (8.3%) 27 (17.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drossman defn. = exposure + threat + contact N=53 abused N=43 abused</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative defn. = contact N=33 abused (as above)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unwanted sexual experiences 14 (8.9%) 16 (10.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSYCHOLOGICAL ABUSE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never 79 (50.6%) 90 (57.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seldom 26 (16.7%) 36 (23.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally 43 (27.6%) 26 (16.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often 8 (5.1%) 4 (2.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse= Never-seldom N=105 (67.3%) N=126 (80.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abuse= Occasionally-often N=51 (33.7%) N=30 (19.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHYSICAL ABUSE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never 92 (59.0%) 137 (87.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seldom 22 (14.1%) 10 (6.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally 33 (21.2%) 7 (4.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often 9 (5.8%) 2 (1.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse= Never-seldom N=114 (73.0%) N=147 (92.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abuse= Occasionally-often N=42 (27.0%) N=9 (5.8%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The definition for adult sexual abuse = 'contact.' Defined as.
Threatened = “Has anyone ever threatened to have sex with you without your consent?”
Exposure = “Has anyone ever exposed your sex organs to you without your consent?”

Distribution of child sexual, psychological and physical abuse

Table 25 (above) shows the distribution of childhood sexual, psychological and physical abuse (see also abuse questionnaire, Appendix C). Figures for the two definitions of child sexual abuse are also included in the above table. Drossman’s et al (1990) definition includes: ‘exposure,’ ‘threat’ and ‘contact’ whereas the more rigid definition of child sexual abuse focused on ‘contact.’

According to Drossman’s et al (1990) definition nearly one-third of the sample

10 ‘Contact’ was made up of three items: ‘touched your sex organs, ‘touched their sex organs’ and ‘tried forcefully to have sex with you without your consent.’
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

(N=53) were sexually abused in childhood. The conservative definition of sexual abuse showed that fewer patients (21.2%) were sexually abused (N=33). On the abuse questionnaire patients were asked: Have you had any other unwanted sexual experiences not already mentioned? Although 14 (8.9%) patients claimed to have had unwanted sexual experiences many of them declined to elaborate what these experiences were, however two patients indicated that anal sex and oral sex had taken place.

Table 25 (page 164) also shows a breakdown of the overall figures for psychological and physical abuse in childhood. The cut off point for psychological and physical childhood abuse and non-abuse is between the categories 'seldom' and 'occasionally' (Drossman et al, 1990) showing that 33.7% of patients have been psychologically abused and 27% have experienced physical abuse.

Relationship between child sexual, psychological and physical abuse

For the following analyses of childhood sexual abuse the conservative definition of sexual abuse was adopted.

According to Table 26 (page 166) child sexual and psychological abuse was related (Chi-square= 21.95; d.f.=1; p=<.0001) similarly, sexual abuse and physical abuse was related (Chi-square=12.87; d.f.=1; p=<.0003).
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

Table 26: Child and Adult Abuse: The relationship between sexual, psychological and physical abuse and non-abuse (N=156)

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>NO ABUSE</th>
<th>ABUSED</th>
<th>Row total</th>
<th>Chi-square</th>
<th>p&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHILD PSYCHOLOGICAL</td>
<td>CHILD SEXUAL N=123 (78.8%)</td>
<td>CHILD SEXUAL N=33 (21.2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse</td>
<td>94</td>
<td>11</td>
<td>105 (67.3%)</td>
<td>21.95  .0001</td>
<td></td>
</tr>
<tr>
<td>Abuse</td>
<td>29</td>
<td>22</td>
<td>51 (32.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILD PHYSICAL</td>
<td>CHILD SEXUAL N=123 (78.8%)</td>
<td>CHILD SEXUAL N=33 (21.2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse</td>
<td>98</td>
<td>16</td>
<td>114 (73.1%)</td>
<td>12.87  .0003</td>
<td></td>
</tr>
<tr>
<td>Abuse</td>
<td>25</td>
<td>17</td>
<td>42 (26.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADULT PSYCHOLOGICAL</td>
<td>ADULT SEXUAL N=113 (72.4%)</td>
<td>ADULT SEXUAL N=43 (27.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse</td>
<td>100</td>
<td>26</td>
<td>126 (80.8%)</td>
<td>15.76  .0001</td>
<td></td>
</tr>
<tr>
<td>Abuse</td>
<td>13</td>
<td>17</td>
<td>30 (19.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADULT PHYSICAL</td>
<td>ADULT SEXUAL N=113 (72.4%)</td>
<td>ADULT SEXUAL N=43 (27.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse</td>
<td>110</td>
<td>37</td>
<td>147 (94.2%)</td>
<td>7.32   .007</td>
<td></td>
</tr>
<tr>
<td>Abuse</td>
<td>3</td>
<td>6</td>
<td>9 (5.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILD SEXUAL</td>
<td>ADULT SEXUAL N=113 (72.4%)</td>
<td>ADULT SEXUAL N=43 (27.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse</td>
<td>102</td>
<td>21</td>
<td>123 (78.8%)</td>
<td>32.05  .0001</td>
<td></td>
</tr>
<tr>
<td>Abuse</td>
<td>11</td>
<td>22</td>
<td>33 (21.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILD PHYSICAL</td>
<td>ADULT PHYSICAL N=147 (94.2%)</td>
<td>ADULT PHYSICAL N=9 (5.8%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No abuse</td>
<td>111</td>
<td>3</td>
<td>114 (73.1%)</td>
<td>7.67   .006</td>
<td></td>
</tr>
<tr>
<td>Abuse</td>
<td>36</td>
<td>6</td>
<td>42 (26.9%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adult sexual, psychological and physical abuse

A breakdown of adult sexual, psychological and physical abuse and non-abuse is shown in Table 25 (page 164). Chi-square (Chi-square 15.76; d.f.=1; p<.0001) showed there was an association between sexual and psychological abuse in adults and sexual and physical abuse (Chi-square=7.32; d.f.=1; p<.006). See Table 26 (above).
Sixteen patients claimed they had endured other unwanted sexual experiences, but only four patients conveyed the nature of these experiences. Two patients reported they had been gang raped and two patients had anal sex.

In the following analyses (from Table 26 onwards) concerning abuse, psychological abuse is not included as it was found that it did not contribute anything to the following findings.

**Relationship between childhood sexual and physical abuse vs adult sexual and physical abuse**

Analysis by Chi-square was used to identify the relationship between childhood and adulthood sexual and physical abuse and non-abuse among 156 patients.

According to Table 26 (page 166) there was an association between sexual abuse in childhood and in adulthood (Chi-square=32.05; d.f.=1; p=<.0001). Similarly there was an association between physical abuse in childhood and in adulthood (Chi-square=7.67; d.f.=1; p=<.006). See Table 26, page 166.

**Reporting of abuse and other emotional problems**

Table X (Appendix C) shows that when patients were asked: ‘Have you ever discussed these experiences with anyone before’ in relation to sexual, psychological and physical abuse, 38% of those who had been abused stated that they had
either confided in a family member, friend(s), minister or lay counsellor, a psychologist or doctor. In response to the question: "Are you seeing a counsellor for these or any other emotional problems?" over 9% affirmed that they were seeing a counsellor.

Distribution of child and adult sexual and physical abuse and the type of treatment recommended and outcome of treatment

Table 27 (below) and Table 28 (page 169) shows the distribution of child and adult abuse and treatment recommended. The association of abuse and no abuse and pathology and no pathology was not significant when examined by Chi-square.

<p>| Table 27: Relationship between type of abuse and type of treatment recommended (N=156) |
|------------------------------------------|----------|----------|</p>
<table>
<thead>
<tr>
<th>ABUSE</th>
<th>NON-ABUSED</th>
<th>ABUSED</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHILD SEXUAL ABUSE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploratory</td>
<td>51</td>
<td>18</td>
</tr>
<tr>
<td>Drugs</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>No treatment</td>
<td>29</td>
<td>5</td>
</tr>
<tr>
<td>CHILD PHYSICAL ABUSE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploratory</td>
<td>50</td>
<td>19</td>
</tr>
<tr>
<td>Drugs</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>No treatment</td>
<td>25</td>
<td>9</td>
</tr>
</tbody>
</table>
Influences on Patients’ Expectations of Treatment and Desire for Hysterectomy

Table 28: Relationship between type of abuse and type of treatment recommended (N=156)

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>NON-ABUSED</th>
<th>ABUSED</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADULT SEXUAL ABUSE</td>
<td>N=113</td>
<td>N=43</td>
</tr>
<tr>
<td>Exploratory</td>
<td>48</td>
<td>21</td>
</tr>
<tr>
<td>Drugs</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>No treatment</td>
<td>27</td>
<td>7</td>
</tr>
<tr>
<td>ADULT PHYSICAL ABUSE</td>
<td>N=147</td>
<td>N=9</td>
</tr>
<tr>
<td>Exploratory</td>
<td>65</td>
<td>4</td>
</tr>
<tr>
<td>Drugs</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>No treatment</td>
<td>31</td>
<td>3</td>
</tr>
</tbody>
</table>

Feelings Towards the Womb Questionnaire

Scores on the 14 paired words on the Feelings Towards the Womb Questionnaire were totalled in order to generate one score which would identify women who have negative feelings in this area. Cronbach’s alpha was 0.89.

Correlations of menstrual symptoms with anxiety, depression, somatization, hypochondriasis and negative feelings towards the womb

Menstrual pain (when periods first started) was positively related to somatization and current menstrual pain was positively related to depression. Menstrual blood loss (when periods first started) positively correlated with anxiety, depression and patients’ negative feelings towards their womb and were negatively related to
Influences on Patients’ Expectations of Treatment and Desire for Hysterectomy

hysteroscopy. Positive correlations were also evident between patients’ current menstrual blood loss and anxiety, depression and negative feelings towards their womb (see Table 29, below).

Correlations of anxiety, depression, somatization, hypochondriasis, negative feelings towards their womb with outcome expectations of treatment

Pearson product moment correlations (see Table 30, page 171) revealed that womb, wellbeing, menstruation, physical symptoms, sex were all positively correlated to depression. But there was no relationship of depression to harm and bowel function. Anxiety and hypochondriasis were not related to any of the outcome expectations of treatment. However, somatization was found to be related to womb, wellbeing, menstruation, harm, physical symptoms, but not to sex or bowel function. A similar relationship was found between these expectations of treatment and feelings towards the womb. The only exception was that there was no correlation between harm and patients negative feelings towards their womb.

| Table 29: Correlations between menstrual symptoms and anxiety, depression, somatization, hypochondriasis and negative feelings towards the womb (N=156) |
|---------------------------------|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Anxiety (HAD)                  | Depression (HAD)               | Somatization (Hopkins)          | Hypochondriasis                 | FTW                             |
| MENSTRUAL PAIN (when periods first started) | -                              | -                              | .16*                            | -                               |
| MENSTRUAL PAIN (now)           | -                              | .21***                         | .24**                           | -                               |
| MENSTRUAL BLOOD LOSS (when periods first started) | .13**                          | .23***                         | .26***                          | .21***                          |
| MENSTRUAL BLOOD LOSS (now)     | .20**                          | .23***                         | .26***                          | -                               |

FTW = negative feelings

* p < .01
** p < .001
*** p < .0001
Influences on Patients’ Expectations of Treatment and Desire for Hysterectomy

Table 30: Correlations between Outcome Expectations of Treatment and anxiety, depression, somatization, hypochondriasis and negative feelings towards the womb (N=156)

<table>
<thead>
<tr>
<th></th>
<th>Womb</th>
<th>Wellbeing</th>
<th>Menstruation</th>
<th>Harm</th>
<th>Physical symptoms</th>
<th>Sex</th>
<th>Bowels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Depression-</td>
<td>.16*</td>
<td>.20*</td>
<td>.22*</td>
<td>.19*</td>
<td>.19*</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Somatization</td>
<td>.24*</td>
<td>.25*</td>
<td>.18*</td>
<td>.18*</td>
<td>.29*</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>.26**</td>
<td>.26**</td>
<td>.27**</td>
<td>.23**</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Differences between abused and non-abused patients on predictor measures (anxiety, depression, somatization, hypochondriasis, negative feelings towards the womb and menstrual pain and bleeding)

Child sexual and physical abuse

Table 31, (page 172) shows that sexually abused patients had higher anxiety scores (F=13.22; d.f.=1,155; p=<.0004) and higher somatization scores (F=7.48; d.f.=1,155; p=<.007) than non-abused patients. There were no significant differences between abused and non-abused patients regarding depression (HAD), hypochondriasis and negative feelings towards the womb (see Table 31, page 172).

When child physical abuse and non-abuse patients were compared on the above factors the only significant difference was that somatization was more evident in abused patients than non-abused patients (F=4.53; d.f.=1,155; p=<.04). But when
child sexually and physically abused and non-abused patients were combined\(^1\) the abused patients were more anxious (F=5.61; d.f.=1,55; \(p=<.02\)), depressed (F=3.85; d.f.=1,55; \(p=<.05\)) and had higher levels of somatization (F=6.81; d.f.=1,55; \(p=<.01\)) than patients who were not abused. Although abused patients reported more negative feelings towards their womb than non-abused patients this difference just failed to reach significance (F=3.65; d.f.=1,155; \(p=.06\)). No differences were found on menstrual symptoms between sexually and physically abused and non-abused patients.

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>N=123</th>
<th>N=33</th>
<th>MEAN (SD) (non-abused)</th>
<th>MEAN (SD) (abused)</th>
<th>F ratio</th>
<th>(p=&lt;.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHILD SEXUAL ABUSE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (HAD)</td>
<td>8.94</td>
<td>11.76</td>
<td>4.27</td>
<td></td>
<td>13.22</td>
<td>0.0004</td>
</tr>
<tr>
<td>Depression (HAD)</td>
<td>6.44</td>
<td>6.45</td>
<td>3.42</td>
<td></td>
<td>2.44</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>Somatization (Hopkins)</td>
<td>24.59</td>
<td>28.97</td>
<td>5.80</td>
<td></td>
<td>7.48</td>
<td>0.007</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>25.17</td>
<td>24.21</td>
<td>2.53</td>
<td></td>
<td>3.28</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>40.34</td>
<td>45.52</td>
<td>10.98</td>
<td></td>
<td>3.67</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>CHILD PHYSICAL ABUSE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (HAD)</td>
<td>9.24</td>
<td>10.33</td>
<td>3.89</td>
<td></td>
<td>2.18</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>Depression (HAD)</td>
<td>5.46</td>
<td>6.17</td>
<td>3.37</td>
<td></td>
<td>1.36</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>Somatization (Hopkins)</td>
<td>24.67</td>
<td>27.83</td>
<td>6.65</td>
<td></td>
<td>4.53</td>
<td>0.04</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>40.93</td>
<td>42.79</td>
<td>13.90</td>
<td></td>
<td>0.54</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>39.82</td>
<td>44.17</td>
<td>13.66</td>
<td></td>
<td>3.65</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>CHILD SEXUAL &amp; PHYSICAL ABUSE</td>
<td>N=98</td>
<td>N=58</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (HAD)</td>
<td>8.94</td>
<td>10.53</td>
<td>4.03</td>
<td></td>
<td>5.61</td>
<td>0.02</td>
</tr>
<tr>
<td>Depression (HAD)</td>
<td>5.25</td>
<td>6.33</td>
<td>3.42</td>
<td></td>
<td>3.85</td>
<td>0.05</td>
</tr>
<tr>
<td>Somatization (Hopkins)</td>
<td>24.20</td>
<td>27.74</td>
<td>7.80</td>
<td></td>
<td>6.81</td>
<td>0.01</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>25.24</td>
<td>24.90</td>
<td>2.41</td>
<td></td>
<td>2.77</td>
<td>(n.s.)</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>39.82</td>
<td>44.17</td>
<td>13.66</td>
<td></td>
<td>3.65</td>
<td>(n.s.)</td>
</tr>
</tbody>
</table>

\(n.s.\)=not significant

\(^1\)See page 151.
Adult sexual and physical abuse

Sexually abused patients were more anxious (F=6.38; d.f.=1,155; p=<.01) (see Table 32, page 174) with much higher negative feelings towards their womb (F=4.71; d.f.=1,55; p=<.03) than non-abused patients. However, non-abused patients manifested higher levels of hypochondriasis, (F=9.99; d.f.=1,155; p=<.002) than the abused patients.

There were no differences between physically abused and non-abused patients on the above variables. But when patients had suffered abuse of either kind (sexual and physical) and compared to non-abused patients some significant differences between the two groups of patients were evident. Specifically: abused patients reported more anxiety (F=4.93; d.f.=1,55; p=<.03) and had higher negative feelings towards their womb (F=4.12; d.f.=1,55; p=<.04) than non-abused patients. Hypochondriasis was significantly higher among non-abused patients than abused patients (F=7.88; d.f.=1,155; p=<.007). The results were identical to those for sexual abuse on depression, somatization and severity of menstrual symptoms in childhood and adulthood.

Relationship of predictor variables to type of treatment desired

Child and Adult sexual and physical abuse and treatment desired

Having previously described the extent to which psychological abuse is associated with sexual and physical abuse, it was decided that the following analyses would now only focus on sexual and physical abuse.
Chi-square Table 33 and Table 34, (page 175) shows that the type of treatment that patients desire (exploratory, drugs, endometrial resection and hysterectomy) is not associated with childhood or adult abuse (sexual and physical). Table 34 indicates that the majority of patients who were abused in adulthood desired an exploratory investigation and a fewer number desired a hysterectomy whereas among the non-abused patients there was little difference between those who desired either drugs, an exploratory investigation or a hysterectomy.

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>MEAN (SD) (non-abused)</th>
<th>MEAN (SD) (abused)</th>
<th>F ratio</th>
<th>p&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADULT SEXUAL ABUSE (N=113)</td>
<td>(N=43)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (HAD)</td>
<td>9.03 (4.18)</td>
<td>10.06 (3.60)</td>
<td>6.38</td>
<td>0.01</td>
</tr>
<tr>
<td>Depression (HAD)</td>
<td>5.45 (3.41)</td>
<td>6.19 (3.05)</td>
<td>1.52</td>
<td>ns</td>
</tr>
<tr>
<td>Somatization (Hopkins)</td>
<td>24.85 (8.53)</td>
<td>27.28 (7.61)</td>
<td>2.68</td>
<td>ns</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>25.38 (3.63)</td>
<td>23.88 (2.66)</td>
<td>9.99</td>
<td>0.002</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>39.96 (13.67)</td>
<td>45.30 (13.66)</td>
<td>4.71</td>
<td>0.03</td>
</tr>
<tr>
<td>ADULT PHYSICAL ABUSE (N=147)</td>
<td>(N=9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (HAD)</td>
<td>9.53 (4.16)</td>
<td>9.67 (3.12)</td>
<td>0.01</td>
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</tr>
<tr>
<td>Depression (HAD)</td>
<td>5.71 (3.35)</td>
<td>4.67 (2.87)</td>
<td>0.64</td>
<td>ns</td>
</tr>
<tr>
<td>Somatization (Hopkins)</td>
<td>25.30 (8.18)</td>
<td>29.11 (10.35)</td>
<td>1.78</td>
<td>ns</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>25.00 (2.68)</td>
<td>24.44 (4.00)</td>
<td>0.35</td>
<td>ns</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>41.41 (14.03)</td>
<td>41.88 (12.99)</td>
<td>0.01</td>
<td>ns</td>
</tr>
<tr>
<td>ADULT SEXUAL &amp; PHYSICAL ABUSE</td>
<td>(N=110)</td>
<td>(N=46)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (HAD)</td>
<td>9.07 (4.22)</td>
<td>10.65 (3.60)</td>
<td>4.93</td>
<td>0.03</td>
</tr>
<tr>
<td>Depression (HAD)</td>
<td>5.50 (3.40)</td>
<td>6.00 (3.15)</td>
<td>0.70</td>
<td>ns</td>
</tr>
<tr>
<td>Somatization (Hopkins)</td>
<td>24.71 (8.53)</td>
<td>27.45 (8.09)</td>
<td>3.59</td>
<td>ns</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>25.35 (2.66)</td>
<td>24.04 (2.65)</td>
<td>7.88</td>
<td>0.007</td>
</tr>
<tr>
<td>Negative feelings towards the womb</td>
<td>39.99 (13.84)</td>
<td>44.89 (13.54)</td>
<td>4.12</td>
<td>0.04</td>
</tr>
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</table>

ns=not significant
### Table 33: Relationship between type of abuse and non-abuse and type of treatment desired (N=156)

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>NON-ABUSED</th>
<th>ABUSED</th>
<th>Chi-square</th>
<th>p=.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHILD SEXUAL ABUSE</td>
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<tr>
<td>N=123</td>
<td>N=33</td>
<td>4.67</td>
<td>ns</td>
<td></td>
</tr>
<tr>
<td>Exploratory</td>
<td>43</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>37</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>34</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILD PHYSICAL ABUSE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>N=114</td>
<td>N=42</td>
<td>0.26</td>
<td>ns</td>
<td></td>
</tr>
<tr>
<td>Exploratory</td>
<td>44</td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>35</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>6</td>
<td>29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>3</td>
<td>11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ns=not significant

### Table 34: Relationship between type of abuse and non-abuse and type of treatment desired (N=156)

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>NON-ABUSED</th>
<th>ABUSED</th>
<th>Chi-square</th>
<th>p=.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADULT SEXUAL ABUSE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=113</td>
<td>N=43</td>
<td>7.74</td>
<td>ns</td>
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<tr>
<td>Exploratory</td>
<td>38</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>35</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>5</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>35</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADULT PHYSICAL ABUSE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=147</td>
<td>N=9</td>
<td>1.62</td>
<td>ns</td>
<td></td>
</tr>
<tr>
<td>Exploratory</td>
<td>54</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>46</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>38</td>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ns=not significant
Relationship of anxiety, depression, somatization and hypochondriasis to type of treatment desired

The results of one-way analyses of variance in Table 35 (page 180) shows that there was no difference according to the type of treatment patients desired (exploratory investigation, drugs, endometrial resection and hysterectomy) on levels of anxiety, somatization, hypochondriasis. However, patients who desired a hysterectomy were more depressed (F=4.30; p=<.01; d.f.=3,152) than those who desired an exploratory investigation or drugs. They also reported more negative feelings towards their womb (F=5.73; p=<.001; d.f.=3,152). Post hoc analyses by Least Significant Difference (LSD) (p<.05) showed that patients who desired a hysterectomy much higher levels of depression than patients who desired an exploratory investigation or drugs. Additionally, post hoc analyses by Least Significant Differences (LSD) also revealed that patients in the hysterectomy group had more negative feelings towards their womb compared to those patients who desired other treatments.

Menstrual symptoms and treatment desired

One-way analyses of variance (F=2.59; p=<.05; d.f.=3,152) indicated that patients who desired a hysterectomy experienced greater menstrual pain when their periods first started than patients who desired drugs or endometrial resection (see Table 36, page 181) and post hoc analyses by Least Significant Difference (LSD) (p<.05) confirmed that patients in the hysterectomy group differed from patients who desired endometrial resection and patients who desired an exploratory investigation. One-way analyses of variance showed there was no difference
in menstrual blood loss between groups desiring different treatments. One-way analyses of variance (F=4.25; d.f.=3,152; p=<.01) showed there was a significant difference between patients who desired different treatments in their severity of current menstrual blood loss. Post hoc analyses (p<.05) revealed that patients who desired endometrial resection reported heavier menstrual blood loss than patients who desired an exploratory investigation. Furthermore, patients who desired hysterectomy reported that their current menstrual blood loss was heavier than patients who desired drugs or an exploratory investigation. When patients' desire for a particular treatment was compared to how they rated the severity of their menstrual symptoms to other women no differences were indicated.

Relationship of predictor variables to outcome expectations of treatment

Child and Adult sexual and physical abuse

Table 37 (page 182) shows that one-way analyses of variance yielded few significant differences between patients who were either sexually or physically abused in childhood and those patients with no such experiences. Physically abused patients had greater expectations of an improvement in sexual function (F=4.39; d.f.=1,155; p=<.04) than non-abused patients. There were no significant differences between adult sexual and physical abused patients and non-abused patients (see Table 38, page 183).
Menstrual symptoms and outcome expectations of treatment

Apart from harm and bowel function, past and present menstrual pain was shown by Pearson product moment correlations to be positively related to all the other dimensions of outcome expectations of treatment. No relationship was found between any of the outcome expectations of treatment and early childhood menstrual blood loss. However, current menstrual blood loss was positively related to expectations for improvements in womb function, wellbeing, menstruation, physical symptoms and sex function. See Table 39, below.

Because menstrual symptoms and depression were significantly correlated with patients outcome expectations of treatment (see Table 30, page 171 and Table 39, below) forward stepwise multiple regression was used to examine which of the predictor variables (menstrual symptoms or depression) explained significant variance for patients outcome expectations of treatment (wellbeing, womb function, menstruation, physical symptoms and sexual function).

Table 39: Correlations between Outcome Expectations of treatment and menstrual symptoms (N=156)

<table>
<thead>
<tr>
<th></th>
<th>Womb</th>
<th>Wellbeing</th>
<th>Menstruation</th>
<th>Harm</th>
<th>Physical symptoms</th>
<th>Sex</th>
<th>Bowels</th>
</tr>
</thead>
<tbody>
<tr>
<td>MENSTRUAL PAIN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(when periods first started)</td>
<td>.20***</td>
<td>.22***</td>
<td>.27*</td>
<td>.20***</td>
<td>.25*</td>
<td>.18**</td>
<td></td>
</tr>
<tr>
<td>MENSTRUAL PAIN (now)</td>
<td>.36*</td>
<td>.24*</td>
<td>.19**</td>
<td>.36*</td>
<td>.22***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MENSTRUAL BLOOD LOSS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(when periods first started)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MENSTRUAL BLOOD LOSS (now)</td>
<td>.25*</td>
<td>.24**</td>
<td>.43*</td>
<td>.25*</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

The results indicate that depression (7%) explained significant variance in patients positive expectations of wellbeing after allowing for past and current...
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

menstrual pain (3% and 3%, respectively), but it did not account for significant variance where womb function was concerned. Current menstrual pain explained 13% of the variance and depression accounted for 4% of the variance.

Depression did not significantly explain variance on patients' outcome expectations of improvement in (1) menstruation (2) physical symptoms and (3) sexual function. Considering each of these factors in turn (1) the combined effect of current menstrual blood (19%) and past menstrual pain (5%) accounted for 24% of the variance, (2) the combined effect of current menstrual pain (13%) and current menstrual blood loss (2%) explained 15% of the variance (3) the combined effect of past menstrual pain (6%) and current menstrual pain (3%) explained 9% of the variance.

Overall the results in Table 40 indicate that current menstrual symptoms appear to have a greater influence on patients outcome expectations of treatment than depression.

Table 40: Regression analyses of predictor variables (depression and menstrual symptoms) for outcome expectations of treatment (N=156)

<table>
<thead>
<tr>
<th>Variables</th>
<th>R</th>
<th>R square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>WELL BEING</td>
<td>0.13</td>
<td>0.02***</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.20</td>
<td>0.04**</td>
<td>2.02</td>
</tr>
<tr>
<td>Menstrual pain (1)</td>
<td>0.17</td>
<td>0.03*</td>
<td>1.20</td>
</tr>
<tr>
<td>Menstrual pain (2)</td>
<td>0.16</td>
<td>0.03*</td>
<td>1.20</td>
</tr>
<tr>
<td>WOMB FUNCTION</td>
<td>0.17</td>
<td>0.03*</td>
<td>1.20</td>
</tr>
<tr>
<td>Menstrual pain (1)</td>
<td>0.32</td>
<td>0.10***</td>
<td>6.82</td>
</tr>
<tr>
<td>Depression</td>
<td>0.19</td>
<td>0.04**</td>
<td>1.56</td>
</tr>
<tr>
<td>MENSTRUATION</td>
<td>0.24</td>
<td>0.06**</td>
<td>1.94</td>
</tr>
<tr>
<td>Menstrual blood loss (1)</td>
<td>0.41</td>
<td>0.17***</td>
<td>1.00</td>
</tr>
<tr>
<td>Menstrual pain (2)</td>
<td>0.23</td>
<td>0.06**</td>
<td>1.56</td>
</tr>
<tr>
<td>PHYSICAL SYMPTOMS</td>
<td>0.15</td>
<td>0.02*</td>
<td>1.20</td>
</tr>
<tr>
<td>Menstrual pain (1)</td>
<td>0.32</td>
<td>0.10***</td>
<td>6.82</td>
</tr>
<tr>
<td>Menstrual Blood (1)</td>
<td>0.13</td>
<td>0.02*</td>
<td>1.20</td>
</tr>
<tr>
<td>SEXUAL FUNCTION</td>
<td>0.08</td>
<td>0.00**</td>
<td>1.20</td>
</tr>
<tr>
<td>Menstrual pain (1)</td>
<td>0.21</td>
<td>0.04**</td>
<td>1.20</td>
</tr>
<tr>
<td>Menstrual pain (2)</td>
<td>0.18</td>
<td>0.03*</td>
<td>1.20</td>
</tr>
</tbody>
</table>

*p < 0.05  **p < 0.01  ***p < 0.001
Table 35: Relationship of anxiety, depression, somatization, hypochondriasis and negative feelings towards the womb to type of treatment desired by one-way analysis of variance (mean scores and standard deviations) (N=156)

<table>
<thead>
<tr>
<th></th>
<th>MEAN (SD)</th>
<th>F ratio</th>
<th>p&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ANXIETY</strong></td>
<td>N=156</td>
<td>0.67</td>
<td>ns</td>
</tr>
<tr>
<td>Exploratory</td>
<td>9.05 (3.87)</td>
<td></td>
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</tr>
<tr>
<td>Drugs</td>
<td>9.90 (4.12)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>10.78 (2.86)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>9.55 (4.64)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DEPRESSION</strong></td>
<td>N=156</td>
<td>4.30</td>
<td>0.006</td>
</tr>
<tr>
<td>Exploratory</td>
<td>4.72 (3.23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>5.58 (3.31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>5.66 (2.35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>7.10 (3.29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SOMATIZATION</strong></td>
<td>N=156</td>
<td>1.81</td>
<td>ns</td>
</tr>
<tr>
<td>Exploratory</td>
<td>23.98 (8.26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>26.65 (7.67)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>22.67 (7.71)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>27.07 (9.04)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HYPOCHONDRIASIS</strong></td>
<td>N=156</td>
<td>0.23</td>
<td>ns</td>
</tr>
<tr>
<td>Exploratory</td>
<td>17.50 (2.94)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>17.29 (2.44)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td>17.22 (2.27)</td>
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<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>17.05 (2.67)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NEGATIVE FEELINGS TOWARDS THE WOMB</strong></td>
<td>N=156</td>
<td>5.73</td>
<td>0.001</td>
</tr>
<tr>
<td>Exploratory</td>
<td>43.54 (14.62)</td>
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<tr>
<td>Drugs</td>
<td>43.10 (14.03)</td>
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<td></td>
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<tr>
<td>Endometrial resection</td>
<td>39.11 (12.00)</td>
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<tr>
<td>Hysterectomy</td>
<td>53.70 (14.83)</td>
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</tr>
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</table>

ns=not significant
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

Table 36: Relationship of menstrual symptoms to type of treatment desired by one-way analysis of variance (mean scores and standard deviations) (N=156)

<table>
<thead>
<tr>
<th>Symptom Description</th>
<th>N=156</th>
<th>MEAN (SD)</th>
<th>F ratio</th>
<th>p=&lt;0.05</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MENSTRUAL PAIN (when periods first started)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploratory</td>
<td></td>
<td>3.25 (1.34)</td>
<td>2.59</td>
<td>0.05</td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td>2.93 (1.31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td></td>
<td>2.55 (1.13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td></td>
<td>3.60 (1.34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MENSTRUAL PAIN (now)</strong></td>
<td></td>
<td></td>
<td>2.22</td>
<td>ns</td>
</tr>
<tr>
<td>Exploratory</td>
<td></td>
<td>3.52 (1.19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td>3.77 (1.06)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td></td>
<td>3.33 (1.11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td></td>
<td>4.05 (0.99)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MENSTRUAL BLOOD LOSS (when periods first started)</strong></td>
<td></td>
<td></td>
<td>0.75</td>
<td>ns</td>
</tr>
<tr>
<td>Exploratory</td>
<td></td>
<td>3.32 (1.07)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td>3.04 (0.94)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td></td>
<td>3.33 (0.50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td></td>
<td>3.20 (0.99)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MENSTRUAL BLOOD LOSS (now)</strong></td>
<td></td>
<td></td>
<td>4.25</td>
<td>0.007</td>
</tr>
<tr>
<td>Exploratory</td>
<td></td>
<td>3.93 (0.92)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td>4.13 (1.00)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td></td>
<td>4.66 (0.71)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td></td>
<td>4.53 (0.82)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MENSTRUAL SYMPTOMS (compared to other women)</strong></td>
<td></td>
<td></td>
<td>1.79</td>
<td>ns</td>
</tr>
<tr>
<td>Exploratory</td>
<td></td>
<td>3.75 (0.86)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td>3.97 (1.06)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td></td>
<td>4.00 (1.00)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td></td>
<td>4.18 (0.78)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ns=not significant
**Table 37: Childhood Abuse: Differences between abused/non-abused patients on outcome expectations of treatment by one-way analysis of variance (mean scores and standard deviations) (N=156)**

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>MEAN (SD) (non-abused)</th>
<th>MEAN (SD) (abused)</th>
<th>F ratio</th>
<th>p=&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CHILD SEXUAL ABUSE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Womb</td>
<td>18.71 (6.28)</td>
<td>18.94 (5.63)</td>
<td>0.04</td>
<td>ns</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>47.02 (9.75)</td>
<td>47.82 (9.56)</td>
<td>0.18</td>
<td>ns</td>
</tr>
<tr>
<td>Harm</td>
<td>21.56 (6.92)</td>
<td>22.33 (7.16)</td>
<td>0.32</td>
<td>ns</td>
</tr>
<tr>
<td>Menstruation</td>
<td>15.57 (4.10)</td>
<td>16.03 (2.88)</td>
<td>0.37</td>
<td>ns</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>23.33 (7.84)</td>
<td>22.88 (7.05)</td>
<td>0.09</td>
<td>ns</td>
</tr>
<tr>
<td>Sex</td>
<td>6.24 (2.07)</td>
<td>6.49 (2.10)</td>
<td>0.37</td>
<td>ns</td>
</tr>
<tr>
<td>Bowels</td>
<td>5.39 (2.19)</td>
<td>5.39 (2.26)</td>
<td>0.00</td>
<td>ns</td>
</tr>
<tr>
<td><strong>CHILD PHYSICAL ABUSE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Womb</td>
<td>18.36 (6.05)</td>
<td>19.83 (6.28)</td>
<td>1.78</td>
<td>ns</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>46.46 (9.22)</td>
<td>49.17 (10.58)</td>
<td>2.45</td>
<td>ns</td>
</tr>
<tr>
<td>Harm</td>
<td>21.23 (6.66)</td>
<td>23.05 (7.62)</td>
<td>2.09</td>
<td>ns</td>
</tr>
<tr>
<td>Menstruation</td>
<td>15.67 (3.87)</td>
<td>15.67 (3.92)</td>
<td>0.00</td>
<td>ns</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>22.69 (7.76)</td>
<td>24.69 (7.25)</td>
<td>2.10</td>
<td>ns</td>
</tr>
<tr>
<td>Sex</td>
<td>6.07 (2.12)</td>
<td>6.86 (1.87)</td>
<td>4.39</td>
<td>.04</td>
</tr>
<tr>
<td>Bowels</td>
<td>5.25 (2.16)</td>
<td>5.79 (2.29)</td>
<td>1.86</td>
<td>ns</td>
</tr>
<tr>
<td><strong>CHILD SEXUAL &amp; PHYSICAL ABUSE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Womb</td>
<td>18.40 (6.35)</td>
<td>19.36 (6.35)</td>
<td>0.90</td>
<td>ns</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>46.90 (9.19)</td>
<td>47.67 (10.44)</td>
<td>0.23</td>
<td>ns</td>
</tr>
<tr>
<td>Harm</td>
<td>21.29 (6.74)</td>
<td>22.47 (7.30)</td>
<td>1.05</td>
<td>ns</td>
</tr>
<tr>
<td>Menstruation</td>
<td>15.59 (4.05)</td>
<td>15.79 (3.59)</td>
<td>0.10</td>
<td>ns</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>23.00 (7.83)</td>
<td>23.62 (7.42)</td>
<td>0.24</td>
<td>ns</td>
</tr>
<tr>
<td>Sex</td>
<td>6.13 (2.16)</td>
<td>6.55 (1.93)</td>
<td>1.48</td>
<td>ns</td>
</tr>
<tr>
<td>Bowels</td>
<td>5.28 (2.16)</td>
<td>5.58 (2.28)</td>
<td>0.72</td>
<td>ns</td>
</tr>
</tbody>
</table>

ns = not significant
Table 38: Adult Abuse: Differences between abused/non-abused patients on outcome expectations of treatment by one-way analysis of variance (mean scores and standard deviations) (N=156)

<table>
<thead>
<tr>
<th>ABUSE</th>
<th>MEAN (SD) (non-abused)</th>
<th>MEAN (SD) (abused)</th>
<th>F ratio p =&lt; .05</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADULT SEXUAL ABUSE N=113 N=43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Womb</td>
<td>18.95 (6.29)</td>
<td>18.25 (5.73)</td>
<td>ns</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>46.50 (10.22)</td>
<td>49.00 (7.76)</td>
<td>ns</td>
</tr>
<tr>
<td>Harm</td>
<td>21.82 (6.92)</td>
<td>21.47 (7.13)</td>
<td>ns</td>
</tr>
<tr>
<td>Menstruation</td>
<td>15.73 (4.87)</td>
<td>15.49 (3.35)</td>
<td>ns</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>23.30 (7.80)</td>
<td>23.05 (7.26)</td>
<td>ns</td>
</tr>
<tr>
<td>Sex</td>
<td>6.14 (2.17)</td>
<td>6.67 (1.80)</td>
<td>ns</td>
</tr>
<tr>
<td>Bowels</td>
<td>5.46 (2.19)</td>
<td>5.20 (2.24)</td>
<td>ns</td>
</tr>
<tr>
<td>ADULT PHYSICAL ABUSE N=147 N=9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Womb</td>
<td>18.79 (6.13)</td>
<td>18.22 (6.36)</td>
<td>0.07 ns</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>47.31 (9.65)</td>
<td>45.11 (10.13)</td>
<td>0.44 ns</td>
</tr>
<tr>
<td>Harm</td>
<td>21.63 (6.89)</td>
<td>23.22 (8.23)</td>
<td>0.44 ns</td>
</tr>
<tr>
<td>Menstruation</td>
<td>15.69 (3.91)</td>
<td>15.33 (3.20)</td>
<td>0.07 ns</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>23.39 (7.54)</td>
<td>20.67 (9.58)</td>
<td>1.07 ns</td>
</tr>
<tr>
<td>Sex</td>
<td>6.33 (2.05)</td>
<td>5.55 (2.46)</td>
<td>1.19 ns</td>
</tr>
<tr>
<td>Bowels</td>
<td>5.43 (2.17)</td>
<td>4.78 (2.68)</td>
<td>0.74 ns</td>
</tr>
<tr>
<td>ADULT SEXUAL &amp; PHYSICAL ABUSE N=110 N=46</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Womb</td>
<td>18.87 (6.27)</td>
<td>18.47 (5.83)</td>
<td>0.13 ns</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>46.49 (10.11)</td>
<td>48.85 (8.29)</td>
<td>1.95 ns</td>
</tr>
<tr>
<td>Harm</td>
<td>21.75 (6.86)</td>
<td>21.65 (7.25)</td>
<td>0.01 ns</td>
</tr>
<tr>
<td>Menstruation</td>
<td>15.70 (4.10)</td>
<td>15.59 (3.32)</td>
<td>0.03 ns</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>23.15 (7.78)</td>
<td>23.43 (7.44)</td>
<td>0.05 ns</td>
</tr>
<tr>
<td>Sex</td>
<td>6.14 (2.18)</td>
<td>6.65 (1.79)</td>
<td>2.01 ns</td>
</tr>
<tr>
<td>Bowels</td>
<td>5.41 (2.17)</td>
<td>5.35 (2.29)</td>
<td>0.03 ns</td>
</tr>
</tbody>
</table>

ns = not significant
Discussion

Over twenty-one per cent of patients reported sexual abuse before the age of 13 and twenty per cent of patients reported it after 13 years old. This is considerably higher than the MORI survey which reports a 12% prevalence rate of sexual abuse in females before age 16 (Baker & Duncan, 1985). Interestingly, in this survey the definition of abuse was similar to Drossman's et al (1990) definition of abuse, it involved 'exposure,' 'touching' and showing pornographic material or talking about sexual things in an erotic way. In a New Zealand study the prevalence of sexual and physical abuse before age 12 was 20%, with 13% reporting genital contact or greater (Mullen et al, 1988). Estimates of sexual and physical abuse in the general population vary greatly mainly because of the problem of definition. Given that the present study has used a rigid definition of sexual abuse which focused on 'contact' the level of abuse reported are exceptionally high.

The main finding of the present study is that patients who have experienced either sexual or physical abuse report higher levels of anxiety, depression and somatization and more negative feelings towards their womb than non-abused patients. These findings are in line with those from Ferber (1993) who found that patients who were sexually and physically abused in childhood manifested higher rates of depression than non-abused patients and Sedney & Brooks (1984) who reported higher levels of anxiety and depression among abused females than non-abused controls. Numerous studies (e.g. Pascoe, 1979; Furniss, Bingley-Miller & Bentovin, 1984; Felic, Grant, Reynolds et al, 1978) have reported that somatic symptoms are often reactions shown by abused children, while other
researchers (e.g. Arnold, Rogers & Cook, 1990) have indicated that patients who have experienced child sexual abuse were receiving psychiatric treatment and as a result of somatization most of these patients had investigations and interventions in gynaecology. Additionally, Reiter, Shakerin, Gambone & Milburn (1991) indicated that the psychosocial profile of women with non-somatic pain differs from that of women with somatic pelvic pain and that previous sexual abuse was a significant predisposing risk for somatization and non-somatic chronic pelvic pain. Similarly, Harrop-Griffiths, Katon, Walker, Holm, Russo & Hickok (1988) study indicated that compared with the control group, the patients with chronic pelvic pain showed significantly greater prevalence of lifetime major depression, current major depression, adult sexual dysfunction and somatization. They were also more likely than the control group to have experienced childhood and adulthood sexual abuse. Since somatization is often associated with depression and anxiety (Kirmayer, 1984) and an absence of pathology, it could be interpreted as a type of defence mechanism (Ford, 1983) particularly where sexual/physical abuse is concerned.

The fact that sexually and physically abused patients had higher negative feelings towards their womb than non-abused patients, tends to support Menninger's (1939) argument that rejection of the female part of themselves (e.g. the womb) is dependent on a deep-lying hostility which in effect is directed towards men. However, following this argument it might be expected that they would want to rid themselves of this offensive organ. But abused patients did not seek a hysterectomy as predicted.
Influences on Patients' Expectations of Treatment and Desire for Hysterectomy

The prediction that patients with a history of sexual and physical abuse would desire a hysterectomy more than non-abused patients was not supported. In fact, most of the abused patients desired an exploratory investigation. Few findings supported the suggestion that abused and non-abused patients had different outcome expectations of hysterectomy. Patients who had experienced childhood physical abuse had much higher expectations of an improvement in sexual function as a result of treatment than non-abused patients.

Patients who desired a hysterectomy reported greater menstrual pain at the menarche than patients who desired drugs or endometrial resection. Also patients who desired hysterectomy reported heavier recent blood loss than patients who desired drugs or endometrial resection. Menstrual symptoms, particularly menstrual pain, was found to be a strong influence on patients outcome expectations of treatment, particularly in the domain of womb function (e.g. relief from pre-menstrual/menstrual pain and pain in general), physical symptoms (e.g. painful breasts, pain and discomfort after sex and headaches) and sexual function (more interest and enjoyment in sex) whereas depression had little or no influence. This finding suggests that it is the severity of patients' menstrual symptoms that lead them to have certain positive expectations of treatment. Interestingly, of the patients in this study who had a hysterectomy, fifty per cent were found to have a healthy uterus. Other studies have also shown that often hysterectomies are performed in the absence of confirmed pathology which can result in the removal of a healthy uterus (Amirikia & Evans; Grant & Hussein, 1984: Pokras & Hufnagel, 1988).
There was no association between menstrual pain and sexual abuse. However, the abused patients in the present sample expected, as a result of treatment, an improvement in sexual function whereas the non-abused patients did not, which might suggest they may have been suffering from sexual dysfunction. But, as no measure of sexual dysfunction was taken in this study, this assumption is mere speculation.

Depression had a stronger influence on gynaecological patients positive expectations of wellbeing than menstrual pain. Many studies (e.g. Greenberg, 1983) have found women attending gynaecology clinics often suffer from depression which might explain why they have high expectations of wellbeing (e.g. less depression, fatigue, irritability, more active and a better social life). Some researchers (e.g. Dennerstein et al, 1986) have proposed that psychological state can affect hormone levels in the ovary thus altering the endometrium and muscles of the uterus which could cause an increase menstrual pain or heavy menstrual blood loss. Therefore invasive treatment for an emotional problem would be unsuitable.

Furthermore, it has also been shown that several factors such as the severity of menstrual symptoms distinguish people who seek hysterectomy. Moreover, it emerged that women who desire hysterectomy expect higher positive benefits on most of the outcome dimensions of treatment (wellbeing, womb, menstruation, physical symptoms and sex) and they\(^\text{12}\) also have higher expectations of harm than patients who desire an exploratory investigation or endometrial resection. This

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\(^{12}\)The patients in the drug group also had high expectations of harm.
supports the findings reported in both study 1 and study 2.

Conclusion
The present study supports the findings of previous studies linking childhood and adulthood sexual abuse with high levels of somatization and depression. Although a range of somatic consequences have begun to be identified among abuse victims, the need continues for studies with control groups and broad based studies (Bachmann et al, 1988). Sexual abuse is a difficult topic to study mainly because of the social stigma and embarrassment attached to it and because much of the material is retrospective. Long-term consequences of childhood sexual abuse are little described in the medical literature and poorly understood and often not reported by patients (Felitti, 1991).

This study has offered answers to the questions that it was designed to answer insomuch that it has been shown that there are several influences that may explain why women desire certain gynaecological treatments. This confirms that medical and surgical treatment for menstrual problems is often not based on objective evidence but rather on a woman's subjective view of her symptoms. Therefore it is important to understand how patients engage doctors in the management of their menstrual symptoms and how decisions are made about their treatment. The next study will explore the negotiation of treatment between doctor and patient.
"The end for which we live is a certain kind of activity, not a quality. Character gives us qualities, but it is in our actions - what we do - that we are happy or the reverse."

Aristotle (384-322 B.C.)

"The Society advocates a policy of full and proper communication with patients. In circumstances where complications or errors arise, it is proper that objective factual information, with appropriate clinical reassurance, is provided. Adequate explanation, ideally from the responsible consultant or principal, assists in reducing fear and uncertainty which may give rise to complaints and claims. The Society does not encourage members to withhold objective factual information."

The Medical Protection Society (1990)
CHAPTER FIVE

THE NEGOTIATION OF TREATMENT BETWEEN DOCTOR AND PATIENT

Abstract

This study examined how gynaecologists negotiate with patients presenting with dysmenorrhoea or menorrhagia after they have undergone an investigative procedure, in five general hospitals in the U.K. The study was conducted in two stages. The first involved a qualitative analysis of audio-taped consultations with the aim of identifying the ways that gynaecologists' and patients' influence are exercised and the ways in which they are negotiated. In the second, a coding system was devised on the basis of this analysis and allowed quantitative testing of specific hypotheses about the way that patients who were recommended hysterectomy presented their problems differently from others. It was found that patients who were assigned hysterectomy had employed different strategies in their negotiation for treatment than the non-hysterectomy patients. They did this by introducing another 'expert' such as a G.P. to support their own suggestion for treatment. They catastrophized about their menstrual symptoms and criticized the failure of other treatments they had already experienced. The gynaecologists reported that patients' influence on the consultation was greater than in those recommended hysterectomy than in others.
Introduction

The earlier studies in this thesis have shown what kind of treatment patients with menstrual problems anticipate when they attend gynaecological outpatient clinics. These studies have also indicated patients’ outcome expectations of certain treatments. Patients who expect hysterectomy have high positive expectations of the beneficial effects of this operation, but they also have high expectations of harm compared to patients who expect other gynaecological treatments. Findings in Chapter 4 revealed that patients who ‘desire’ hysterectomy have higher expectations of benefit and harm than patients who desire other treatments. These findings were also found in study 1 and 2. Additionally these patients show higher levels of depression and more negative feelings towards their womb than patients who do not desire hysterectomy. In study 3 it was found that hysterectomy was recommended in the absence of confirmed pathology. Following this procedure, fifty per cent of patients were found to have a healthy uterus. This suggests that subjective, psychological characteristics of patients distinguish those who go on to have a hysterectomy. Putting this together with the evidence of extremely high expectations of hysterectomy, the question then arises as to whether and how women communicate these subjective characteristics to as to seek a hysterectomy.

The present study changes the focus from the previous studies by investigating some of the ways in which patients negotiate for treatment in their consultations with gynaecologists. These doctor-patient interactions are of particular importance because many of these encounters lead to hysterectomy. As discussed earlier Chapter 1, the majority of hysterectomies are carried out as a
result of such interactions rather than being based on demonstrable pathology (Chimbira, Anderson & Turnbull, 1980; Fraser, McCarron, Markham, Resta & Watts, 1986).

**The hysterectomy decision**

Because of the serious implications of hysterectomy, both for patients and for the NHS, it is important to understand its rise in popularity. This is, however, not a simple issue for a number of reasons. Chapter 1 indicated that only a small proportion of hysterectomies (less than 10%; Coulter and McPherson, 1986) are performed in the presence of clear organic pathology, the majority are performed for benign conditions (Amirikia and Evans, 1979; Pokras and Hufnagel, 1988) such as menorrhagia and dysmenorrhoea. It was also reported in Chapter 1 that a subjective report of blood loss bears little relation to true blood loss (Hallberg et al, 1966; Fraser et al, 1984) and objective evidence of menorrhagia is usually also missing (Fraser et al, 1986). It is clear that high levels of emotional distress, and even psychopathology, characterize women who attend gynaecological clinics with menstrual symptoms (Hunter, 1990). *See introduction to the thesis and Chapter 1.*

Some researchers (e.g. Hunter, 1990) suggest that, in a proportion of such cases, the presentation of gynaecological symptoms represents somatization of psychological distress. As a result, hysterectomy may often be an inappropriate, somatic treatment for an emotional problem. There is also a popular view (e.g. Daly, 1991) that high levels of hysterectomy represent doctors (males) exerting
power over female patients while the complexity of patients' subjective symptoms are often neglected. But it is also possible that gynaecologists' agreement to operate is the result of their patients' own insistence on hysterectomy and reflects the extent to which a patient is able to influence the gynaecologist's decision by presenting inherently subjective symptoms (see Shorter, 1992).

Methodological problems

Empirical investigation (e.g. Waitzkin & Stoeckle, 1972; Waitzkin, 1979) into doctor-patient interaction have shown that these interactions are often filled with misunderstandings, insensitivity, and frustration (Waitzkin, 1984). Poor communication between doctor and patient often arises because of differences in class, sex and usage of medical jargon and a failure to share information. These studies have used a wide range of techniques to examine doctor-patient encounters. Samples have varied in size and in location. Some investigations have used general practitioners' surgeries, others have used hospital settings (state and private) and have included consultants, registrars and junior doctors. In some studies the sex and age and ethnic origin of the doctors (and patients) and researchers have been omitted. Communication has been investigated through retrospective questionnaires, video-recordings, audio-recordings and analyzed either quantitatively and/or qualitatively. Each method employed has its own strengths and weaknesses (Waitzkin & Stoeckle, 1972) and essentially these studies as a whole have emphasized the enormous difficulties that arise in doctor-patient interactions (Waitzkin, 1984). In order to fully understand medical encounters they must be evaluated in a historical, medical, psychological and
sociological framework. Those who have examined doctor-patient encounters in the context of social control have mainly relied on anecdotal accounts (Ehrenreich & English, 1973; Harrington, 1975; Zola, 1975) and many empirical investigations have neglected contextual material. Finally, those theoretical studies that critically evaluate medical encounters have often lacked empirical substantiation (Waltzkin, 1984).

Satisfaction

The majority of research on doctor-patient communication has been concerned with satisfaction. Several studies have attempted to evaluate the extent to which patients are satisfied with the health care that they receive and to identify the factors which influence patients views (Fitzpatrick and Hopkins, 1981). Kincey, Bradshaw and Ley (1975) reported that patients were not satisfied with their G.P.'s communication, for example with regard to aetiological information. Other studies (e.g. Locker & Dunt, 1978; Ley, 1976) have tried to explain this dissatisfaction in terms of patient characteristics such as age, sex, education, social class and personality factors (cited in Fitzpatrick & Hopkins, 1981). In general these findings have been inconsistent.

Numerous reports have shown that patients experiencing high levels of psychological distress are less satisfied with medical services than patients who are not distressed (Greenley, Young and Schoenherr, 1982). Yet other investigations have not confirmed these associations (e.g. Ware, Allyson, and Stewart. 1978; Ware, Synder, and Wright, 1976). Other criticisms of the doctor-
patient relationship have concerned the doctors' inapproachability and lack of explanations regarding investigations that patients have undergone (Ley, 1983). Golden and Johnston (1970) tape-recorded 25 doctor-patient interactions where doctors gave important information to hospitalized patients about the results of diagnostic tests or the need for surgery. After the consultation had finished, the patients were asked to tell the researcher the content of their conversation with the physician. Nearly fifty per cent of the patients misconstrued what they had been told. Most of these misconstructions resulted from insufficient explanations by the doctor. Only one doctor had bothered to check that the patient had understood what had been said (Freidman & D'Matteo, 1989).

**Power**

Although not the focus of so much quantitative research, it is crucial to understanding how decisions are reach. The medical and psychological literature suggests that power in doctor-patient interactions rests with the doctor who has a 'social monopoly of expertise and knowledge' (Turner, 1987) and so can maintain medical control. Freidson (1971:28) stated "Knowledge itself does not give special power: only exclusive knowledge gives power to its possessors."

Haug (1975) adds, "the claimed monopoly of the professional over an area of expertise is productive of the aura of mystery which haloes professional tasks and of the myths about their difficulty and effectiveness." Because doctors have professional autonomy it means that when they deal directly with patients they can make decisions or judgements about practice without instructions or interferences from any superordinate power (Haug, 1975). Moreover, this
autonomy means power can be exerted over subordinates, especially the patients, who, impressed by superior knowledge and trusting in good intentions, obey. In the past the lack of a systematic evaluation of medical technique made it difficult to demonstrate medical incompetence, and the occasional expulsion of deviants, who broke the medical code of practice, served to uphold the basic integrity of the profession as a whole (Hart, 1985). Such a power structure led Illich (1976) to suggest that "the medical establishment has become a major threat to health...... medical monopoly over health care has expanded without checks and has encroached on our liberty with regard to our own bodies." Moreover, when a patient attempted to challenge the doctor's view s/he risked being considered deviant or neurotic. With recent changes in the health care system and with the growth of consumerism supported by such devices as The Patient's Charter, informed consent, and the demand for a sharing of information about illness between doctor and patient, the autonomy of the medical profession is being questioned.

In most medical encounters doctors have control simply because of their expertise and knowledge. However, Johnson (1972) suggests that only by sharing wider sources of power, namely membership in a dominant class, can occupations enforce their "own definitions of the producer-consumer relationship," as occurs with the professions (cited in Haug, 1976). Becker (1962) states that even in medicine, "clients continually make judgements about the work and capabilities of the professionals they use. Medical patients often change doctors...."

Patients may be influential in the outcome of the consultation through careful negotiation. This can be done in a number of ways. In a single case study, Salmon & May (1995) described how a female patient with no demonstrable
pathology continually complained of breast pain, exerted considerable power in a consultation with a doctor by presenting her problems in a way that resulted in a mastectomy. Bloor (1977) demonstrated other strategies used in consultations in a study of parents and specialists in ear, nose and throat (ENT) clinics where parents consistently referred to the G.P.’s diagnosis, and the G.P.’s recommendations that tonsillectomy might be necessary - rather than directly stating their opinion that their child’s tonsils require removal. The strategy was that the consultant was more likely to be impressed by the doctor’s opinion than by that of the patient. To convince themselves that their course of action is better, doctors may provide evidence in the form of laboratory tests, or even their own previous experience in treating patients with similar types of condition, additionally warning of the likely consequences of neglecting their advice (Bloor, 1977). Although there might be differences of opinion concerning treatment, often a compromise is reached.

Managing consultations

In managing consultations with patients, doctors, either deliberately or unwittingly, use a particular style or manner of conducting interviews (Locker, 1986). Analyzing doctor-patient interviews has revealed several distinct styles of communication (Plaja & Cohen (1986) cited in Locker, 1986). The most common approach identified has been described as ‘bureaucratic, task-oriented’, featuring efficient questioning, little sensitivity to the patient and variation from patient to patient. Most patients responded to this approach with matter-of-fact collaboration, answering questions but making little attempt at broadening the
dialogue. Plaja & Cohen (1968) found that 'a person oriented' style (in which empathy and awareness of patients' feelings were essential to the interaction) was only apparent in a few of the doctors in their study. These results were supported by a study conducted by Byrne & Long (1976) who examined 2500 interviews conducted by 60 general practitioners. Numerous styles of doctor-patient interaction emerged from this analysis ranging from 'doctor centred' to 'patient centred'. Three quarters of the interviews were doctor-centred in which doctors used information-gathering or analyzing and probing plus clarifying and interpreting techniques. Using these types of interviewing techniques denies patients' emotions and worries since doctors are mainly concerned with physical symptoms. These series of studies suggest that doctors follow the traditional biomedical model (Locker, 1986) in which the doctor takes a history, performs examinations and investigations, and makes a diagnosis in order to prescribe treatment (Butler, Campion & Cox, 1992). Doctors adopting this type of approach tend to withhold information from patients (Locker, 1986). However, doctors adopting a patient-centred approach may also use the biomedical model. Additionally they acknowledge that they could have specific ideas about the causes of their illness and expectations of the interaction, and that people may react in different ways to similar disease states (Morgan, 1991). Thus, these doctors pay greater attention to eliciting patients' ideas, feelings and expectations and integrating this with their own disease-centred anxieties. By applying this technique doctors may also focus on the psycho-social aspects of illness regarding its possible social origins and to patients' experience of anxiety, depression and other emotional problems (Morgan, 1991).
Roles of doctor and patient

In most situations in life people act out roles according to their environment, e.g. a hospital has the roles of administrator, consultant, doctor, nurse and porter. Each role carries with it certain expectancies of behaviour. Some roles carry more power than others. Thus assumptions about the role of the participants can influence the course of the interaction (Thompson, 1984). Parsons (1951) identified the roles of doctor and patient in his ideal type model. He believed that the equilibrium of the social system depended on everybody acting out a role. To Parsons the doctor-patient relationship is where the doctor plays the superior role because of his expertise in medical matters. However, Parsons' model neglects to consider the conflicts and tensions that may arise between doctors and patients.

Szasz & Hollander (1956) cited in Hart (1985) believe that the type of relationship between doctors and patients depends on where it takes place and the nature of the medical problem involved. In Fig. 22 below shows three basic models of the doctor-patient therapeutic relationship. This therapeutic relationship can be seen as the kind of relationship the doctor wishes to achieve in treating specific disorders (Morgan, 1991).

This is the kind of doctor-patient interaction where the nature of the
encounter is often open to negotiation. However, in this "mutual participation" model the asymmetry which Parsons considered as vital to the social control function of medicine is missing (Hart, 1985). Freidson (1970) recognized that both Szasz and Hollender's and Parsons' model of the doctor-patient relationship failed to consider that the patient also could operate within three roles like the doctor. The roles in question being: active, guiding and participating. Freidson proposed an additional two types of interaction: i) guidance-cooperation - here the patient guided the doctor, who cooperated, and ii) passivity-activity where the doctor was passive and the patient active (cited in Armstrong, 1994). Therefore, the consultation could be led by either the doctor or patient.

Generally, the relationship between doctor and patient is mainly described in terms of expertise and knowledge (see Turner, 1987) interviewing style, withholding of information, use of medical jargon, satisfaction, emphasis on somatic rather than emotional affects, and different responses according to patients' age, sex, social class or ethnic origin (Clark, Potter & McKinlay, 1988; Simpson, Buckman, Stewart, Maguire, Lipkin, Novack & Till, 1991). The main focus of research into these interactions has been doctors' position of power and influence. For this reason it was decided in the present study to change this emphasis and look at power and influence in doctor-patient interactions to find out whether women can be said to 'seek' hysterectomy or whether, as the bulk of the literature suggests, doctors exert all the power. Particular consideration will be given to whether and how the patients present what are subjective symptoms and attitudes so as to influence the doctor to give hysterectomy.

Traditionally, psychologists have approached this kind of problem through
quantitative methods; for example by using rating scales or interview assessments. This is a simplistic approach which allows generalizable conclusions, but at the risk of a reductionist approach to doctor-patient interactions. The richness of the communication may be lost by simply reducing communication strategies to theoretical or traditional ideas and thus as a result could be insensitive to the ways that communication actually takes place; also, these approaches often neglect the fact that the meaning of a strategy depends on the context. However, others have used qualitative techniques to allow a rich and holistic analysis of doctor-patient interaction, but usually at the cost of generalizability and predictive power. The main advantage of combining quantitative and qualitative methods is that, the results of qualitative analyses can be used to ensure that the ratings used in quantitative analyses are as meaningful as possible for the interactions under investigation. In the present study in particular this combined approach will be used to test the view that clinical decision-making in this area reflects the practice of a predominantly male profession exerting power over female patients versus the notion that it reflects the influence that patients exert over their doctors.

A rather basic way to address the control and influence issue is to ask both doctor and patient who had the most influence in the outcome of the consultation. This is a rather crude way to approach the problem, but at least it will give the experimenter some idea of how the balance of influence is distributed in such interactions.

The present study examines how gynaecologists negotiate treatment with women presenting with dysmenorrhoea or menorrhagia. It is the first study to describe
this process in detail, using a combination of qualitative and quantitative techniques. The results may enable the development of educational interventions aimed at both gynaecologists and patients. The ultimate goals are: (i) to improve the match of health care to patients’ needs and (ii) to improve the efficiency with which NHS resources are used.

To approach this issue this study investigated:

(i) whether patients who are recommended hysterectomy negotiate for treatment by using different strategies from patients who are offered other treatments.

(ii) whether patients who are recommended hysterectomy had themselves suggested/recommended hysterectomy as a treatment for their menstrual symptoms.

(iii) whether recommendations for hysterectomy emerged from consultations in which the doctor and patient saw the patient as having most influence.
Method

Design

The study was conducted in two stages. The first involved the collection of qualitative data and its subsequent transcription and analysis. See Appendix D. The qualitative results identified the ways in which gynaecologists' and patients' influence are asserted and the ways in which they are negotiated. These results were used to construct a coding system which was used to allow quantitative test of specific hypotheses. Patients were divided into two groups for comparison: those who were offered a hysterectomy as a result of consultation and those who were offered other treatments (non-hysterectomy patients).

Subjects

The study was based on eighty-eight patients returning to outpatient gynaecology clinics for their second consultation as part of the referral episode, at one of five general hospitals: City Hospital, Nottingham (N=29; 33%); Queen Elizabeth II Hospital, Welwyn Garden City (N=10; 11.4%); Hillingdon Hospital, Uxbridge (N=10; 11.4%); Watford General Hospital (N=3; 3.4%); Whittington Hospital, London (N=36; 40.9%). See Table 41, page 212. Patients were identified through their medical records by the experimenter and medical staff attached to each of the general hospitals. All these patients had undergone an investigative procedure such as: D&C, hysteroscopy, pipelle, laparoscopy, ultrasound/transvaginal ultrasound. Patients' records were used to determine whether there was any known pathology underlying their symptoms. The mean age of the patients was 39 years (range 24 to 50 years, standard deviation 6.50).
The majority of patients were caucasian (89.8%), 3.4% were African, 3.4% were Asian and 3.4% were West Indian.

The inclusion criteria specified that subjects must be presenting with menorrhagia (heavy menstrual blood loss) and/or dysmenorrhoea (menstrual pain) attending a gynaecology clinic who had had a previous consultation, and been previously investigated, with negative results, as part of the referral episode.

Patients with confirmed or provisional diagnoses of gynaecological cancer, endometriosis, fibroids or cysts or if they had menopausal symptoms or any other organic medical condition which explained the symptoms were not included in the study. Furthermore, patients taking part in any other research project involving randomized allocation to treatment management were omitted from the study.

Of the patients approached, all took part.

Gynaecologists

Five consultants (four males and one female), and six registrars (four males and two females) participated in the study. The mean age of the gynaecologists was 38.8 years (range 28 to 57 years, standard deviation 10.09). The mean age of the male gynaecologists was 41.5 years (range 28 to 57 years, standard deviation 11.15) and the mean age of the female gynaecologists was 38 years (range 32 to 44, standard deviation 6). Most of the gynaecologists were caucasian and the remainder were African and Asian. See Table 43, page 212.
Questionnaires

The front sheet consisted of a consent form and a brief explanation of the study which stated that a tape-recording would be made of the interaction (see Appendix D). This was followed by questions about the woman's age, marital status, number of children, occupation and religion. A health questionnaire asked four general questions: (1) the main reason for attending the clinic (e.g. menstrual bleeding and/or pain), (2) the length of time they had experienced these symptoms, (3) if the symptoms had worsened while waiting for their hospital appointment with a gynaecologist and, (4) type of contraception used. This was followed by Zigmond & Snaith's (1983) Hospital Anxiety and Depression Questionnaire (HAD) - see Chapter 4. In a self-sealed envelope patients were given a Post-Consultation Questionnaire (PCQ). The PCQ (see Appendix D) consisted of 2 statements on which patients marked their responses after their consultation with a gynaecologist. The first statement asked patients: 'overall were you satisfied with your consultation with the doctor?'. Patients marked their response on a two-point scale: definitely no—definitely yes. The second statement asked patients: 'who had most influence on the consultation?' Here the patients response were recorded on a three-point scale: mainly the doctor---doctor and me equally---mainly me.' An equivalent version of the PCQ was given to gynaecologists to complete after their consultation with each patient (see Appendix D). These PCQs were returned completed to the experimenter both by the gynaecologist and patient after the interaction. An Additional Information Form (AIF) was completed by the experimenter during each doctor-patient interaction. This contained a code number for each hospital, doctor and patient. It also included status, sex and age of each doctor. Each patient's menstrual
problem(s), any additional medical complaints previous investigations and consultations were noted. Duration of the interaction and the nature of the treatment decided upon were recorded.

**Materials**

All doctor-patient interactions were recorded on a Sony tape-recorder (*SC stereo cassette-corder TC-D3*) with a Sony stereo PC-62 pin-on microphone and 90-minute Konica KX-1-90 cassette tapes. The tape-recorder was carried in the pocket of the white coat (*a uniform doctor's coat*) which the experimenter wore for each doctor-patient interaction. The tape-recorder was kept out of view to minimize its influence on the interaction, thus making the interaction more natural and therefore less inhibiting.

**Procedure**

Patients were approached individually in either a morning or afternoon gynaecology clinic by the experimenter wearing a white coat who introduced herself as a research worker independent of the hospital. In a private area of each clinic, each patient was asked if she would like to participate in a study 'designed to find out what patients expect from consultations with gynaecologists.' They were informed that the study was looking at women who sought medical advice for menstrual problems (*heavy bleeding and/or pain*) and that they would be required to answer some questionnaires. They were asked to read the information sheet carefully before they consented to take part in the study.
Each patient was told that the experimenter would be present during the consultation with the gynaecologist and that the questionnaires should be completed and handed back to the experimenter before the consultation. They were also informed that the Post-consultation Questionnaire (PCQ) should be completed immediately after the consultation and handed back to the experimenter in the self-seal envelope provided. Each gynaecologist was also asked to hand back his or her completed PCQ to the experimenter after each interaction.

It was emphasized to patients that they would remain anonymous and they were under no obligation to take part in the study, and that whether or not they did would not affect their own treatment. The questionnaires took approximately 1 to 2 minutes for each patient to complete. Each patient had signed a consent form.

**Design of coding system**

The coding system was based on the qualitative data and its subsequent transcription and analysis (refer to Appendix D). This permitted the experimenter to explore the question of 'power' and 'influence' in doctor-patient interactions by identifying the factors by which to predict the difference between patients who are offered hysterectomy and those who are offered other treatments.

The coding system was created on the basis of the qualitative analysis. From a set of transcripts (N=8) and repeated reading of these by the investigators, a
preliminary account was constructed which was first ‘tested’ by rereading and the coding the transcripts in the light of the account and secondly by discussion with a colleague who had read the same transcripts. After further ‘cycling’ between account and transcripts, the resulting account was further tested and developed by reading of further transcripts (N=8) until this became unfruitful. A final coding sheet was formulated and consisted of a total of 14 patient strategies and 7 gynaecologist’s strategies. Some of the strategies were divided into subsets which resulted into 56 patient/doctor strategies overall.

The strategies were identified that, although interesting in their own right, went beyond the remit of the present study. Therefore only those strategies which were seen as relevant to the aims of the study were considered (see Appendix D for a complete list).

The patient strategies consisted of:

(1) symptom presentation of menstrual problems. This is where the patient volunteers symptoms/responds to doctor’s question on (i) pain, (ii) bleeding (including clots), and (iii) extra symptom (non-menstrual physical symptom).

(2) manner of report. Here patients describe their experience of symptoms (e.g. how bad or upsetting the pain or bleeding are).

(3) psychosocial disruption which consisted of: (i) emotional effects (e.g. reporting distress, tiredness, moodiness, tearful, fed-up), (ii) social effects (e.g. how work is affected).

(4) state of symptoms reported whether the patient’s symptoms had improved or deteriorated: (i) improved/fine, (ii) no change, (iii) worse, and (iv) catastrophizing (I can’t go on, can’t carry on, end of my tether).
(5) criticism of procedures experienced was divided into: (i) failure of treatment (it did not work); (ii) damage of treatment (got sick, got fat, fluid retention) and (iii) previous episodes experienced with other doctors.

(6) criticism of procedures anticipated. Here responses are noted on: (i) failure of treatment (does not work), (ii) damage of treatment (causes sickness, weight gain) and (iii) fear of damage (through side effects).

(7) patient introduces medical/physical explanation for patient’s gynaecological symptoms (e.g. cysts, fibroids, adhesions).

(8) a patient uses lay physical explanations for her gynaecological symptoms (e.g. weak womb).

(9) patient explains her symptoms by using medical psychological terms (e.g. anxiety).

(10) patient uses lay psychological terms to describe her symptoms (e.g. nerves);

(11) patient suggests/recommends medical/surgical treatment for her symptoms (i) non-specific (e.g. something has to be done/do something) (ii) medical (drugs, HRT), (iii) scrape; (iv) have a look and see what’s going on (v) ER (vi) hysterectomy (get rid of it).

(12) patient introduces another expert (to justify a diagnosis) (i) GP or other professional; (ii) relatives, friends (iii) media.

(13) patient asks doctor what s/he recommends.

The gynaecologist’s strategies consisted of:

(1) statement about investigations carried out (i) objective report of results (e.g. scan negative or any mention of a gynaecological investigation); (ii) personalized report (e.g. taken a look/seen inside).
(2) statement about pathology: (i) no pathology, (ii) normal/completely normal, (iii) fairly/essentially normal (e.g. this is used when doctor has indicated any abnormality in concrete, anatomical or physiological terms, including reference to, e.g. womb being slightly enlarged), (iv) possible pathology (not confirmed), and (v) pathology (e.g. fibroids, cysts, endometriosis).

(3) explanation of symptoms (i) mystery (doctor says he cannot explain, no reason for these symptoms) (ii) something going on but within what is normal: (e.g. aches and pains, fine tuning, weight).

(4) doctor raises psychosocial agenda (e.g. gynaecologist asks the patient how her periods are affecting her life/reflects to the patient that she looks or feels fed up).

For the purpose of this study, the experimenter did not score and analyze numbers of strategies exhibited by each patient, but just scored whether or not a particular strategy was exhibited (see Appendix D).

The reliability was assessed, for each patient, as a percentage agreement across all strategies. Two raters each assessed the specific strategies the patients (N=6) were using in their interactions with doctors. (See Appendix D for scoring guide).

Refer also to qualitative study in Appendix D.
Statistical Analyses

Statistical analyses were computed by the SPSS/PC+ computer package:

For the purposes of analysis the data are divided into those patients who were offered a hysterectomy as a result of consultation (hereafter called hysterectomy patients) and those who were offered other treatments (non-hysterectomy patients).

Chi-square and Fisher’s Exact Test were used to explore strategies and treatments and One-way analyses of variance were used to compare levels of depression and anxiety and the treatments patients were offered.

Results

Demographic details

Most patients were married (52.3%), were divorced (18.2%) and 27.3% were either living with a partner or single (see Table 44, page 212). Over sixty per cent (63.6%) of patients were multiparous; 10.2% had one child and 26.1% were nulliparous (see Table 45, page 213). The majority (67.7%) of patients were involved in shopwork/clerical work and fewer were in professional/managerial (20.5%) or unskilled manual work employment (see Table 46, page 213). The sample was predominantly Church of England (59.1%) or Roman Catholic (17%) with the remainder belonging to various dominations (17.7%) or having no religion (5.7%). See Table 47, page 213.
The main complaint of most patients was menstrual pain and bleeding (54.5%) while others complained of menstrual bleeding (34.1%) or menstrual pain (11.4%) alone. Most women had suffered from these symptoms for between one to five years (53.4%) and 27.3% for over six years. Furthermore, several patients complained that their symptoms had recently got worse (58%). See Table 48, page 213. Some form of contraception was used by over three-quarters of the sample (see Table XI, Appendix D).

Table 41: Breakdown of Hospitals (Study 4)

<table>
<thead>
<tr>
<th>HOSPITALS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>City Hospital, Nottingham</td>
<td>29</td>
<td>33.0</td>
</tr>
<tr>
<td>Hillingdon Hospital, Uxbridge</td>
<td>10</td>
<td>11.4</td>
</tr>
<tr>
<td>Queen Elizabeth II Hospital, Welwyn Garden City</td>
<td>10</td>
<td>11.4</td>
</tr>
<tr>
<td>Watford General Hospital, Watford</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Whittington Hospital, London</td>
<td>36</td>
<td>40.9</td>
</tr>
</tbody>
</table>

Table 42: Age and Ethnic Origin of Patients (Study 4)

<table>
<thead>
<tr>
<th>PATIENTS</th>
<th>MEAN (SD)</th>
<th>RANGE (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>39 years</td>
<td>24-50 (6.50 SD)</td>
</tr>
<tr>
<td>ETHNIC ORIGIN</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>79</td>
<td>89.8</td>
</tr>
<tr>
<td>African</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>West Indian</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Total: 88</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 43: Demographic Details of Gynaecologists (Study 4)

<table>
<thead>
<tr>
<th>STATUS</th>
<th>%</th>
<th>MALES</th>
<th>FEMALES</th>
<th>AGE RANGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultants</td>
<td>5</td>
<td>36</td>
<td>4</td>
<td>1 age range 44-57</td>
</tr>
<tr>
<td>Registrars</td>
<td>6</td>
<td>54</td>
<td>2</td>
<td>2 age range 28-32</td>
</tr>
<tr>
<td>Total: 11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ETHNIC ORIGIN</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>8</td>
<td>72.7</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>African</td>
<td>2</td>
<td>18.2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>9.1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total: 11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 44: Breakdown of Marital Status (Study 4)

<table>
<thead>
<tr>
<th>MARITAL STATUS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>16</td>
<td>18.2</td>
</tr>
<tr>
<td>Married</td>
<td>46</td>
<td>52.3</td>
</tr>
<tr>
<td>Living with partner</td>
<td>8</td>
<td>9.1</td>
</tr>
<tr>
<td>Divorced</td>
<td>16</td>
<td>18.2</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Total: 88</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 45: Breakdown of Parity (Study 4)

<table>
<thead>
<tr>
<th>NUMBER OF CHILDREN</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>One child</td>
<td>9</td>
<td>10.2</td>
</tr>
<tr>
<td>Two children</td>
<td>35</td>
<td>39.8</td>
</tr>
<tr>
<td>Three children</td>
<td>15</td>
<td>17.0</td>
</tr>
<tr>
<td>Four children</td>
<td>4</td>
<td>4.5</td>
</tr>
<tr>
<td>Five children</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>No children</td>
<td>23</td>
<td>26.1</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>88</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Table 46: Breakdown of Patients' Employment (Study 4)

<table>
<thead>
<tr>
<th>EMPLOYMENT*</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>55</td>
<td>62.5</td>
</tr>
<tr>
<td>Unemployed</td>
<td>11</td>
<td>12.5</td>
</tr>
<tr>
<td>Self-employed</td>
<td>4</td>
<td>4.5</td>
</tr>
<tr>
<td>Housewife</td>
<td>18</td>
<td>20.5</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>88</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Table 47: Breakdown of Patients' Religion (Study 4)

<table>
<thead>
<tr>
<th>RELIGION</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church of England</td>
<td>52</td>
<td>59.1</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>15</td>
<td>17.0</td>
</tr>
<tr>
<td>Jewish</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Hindu</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Sikh</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>13.6</td>
</tr>
<tr>
<td>Agnostic</td>
<td>5</td>
<td>5.7</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>88</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Table 48: Breakdown of Patients' Complaint (Study 4)

<table>
<thead>
<tr>
<th>COMPLAINT*</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>10</td>
<td>11.4</td>
</tr>
<tr>
<td>Bleeding</td>
<td>30</td>
<td>34.1</td>
</tr>
<tr>
<td>Pain and Bleeding</td>
<td>48</td>
<td>54.5</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>88</strong></td>
<td></td>
</tr>
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</table>

### Table 49: Breakdown of Patients' Previous Procedures (Study 4)

<table>
<thead>
<tr>
<th>TREATMENT*</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>D&amp;C</td>
<td>59</td>
<td>67.6</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>28</td>
<td>31.8</td>
</tr>
<tr>
<td>Laparoscopy</td>
<td>26</td>
<td>29.5</td>
</tr>
<tr>
<td>Scan</td>
<td>14</td>
<td>15.9</td>
</tr>
<tr>
<td>Cervical smear</td>
<td>6</td>
<td>6.7</td>
</tr>
<tr>
<td>Blood test</td>
<td>17</td>
<td>19.3</td>
</tr>
<tr>
<td>Hormones</td>
<td>38</td>
<td>43.2</td>
</tr>
<tr>
<td>Mefenamic acid</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>88</strong></td>
<td></td>
</tr>
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</table>

### Table 50: Treatment Decision (Study 4)

<table>
<thead>
<tr>
<th>TREATMENT*</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploratory</td>
<td>6</td>
<td>6.8</td>
</tr>
<tr>
<td>Drugs</td>
<td>28</td>
<td>31.8</td>
</tr>
<tr>
<td>Endometrial Resection</td>
<td>5</td>
<td>5.7</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>15</td>
<td>17.0</td>
</tr>
<tr>
<td>No treatment</td>
<td>34</td>
<td>38.7</td>
</tr>
</tbody>
</table>

*Based on 88 patients
Table 51: Duration of Consultation (Study 4)

<table>
<thead>
<tr>
<th>MEAN</th>
<th>RANGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration for whole sample</td>
<td>10.55 minutes</td>
</tr>
</tbody>
</table>

| Duration between 2 to 5 minutes | N=25 (28.4%) |
| Duration between 6 to 10 minutes | N=32 (36.4%) |
| Duration between 12 to 16 minutes | N=17 (19.3%) |
| Duration between 17 to 23 minutes | N=10 (11.3%) |
| Duration between 24 to 32 minutes | N=4 (4.4%) |
| Total: 88 |

Treatment and investigations

A breakdown of the patients’ past treatment and investigation is shown in Table 49 (page 213). Table 50 (page 213) shows the treatment decided on as a result of the consultation.

Duration of consultation

Table 51 (above) shows the breakdown of duration of the consultation. The mean time of interactions was 10.55 minutes (range 2 to 32 minutes, standard deviation 6.59). Encounter interruptions (e.g. telephone calls, pages) were excluded from the duration recorded.

Reliability

The mean duration of the tapes referred to in Table 52 (page 215) was 9.83 minutes (range 2 to 19 minutes, standard deviation 5.98 minutes). The table
also shows the percentage of agreement on six randomly selected tapes scored by two independent raters. These comparisons were based on 56 strategies for each patient and doctor. There was very little disagreement on the specific strategies that the raters have recorded. For patient 186 there is no disagreement on the specific strategies each rater had scored. This may be due to the fact that the interaction only lasted two minutes and it was not difficult to recognize the strategies used. Furthermore, the high level of agreement on recognizing the same strategies could be due to fact that only a narrow range of strategies (56) were used in these interactions. It could also be a reflection of a well designed system of recognizing specific strategies used by patients and doctors.

<table>
<thead>
<tr>
<th>Table 52: Reliability of scoring audio-tapes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENT</strong></td>
</tr>
<tr>
<td>Patient 116</td>
</tr>
<tr>
<td>Patient 186</td>
</tr>
<tr>
<td>Patient 283</td>
</tr>
<tr>
<td>Patient 222</td>
</tr>
<tr>
<td>Patient 810</td>
</tr>
<tr>
<td>Patient 311</td>
</tr>
</tbody>
</table>

The reliability results are based on 6 patients.

**Patients’ Strategies**

**Relationship of symptom presentation of menstrual problems, manner of report, psychosocial disruption, state of symptoms, criticism of treatment experienced, anticipated and treatment recommended**

Analysis by Fisher’s Exact Test: (12.01 d.f.=1; p=<.002) identified that there was a relationship between the treatment that was recommended and patients complaints of psychosocial disruption. Over fifty per cent (53.3%) of patients
who were recommended hysterectomy reported higher levels of psychosocial disruption as a result of their menstrual problems which was greater than patients who were not recommended hysterectomy (13.7%). It was more likely that symptoms had improved in the non-hysterectomy group (57.5%) and to a lesser extent in the hysterectomy group (26.7%). A relationship emerged between the catastrophizing of symptoms and treatment recommended. Patients who were recommended hysterectomy catastrophized to greater extent (53.3%) about the effects of their symptoms than those in the non-hysterectomy group (4.1%) (Fisher's Exact Test: 8.65; d.f.=1; p=<.02). Failure of treatment already experienced was associated more with recommended hysterectomy (53.3%) than non-hysterectomy (20.5%) (Fisher Exact Test=6.93; d.f.=1; p=<.02). A breakdown of the above is shown in Table 53, page 219. Table 53 gives a breakdown of analyses by Chi-square and Fisher's Exact Test were there was no significant relationship between symptom presentation (menstrual pain and bleeding and non-menstrual symptoms); manner of report (experience of symptoms); state of symptoms (no change in symptoms or symptoms have worsened); criticism of actual treatments experienced and criticism regarding the effects of an investigation (damage of treatment and previous episodes experienced with other doctors) and perceived damage or damage of alternative procedures anticipated.

Relationship between medical, physical, psychological explanations for gynaecological symptoms and treatment recommended

Table 53, page 219 shows that there was no significant relationship between any of the above factors.
Relationship between patients ideas and recommendation of medical and surgical treatment for their symptoms, and the kind of treatment recommended

An association was shown by Fisher's Exact Test (29.38; d.f.=1; p=<.00001) between the treatment recommended and ideas put forward by patients about treatment. Sixty per cent of patients in the hysterectomy group recommended to the gynaecologists this operation to resolve their menstrual symptoms whereas only 5.5% of patients in the non-hysterectomy group suggested this procedure. Analyses by Fisher's Exact Test showed an interesting pattern emerging among over 50% of the hysterectomy group when it came to introducing another 'expert(s)' to support their suggestion of treatment. Specifically to support this suggestion they introduced another doctor (Fisher's Exact Test=6.92; d.f.=1; p=<.02) and/or friends (33.3%) (Fisher's Exact Test=15.91; d.f.=1; p=<.001) whereas a lower number of the non-hysterectomy patients made these suggestions (5%, 20.5%, 2.7%, respectively). A breakdown of the above is shown in Table 53, page 219. No relationship was found between introducing the media as another expert and type of treatment offered (see Table 53, page 219). Table 53 also shows that there was no relationship between patients suggestions for medical/surgical treatments and the treatment offered by doctors.

Gynaecologists’ Strategies

Relationship between the reporting of the outcome of investigations and the kind of treatment recommended

A significant relationship was evident between objectively reporting the results of investigations carried out and the kind of treatment patients were
recommended. Chi-square (Chi-square=6.56; d.f.=1; p=<.01) revealed that gynaecologists gave more objective feedback of investigations to non-hysterectomy patients (68.5%) than to hysterectomy patients (33.3%). A similar relationship was also revealed by Chi-square (Chi-square=12.89; d.f.=1; p=<.0001) with gynaecologists reporting that the results of the investigations were 'normal' and there was 'no pathology' (Chi-square=7.33; d.f.=1; p=<.01) more frequently to non-hysterectomy patients (57.4% and 43.8%, respectively) than with hysterectomy patients (6.7% and 6.7%, respectively) even though there was no known pathology in either group. Additionally, Fisher's Exact Test (9.14; d.f.=1; p=<.01) indicated an association with gynaecologists mentioning to patients who were recommended hysterectomy that there was might be some 'possible' pathology that could account for their menstrual symptoms (even though this was not confirmed by an investigation already undertaken) than to patients not recommended hysterectomy. Feedback on the results to patients such as: 'something is going on but within what is normal' was only associated with non-hysterectomy patients (32.9%) (Fisher's Exact Test=6.78; d.f.=1; p=<.01). (See Table 53, page 219). Table 53 also shows that other forms of reporting about investigations carried out and statements about pathology and symptoms were not related to the kind of treatment patients were offered. Nor was there any association between a psychosocial agenda being raised by doctors and the treatment recommended (see Table 53, page 219).

As previously stated (under 'design of scoring system,' page 207) not all the strategies listed on the scoring sheet (see Appendix D) are included in the results section as they did not apply to the hypotheses under investigation. Nevertheless, analyses of these data by Fisher's Exact Test is shown Appendix D, Table XII.
## Table 53: Patient and doctor strategies (Study 4)

<table>
<thead>
<tr>
<th>PATIENT STRATEGIES</th>
<th>NH</th>
<th>H</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>36 (49.3%)</td>
<td>10 (66.7%)</td>
</tr>
<tr>
<td>Blood</td>
<td>56 (76.7%)</td>
<td>10 (66.7%)</td>
</tr>
<tr>
<td>Extra symptom</td>
<td>16 (21.9%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Experience of symptoms</td>
<td>45 (61.6%)</td>
<td>11 (73.3%)</td>
</tr>
<tr>
<td>Psychosocial disruption</td>
<td>10 (13.7%)</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>Improvement in condition</td>
<td>42 (57.5%)</td>
<td>4 (26.7%)</td>
</tr>
<tr>
<td>No change in symptoms</td>
<td>12 (16.4%)</td>
<td>4 (26.7%)</td>
</tr>
<tr>
<td>Symptoms worse</td>
<td>14 (19.2%)</td>
<td>6 (40.0%)</td>
</tr>
<tr>
<td>Catastrophizing of symptoms</td>
<td>3 (4.1%)</td>
<td>4 (26.7%)</td>
</tr>
<tr>
<td>Failure of treatment</td>
<td>15 (20.5%)</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>Damage of treatment</td>
<td>23 (31.5%)</td>
<td>4 (26.7%)</td>
</tr>
<tr>
<td>Previous episodes experienced with other doctors</td>
<td>10 (13.7%)</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Anticipated failure of alternative procedures</td>
<td>4 (4.5%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Anticipated damage of alternative procedures</td>
<td>5 (6.8%)</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Fear of damage of anticipated procedures</td>
<td>19 (26.0%)</td>
<td>7 (46.6%)</td>
</tr>
<tr>
<td>Patient's medical/physical explanation of her symptoms</td>
<td>18 (24.7%)</td>
<td>3 (20.0%)</td>
</tr>
<tr>
<td>Patient's lay physical explanations for her symptoms</td>
<td>6 (8.2%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Patient explains her symptoms by using medical psychological terms</td>
<td>6 (8.2%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Patient uses lay psychological terms to describe her symptoms</td>
<td>1 (1.4%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Patient recommends 'something' (medical/surgical) to be done for her symptoms</td>
<td>7 (9.6%)</td>
<td>3 (20.0%)</td>
</tr>
<tr>
<td>Patient recommends endometrial resection for her symptoms</td>
<td>1 (1.4%)</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Patient recommends hysterectomy</td>
<td>4 (5.5%)</td>
<td>9 (60.0%)</td>
</tr>
<tr>
<td>Patient introduces another expert (doctor) to justify a diagnosis or treatment</td>
<td>2 (2.7%)</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>Patient introduces another expert (friends or relatives) to justify a diagnosis or treatment</td>
<td>15 (20.5%)</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>Patient introduces another expert (media) to justify a diagnosis or treatment</td>
<td>2 (2.7%)</td>
<td>5 (33.3%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GYNAECOLOGIST'S STRATEGIES</th>
<th>NH</th>
<th>H</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective report of the results</td>
<td>50 (68.5%)</td>
<td>5 (33.3%)</td>
</tr>
<tr>
<td>Doctor gives a personalized report about investigations carried out on the patient</td>
<td>15 (20.5%)</td>
<td>5 (33.3%)</td>
</tr>
<tr>
<td>Doctor reports no pathology</td>
<td>32 (43.8%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Doctor reports the results are normal</td>
<td>42 (57.5%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Doctor reports pathology being fairly normal</td>
<td>16 (21.9%)</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Doctor states there is 'possible' pathology</td>
<td>7 (9.6%)</td>
<td>6 (40.0%)</td>
</tr>
<tr>
<td>Doctor reports that the patient's symptoms are a 'mystery'</td>
<td>14 (19.2%)</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Doctor reports 'something' is going on</td>
<td>24 (32.9%)</td>
<td></td>
</tr>
<tr>
<td>Doctor raises psychosocial agenda</td>
<td>5 (6.8%)</td>
<td>3 (20.0%)</td>
</tr>
</tbody>
</table>

Based on 88 patients and 11 gynaecologists
NH = non-hysterectomy   H = hysterectomy
Comparison of influence and satisfaction in doctor-patient interactions

Over sixty per cent of patients in the non-hysterectomy and hysterectomy group reported that there was an equal amount of influence between themselves and the doctors in the outcome of the consultation. Table 54, page 221, indicates that only twenty-eight percent of doctors believed this assumption in the case of the non-hysterectomy group and only 13.3% doctors thought this in the case of the hysterectomy group. The most important finding was that doctors reported that 60% of hysterectomy patients had a greater influence in the outcome of the consultation (Chi-square=13.0; d.f.=2; p=<.001). Only 5% of non-hysterectomy and 20% of hysterectomy patients indicated that they had an influence in outcome come of the consultation and analysis by Chi-square confirmed that there was no significant relationship between influence and treatment recommended (Chi-square=3.97; d.f.=2; p=>.05).

The Fisher's Exact Test showed there was no relationship between patient or doctor satisfaction or patient satisfaction and the treatment recommended. However some interesting results have emerged from these analyses. Table 54, page 221 shows that overall doctors and patients were satisfied with their consultation regardless of the treatment outcome.
Comparison of levels of depression and anxiety and treatment recommended

One-way analyses of variance revealed that there was no difference on levels of depression between patients in hysterectomy and non-hysterectomy treatment groups (F=.27; d.f.=4,83; p=>.05. Furthermore there were no differences between these groups of patients on levels of anxiety (F=2.12; d.f.=4,83; p=>.05).

The results of this study have confirmed the findings of study 1, 2 and 3, insomuch that patients who expect, desire or who are recommended hysterectomy emerge as a group of patients who not only have high expectations of this procedure, but they also use different strategies in a doctor-patient interaction in order to get such a treatment.
Discussion

The aim of this study was to identify the ways in which gynaecologists' and patients' influence are asserted and the ways in which treatments are negotiated. Specific hypotheses were formulated once a qualitative analysis had identified the strategies which patients and gynaecologists actually used. A model was devised and was then tested quantitatively. This resulted in a unique coding scheme covering a wide range of strategies whereby doctors and patients could influence the consultation. The scoring system that was used did not involve scoring and analyzing the numbers of strategies exhibited by each patient, instead it recorded whether or not a particular strategy was exhibited. There are obvious limitations to this approach. Firstly, it denies the experimenter knowledge of the strength of a particular variable and whether a certain treatment is negotiated for on the strength of such reporting. Secondly, it limits the scope of the analyses by not allowing associations with the intensity of variables to be tested.

However, the method employed for this study has provided a set of tools with which researchers can make certain conclusions about doctor-patient interactions. It has gone beyond other techniques which have been narrow in their focus, enabling the experimenter to examine a wide range of material and to reduce it to strategies which can be quantified without sacrificing its richness. Enquiry has been taken from a holistic perspective by considering the underlying significance and the context as part of the event (see Appendix D).

Another limitation to this study was the comparison of strategies observed by two independent raters. The reliability may be an overestimate because (i) it was inflated by the large number of strategies which were scored zero by both (ii) it
did not take account of where in the consultation the two raters thought that the specific strategies occurred and, most importantly, (iii) both raters were experienced in the derivation and use of the coding system.

It was found that patients who are recommended hysterectomy negotiate for treatment by using different strategies from those who are recommended non-hysterectomy treatments. Hysterectomy patients reported psychosocial disruption and not only catastrophized about their menstrual symptoms often stating that: 'I can't go on,' 'I'm at the end of my tether,' but at the same time they criticized the failure of other treatments they had already experienced. Additionally, they introduced another 'expert' such as a G.P. or a friend to support their own suggestion for treatment. In contrast to the hysterectomy patients, non-hysterectomy patients (nearly fifty-eight per cent) reported improvement in their condition, although in some instances they did report the failure of previous treatments they had experienced. Like the hysterectomy patients, the non-hysterectomy patients also introduced an 'expert' to support their own recommendation for treatment, but this was less frequently as a strategy.

One of the main findings of the study was that doctors reported that the majority of hysterectomy patients had a greater influence than other patients on the outcome of the consultation. Contrary to this result, the majority of hysterectomy and non-hysterectomy patients felt there had been an equal amount of influence on the outcome of the consultation.

Some of the differences that were expected to occur between hysterectomy
patients and non-hysterectomy patients were not substantiated. For example, it was expected that hysterectomy patients would mention their symptoms (pain and/or bleeding) together with experience of the symptoms (e.g. reporting tiredness, moodiness and tearfulness) but this was not the case. Nor did they report that their symptoms had worsened or mention anticipated failure, damage, fear of damage of alternative procedures being offered to them. Furthermore, they did not offer medical, physical or psychological explanations for their symptoms. Also there were no differences between hysterectomy and non-hysterectomy patients on their levels of depression and anxiety. It was also expected that more gynaecologists would have raised a psychosocial agenda with patients who were offered hysterectomy than those who were not offered this operation, but this was not found.

On the basis of the above results it seems reasonable to suggest that a distinct picture has emerged of the strategies employed by the hysterectomy patient. Moreover, it is possible that the differences between the hysterectomy patients and patients offered other treatments reveal that certain strategies used by patients can influence doctors to offer hysterectomy. This provides the first quantitative support for the suggestion of Salmon & May (1995), based on a single case study, that patients can present essentially psychosocial material to a surgeon in order to compel the surgeon to offer surgery in the absence of demonstrable pathology. However, the present results go beyond that study in detailing the specific strategies whereby the psychosocial material is presented.

In the present study suggests that patients who are recommended hysterectomy emerge as a group who use a series of strategies in order to get a treatment they
seek. One of the limitations of this study was that a record was not taken of patients’ desire for a specific treatment. It was not the intention of the study to investigate outcome expectations of treatment as the previous three studies had established these outcomes. However, it is very clear from this study that its results are inconsistent with the notion that it is common practice of predominantly male surgeons to exert power over female patients (Turner, 1987). When it came to the clinical decision-making, patients who were offered hysterectomy appeared to have exerted power over their doctors.
Discovery consists of seeing what everybody has seen and thinking what nobody has thought.

Albert Szent-Gyögyi (1893- )
CHAPTER SIX

GENERAL DISCUSSION AND CONCLUSIONS

General discussion and conclusions

Study 1 and study 2 (Chapter three) explored anticipated treatment and expectations of outcome of treatment (exploratory, drugs, endometrial resection and hysterectomy) in gynaecological patients presenting with menstrual problems at outpatient clinics. In study 1 patients who expected hysterectomy as part of the treatment process emerged as being significantly different from patients who expected other treatments insomuch as they had higher positive outcome
expectations of benefit and higher negative expectations of harm. When patients were randomly allocated to different (imagined) treatment groups (study 2), patients in the "hysterectomy" group were found to have the same outcome of treatment expectations as those demonstrated for hysterectomy in study 1.

Influences on patients' expectations of hysterectomy and other treatments were examined in Study 3 (Chapter Four). The results of this study supported the main finding in the two previous studies: that is patients who 'expected' or 'desired' hysterectomy saw this procedure as the most 'powerful' treatment insofar as it was again perceived as having both beneficial effects on patients and among the most harmful effects. The factors that predict patients to 'desire' hysterectomy were identified as: severity of menstrual symptoms, high levels of depression and high negative feelings towards the womb.

Study 3 also confirmed previous work which showed that patients who have a background of physical and sexual abuse manifest higher levels of depression, anxiety and somatization and negative feelings towards their womb than those without such experiences. Although there was no significant difference between abused and non-abused patients' 'desire' for a particular treatment, it is still interesting to note that a high proportion of the gynaecology patients reported some form of abuse. It is possible that abused patients do not 'expect' or 'desire' hysterectomy as their first stage of treatment, but they may eventually be more likely than non-abused patients to take the path that leads to this operation. This information can be accessed in future follow-up studies of these patients. The high incidence of physical or sexual abuse or both in patients, supports the findings of Ribberink, Slurink, Everaerd & Hanewald (1989) who reported a high
incidence of childhood sexual abuse in populations attending gynaecological out-patient clinics. It is possible that presentation at a gynaecological clinic is one appropriate route to seeking help in the aftermath of sexual abuse (Fry, 1993). The fact that the abused patients in study 3 manifested high levels of somatization, depression and anxiety, not only supports the findings in previous studies (e.g. Sedney & Brooks, 1984; Arnold & Cook, 1990) it also signifies the importance of identifying history of abuse in such patients.

Because the first two studies indicated that patients had positive outcome expectations of hysterectomy, this led on to the idea that patients may actively seek this operation. One of the aims of study 4 was to test this notion by exploring the negotiation of treatment between doctor and patient in gynaecology out-patient clinics. Previous work on doctor-patient interaction has mainly focused on the exchange of information and satisfaction in health-care settings, whereas the approach that was adopted in study 4 moved to a less researched but the equally important area of power and influence. The results clearly show that patients who are offered hysterectomy have negotiated for treatment by using quite specific strategies different than those of patients who are recommended other treatments. This result lends some weight to the argument that many patients who are offered hysterectomy in the absence demonstrable pathology actively seek this procedure. Additionally, gynaecologists reported that patients who were eventually offered hysterectomy had exerted a greater influence on the outcome of the consultation than patients offered other treatments. Thus, the traditional concept that power in doctor-patient interactions is generated, directed and controlled by (male) doctors is incorrect. Patients can and do adopt certain strategies which they work to their advantage.
Whilst patients are increasingly becoming more knowledgeable about health matters (Morgan, 1991), the above studies exploring patients' expectations of treatment suggest there is a need for patients to have a greater understanding of hysterectomy. The development of the Expectations of Treatment Questionnaire (ETQ) has provided a method of measuring outcome expectations of hysterectomy and other gynaecological procedures and can be used in future research programmes in this area.

The development of the novel coding system in study 4 has offered researchers a technique of quantifying strategies exhibited by patients in gynaecological settings. It has enabled researchers to identify ways in which gynaecologists' and patients' influence are asserted and the ways in which treatment plans are negotiated. It can be used in training programmes for medical students and doctors.

Examining the psychological aspects of hysterectomy involved interviewing 544 patients and much this data will form the basis of other studies in this area. Hysterectomy is one of the most common major surgical operations in the UK (DHSS/OPCS, 1985) and a procedure that will continue to be an important component of health care in the foreseeable future (Teo, 1990). Therefore, it necessary to be certain, on the basis of good research, that when a woman is offered hysterectomy that the operation is both safe and appropriate. Blais (1988) stated that "It is not whether there are too many or too few [hysterectomies], it is, is it indicated?".
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References


Glossary

Adenomyosis - invasion of endometrium into the muscular layer of the womb. Also called internal endometriosis.

Adhesions - bands of abnormal fibrous tissue, sometimes a result of infection or surgery, which cause the adjoining structures to bind together.

Adnexa - a collective term for the ovaries, fallopian tubes, and uterine ligaments.

Adnexal inflammation - inflammation of the adnexal organs.

Amenorrhea - absence of periods.

Analgesia - pain relieving drug.

Biopsy - taking of a sample (e.g. tissue) for laboratory testing.

Briquet's syndrome - a chronic illness mainly occurring in women usually before the age of 30 - complaining of at least 25 medically unexplained symptoms.

Carcinoma - cancer; generally applied to one group of cancers, the commoner, arising in covering and lining membranes (as opposed to sarcoma, cancer arising in bone, connective tissue, muscle etc.).

Cervix - the neck of the uterus.

Cervicitis - inflammation at the neck of the uterus.

Cervical stenosis - narrowing of the neck of the uterus.

Cholecystectomy - removal of the gall-bladder, e.g. the operation for gallstones which form within it.

Clomid - a drug that stimulates ovulation and reduces heavy bleeding.

Colposcopy - a procedure using a magnifying lens to examine the cervix.

Contraindication - a warning of treatment or drug that could be hazardous.
**Correlation** - "a measure of association between two variables; generally assumed to be the product-moment $r$ (or Pearson's $r$); equivalent to the covariance between two standardized variables; also used as a general term for any type of colinear association between variables" (Kim and Mueller, 1978)

**Cronbach’s Alpha** - test of reliability which looks at internal consistency which is the same as internal reliability (see internal consistency)

**Cyklokapron (see tranexamic acid)**

**Cyst** - abnormal swelling containing fluid, in a sac-like holder.

**Cystic hyperplasia** - overgrowth of tissue within cyst formation.

**Cystocele** - prolapse of part of the bladder into the vagina.

**Danazol** - a drug used to reduce or stop menstruation.

**Depression** - a psychological disorder involving dejection, sadness, apathy, and self-blaming attitudes.

**Dilatation and Curettage (D&C)** - a mainly diagnostic procedure - the standard response to dysfunctional uterine bleeding. The endometrium is removed for study of abnormalities in the same manner as an endometrial biopsy.

**Dianette** - pill containing estrogen and progesterone.

**Dysmenorrhoea** - painful menstrual periods.

**Dyspareunia** - painful intercourse.

-ectomy - cutting out.

**Eigenvalue (or characteristic root)** - see scree test.

**Endometriosis** - a condition whereby tissue normally found only lining the uterus is present in abnormal locations throughout the body.

**Endometrial ablation** - (or endometrectomy) - a technique which uses a laser and resectoscope for cautery to destroy or remove the endometrium.

**Endometrium** - the tissue comprising the lining of the uterus.

**Estrogen** - a sex hormone produced in the ovaries.
Normal secretory endometrium - endometrium in the second stage of menstrual cycle.

Normal proliferative - first stage of menstrual cycle.

Endometrial biopsy - biopsy of the lining of the uterus.

Endoscope - any instrument designed to be passed into a body cavity allowing it to be examined by a doctor.


Fallopian tubes - the structures located between the uterus and ovaries responsible for transport of the egg and sperm. Also called oviducts.

Fibroids (leiomyoma) - a non-cancerous tumor comprised of uterine muscle tissue. There are three types: serosal, intramural, and submucous.

Fundus - widest part of the uterus.

Hormone - a chemical produced at one site in the body which is responsible for the actions of an organ at another site.

Hyperplasia - (overgrowth) the growth of normal cells in abnormally large numbers (e.g. endometrial hyperplasia). Endometrial hyperplasia indicates too much estrogen, therefore hormonal imbalance, therefore this is considered abnormal.

Hysteria - a neurosis arising out of anxiety or frustration in which the patient presents bodily symptoms as an expression of mental disturbance. It is a vague term to denote neurotic conditions varying from the moderate to the severe, but not verging on psychosis.

Hysterectomy

Hyster-oöphorectomy - when ovaries are removed at the same time as the uterus.

Total - removal of the uterus and cervix.

Pan-hysterectomy - removal of tubes, ovaries, cervix and body of uterus.

Sub-total procedure - only the uterus is removed.
**Radical hysterectomy** - where the lump nodes support ligaments, and upper portion of the vagina are removed.

**Wertheim's hysterectomy** - removal of uterus with the tubes, ovaries, pelvic cellular tissues, pelvic lymph glands and upper part of the vagina.

**Unilateral or bilateral salpingo-oophorectomy** - is where one or both of the fallopian tubes and ovaries are removed.

**Abdominal hysterectomy** - usually takes less than one hour to complete, depending on the nature of the disease and the organs to be removed. The more severe cases of a particular disease often require a more extensive and intricate approach and longer operating time. Total hospitalization for an abdominal hysterectomy is approximately 3 to 5 days.

**Vaginal hysterectomy** - involves the removal through the vagina of the uterus and the cervix

**Hystero** - relating to the uterus.

**Hysteroscope** - instrument to examine the cavity of the uterus.

**Hypothyroidism** - hypoactive thyroid gland.

**Hysteroscopy** - a diagnostic test during which a fiberoptic scope is introduced into the uterus.

**Idiopathic** - an abnormal condition which has developed without an obvious cause.

**Illness behaviour** - refers to the ways in which symptoms may be differentially perceived, evaluated, and acted (or not acted) upon by different kinds of persons.

**Internal consistency** - this is usually measured by checking whether persons tend to answer each item in the same way as they answer all others.

**Laparoscopy** - a diagnostic test where a fiberoptic scope is inserted through the navel. It allows a surgeon to directly view the uterus, ovaries, and fallopian tubes. It is carried out under local or general anaesthetic. Prior to the incision, carbon dioxide gas is instilled into the abdomen which pushes other abdominal structures out of the viewing area.

**Leukotriene** - a local hormone related chemically to prostaglandin with powerful effects on involuntary muscles, and in the process of inflammation.
**Glossary**

**Lymphoma** - a tumour-like growth of some element of the lymphatic system.

**Mefenamic acid (see also ponstan)** - prevents the action of postaglandin on muscle as well as inhibiting its production.

**Menarche** - the onset of menstruation.

**Menopause** - cessation of menstruation.

**Menorrhagia** - excessive bleeding from the vagina. One of the most common menstrual disorders.

**Metrorrhagia** - bleeding from the uterus other than menstruation.

**Myoma** - also known as fibroids.

**Myomectomy** - the surgical removal of uterine fibroids.

**Neoplasm** - new growth (tumour).

**Neurosis** - any sustained abnormal mental condition in which the sufferer has altered behaviour or beliefs without losing his sense of reality. The sufferer is aware that he/she is mentally disturbed.

**Norethisterone** - a synthetic progestin.

**Nosology** - classification of diseases

**Oestrogen** - a group of hormones that have a similar action. The three most common oestrogens are: oestrone, oestradiol and oestriol.

**Oligomenorrhoea** - infrequent, light periods.

**Oöpho-** - a prefix meaning ‘relating to the ovaries’.

**Oöphorectomy** - surgical removal of an ovary.

**Orthognathic** - pertaining to correction of position of teeth.

**Ovary** - the female sex glands. Their main functions are to release a mature ovum (the female reproductive cell) each month and to secrete the female sex hormones - oestrogen and progesterone.

**Ovariectomy** - surgical removal of an ovary.
Glossary

**Pessary** - a small structure inserted into the vagina to support the uterus in cases of prolapse.

**Phlebitis** - inflammation of a vein.

**Pipelle** - instrument to sample endometrium.

**Pituitary gland** - an endocrine gland underneath the brain which controls other glands.

**Polymenorrhagia** - excessive, heavy menstrual bleeding.

**Polyp (polypus)** - a harmless overgrowth.

**Ponstan (mefenamic acid)** - usually given for arthritis, but is known to help relieve period pain and lessen menstrual blood flow.

**Premarin** - is a preparation of conjugated oestrogens.

**Prempak** - is a preparation of conjugated oestrogens together with the progesterone norgestrel.

**Principal Components** - these are linear combinations of observed variables, possessing properties such as being orthogonal to each other, and the first principal component representing the largest amount of variance in the data, the second representing the second largest and so on; often considered variants of common factors, yet more accurately they are contrasted with common factors which are hypothetical (see Kim & Mueller, 1978).

**Progesterone** - a hormone secreted by females during the second half (*luteal phase*) of the menstrual cycle (*after ovulation*).

**Progesterons** - synthetically prepared progesterone.

**Prolapse** - a falling down of an organ, e.g. a uterus, from its normal position.

**Uterine prolapse** - the uterus drops down into the vagina due to weakening of its support structure.

**Prostagladins** - a group of chemicals present in many parts of the body. Their actions include an effect on the contraction of the uterus, role in pain and inflammation, and the ability to lower the blood pressure.
Resection - cutting out.

Psychosexual - link between one’s mental state and the characteristics of one’s sex life.

Rectocele - protrusion of part of the rectum into the vagina.

Scree test - a test for determining the number of significant factors to retain; it is based on the graph of eigenvalues (or characteristic roots). When the slope of the eigenvalues begin to level off forming a straight line it indicates that no more factors should be extracted.

Somatic - relating to the body.

Somatization disorder - a disorder in which a person constantly seeks medical help for many physical symptoms that have no organic cause.

Standardization (Z scores) - a knowledge of the mean and standard deviation of a group of scores allows researchers to convert any individual score into what is known as a standard score or Z score (Heyes, Hardy, Humphreys & Rookes, 1986). Z scores are a statement of how many standard deviations a subject’s raw score is from the mean (Z=the mean value of the variable from each case value and divided by the standard deviation of the variable). The advantage of standard scores is that they allow researchers to pinpoint exactly how the individual compares with other people.

Systemic - relating to the body as a whole. A drug taken systemically, by mouth or by injection, is distributed throughout the body.

Testosterone - male sex hormone produced by the testes.

Tranexamic acid - a prostaglandin synthetase inhibitor, suitable for bleeding disorders.

Transcervical resection of endometrium - introduction of a fine instrument through the cervix to cut away the lining of the uterus.

Ultrasound - high-pitched sound waves (beyond the range of the human ear). A diagnostic test utilizing sound waves to detect differences in tissue densities and thus to analyze body organs.

Uterine septum - division in the uterus.
Uterus - womb.

Vagina - the ‘front passage’ of the female leading from the vulva to the opening of the womb.

Varimax - this is a method of orthogonal rotation which simplifies the factor structure by maximizing the variance of a column of the pattern matrix.

Voltarol suppositories - used for pain relief.

Vulva - the external female genitals (the entrance to the vagina).
APPENDIX A: Study 1

Examples of statements from patients on preliminary study page 273
Patient information and consent form 274
Demographic questionnaire 275
Health questionnaire 276
Expectations of Treatment Questionnaire (ETQ) 277

Table I Relationship between age, complaint and duration 282
Table II Breakdown of patients’ complaint 282
Table III Breakdown of patients’ contraceptives 282
Table IV Duration of symptoms and treatment expectations 283
Fig. 1 Scree test 283
Table V Results of principal components analysis: items that did not load on components 283
EXAMPLES OF STATEMENTS FROM PATIENTS

1. **Relief from period pain.**
   *I just want to get rid of the pain.*
   *Have to stay in bed because of periods cos they're painful - it's painful to stand up and even sit down.*
   *Always get the cramps.*
   *Get pain in the groin and across stomach.*
   *Intense pain in legs.*
   *Lot of pain from waist to feet, back of legs and stomach.*
   *Have cramps in tummy and legs and aches all over.*
   *Feel my stomach and back is being cut open.*
   *Have a dragging feeling below.*
   *Tops of legs feel like jelly.*

5. **My stomach will be less swollen or bloated.**
   *It's the heaviness and pain I can't take.*
   *Stomach is very swollen and tender most of the time... just bloat.*
   *Get bloating... me feet feel tight beneath the skin.*
   *Feel heavy and bloated before periods. Get swollen stomach.*
   *Stomach makes me look pregnant.... but goes down afterwards.*
   *Stomach and face swell.*

10. **I will be less tired.**
    *Have very little energy.*
    *I'm wacked with this bleeding.*
    *Feel lifeless with the curse.*
    *Feel like going to bed and sleeping.*
    *Tired most of the time during period.*
    *Get weak and tired - even making the tea is tiring.*
    *Feel very tired, feel drained. Don't feel well. Everything's an effort - even to go to work.*
    *Feel worn out... feel like a punch bag. Lifeless.*

44. **I will be less irritable.**
    *Always shouting at children because of periods.*
    *Really bad temper, don't want anyone near me.*

51. **I will be able to do things that I haven't be able to do.**
    *Can't go on holiday because of periods.*
    *Messes up my holidays.*
    *Can't plan holidays because of periods.*
    *Affects swimming cos it pulls to stomach.*
    *Can't run around and play with children.*
UNIVERSITY COLLEGE LONDON
CITY HOSPITAL, NOTTINGHAM
GYNAECOLOGICAL PATIENTS' EXPECTATIONS OF TREATMENT STUDY

PATIENT INFORMATION AND CONSENT

This study is designed to find out more about what patients expect from treatment. We will be looking at women who seek medical advice for menstrual problems (heavy bleeding and/or pain).

By knowing more about women's expectations of treatment, we hope to be able to improve the care of women suffering from menstrual problems.

This study will require you to fill out some questionnaires about your symptoms and your expectations of treatment. You will remain ANONYMOUS on these questionnaires.

You are under no obligation to participate in this study and whether or not you do, will not affect your own treatment.

If you are willing to take part in the study, please sign the form below.

Thank you for your cooperation.

I hereby consent to take part in the University College London and the City Hospital, Nottingham, Expectations of Treatment Study.

Signature: ........................................................................................................
1. Date of birth: ..... ..... .....  
   day month year

2. Please tick (√) one of the following:  
   Single ( )  
   Married ( )  
   Living with a partner ( )  
   Divorced ( )  
   Widowed ( )  
   Other ( )

3. How many children do you have? .....  

4. Please tick one (√) of the following that best describes your employment:  
   Employed ( )  
   Unemployed ( )  
   Self-employed ( )  
   Housewife ( )  
   Retired ( )  
   Student ( )

5. If you do have a job tick (√) the one of the following that best describes it:  
   Unskilled manual ( )  
   Skilled manual ( )  
   Shopwork/clerical/office work ( )  
   Skilled technical ( )  
   Professional/managerial ( )  
   (If you do not have a job tick (√) your partner’s job)

6. Please tick (√) one of the following to show your religion:  
   Church of England/Protestant ( )  
   Catholic ( )  
   Jewish ( )  
   Hindu ( )  
   Muslim ( )  
   Sikh ( )  
   Jehovah’s Witness ( )  
   Other ( )  
   None ( )
UNIVERSITY COLLEGE LONDON
CITY HOSPITAL, NOTTINGHAM
Health Questionnaire

It would be helpful if you could now answer a few questions about your symptoms.

The questionnaire is anonymous: DO NOT WRITE YOUR NAME.

1. What is the main reason for your attendance at this clinic? (Please tick)
   Pain  Bleeding  Pain and Bleeding
   ( )  ( )  ( )

2. How long have you experienced these symptoms? Please specify length of time:
   (1-4)  (1-11)  (1-5)  (6+)
   Weeks  Months  Years  Years

3. Have your symptoms become worse? If yes, please state when:
   (1-7)  (1-4)  (1-11)  (not worse)
   Days  Weeks  Months

4. Are you using any form of contraception? (Please tick)
   Yes  No
   ( )  ( )

   If yes, please tick and say what type of contraception:
   Pill  ( )
   I.U.D.  ( )
   Cap  ( )
   Creams  ( )
   Condom  ( )
   Sterilized [me]  ( )  Partner  ( )
   If other, please specify

5. What treatment do you expect to receive for your menstrual problems? 
Drugs  D&C  Hysterectomy  Endometrial Resection
   ( )  ( )  ( )  ( )
   Laparoscopy  Hormone  Laser  The 'pill'
   ( )  ( )  ( )  ( )
EXPECTATIONS OF TREATMENT QUESTIONNAIRE

Women coming to this clinic say they anticipate different things from the treatment they expect to receive. Below is a list of some of the changes that women may expect following their treatment.

For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow your treatment. If any item does not apply to you, please tick (✓) 'definitely won’t happen'. Remember, there are no right or wrong answers - what we need to know are your own views.

<table>
<thead>
<tr>
<th></th>
<th>Definitely won’t happen</th>
<th>Probably won’t happen</th>
<th>Don’t know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
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<tbody>
<tr>
<td>1. Relief from period pain.</td>
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<td>2. My periods will not last so long.</td>
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<td>3. I will need hormone replacement therapy (HRT).</td>
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<td>4. Relief from pre-menstrual pain.</td>
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<td>5. My stomach will be less swollen or bloated.</td>
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<td>6. I will lose interest in sex.</td>
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<td>7. It will reduce or stop heavy bleeding after sex.</td>
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<td>8. I will put on weight.</td>
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<td>9. Relief from pain (other than pre-menstrually and during periods).</td>
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<td>10. I will be less tired.</td>
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<td>11. I will lose my femininity.</td>
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</table>
Appendix A:

For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow your treatment. If any item does not apply to you, please tick (√) ‘definitely won’t happen’. Remember, there are no right or wrong answers - what we need to know are your own views.

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<tr>
<td>12.</td>
<td>Less soiling of clothes because of periods.</td>
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<td>13.</td>
<td>Sex will no longer be enjoyable.</td>
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<tr>
<td>14.</td>
<td>Reduce or stop blood clots during my periods.</td>
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<tr>
<td>15.</td>
<td>There will be less pain or discomfort after sex.</td>
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<td>16.</td>
<td>It will stop my body from feeling ‘normal’ again.</td>
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<td>17.</td>
<td>Reduce or stop bleeding in between periods.</td>
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<td>18.</td>
<td>My stomach will be less tender.</td>
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<td>19.</td>
<td>Men will no longer find me attractive.</td>
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<td>20.</td>
<td>It will reduce or stop heavy period bleeding (flooding).</td>
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<td>21.</td>
<td>I will use fewer tampons or sanitary pads.</td>
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<td>22.</td>
<td>I will be more active.</td>
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<td>23.</td>
<td>My partner will lose interest in our relationship.</td>
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</table>
Appendix A:

For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow your treatment. If any item does not apply to you, please tick (✓) ‘definitely won’t happen’. Remember, there are no right or wrong answers - what we need to know are your own views.

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<tr>
<td>24.</td>
<td>My bowels will be less loose pre-menstrually or during my periods.</td>
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<td>25.</td>
<td>I will be less constipated.</td>
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<td>26.</td>
<td>It will stop my periods from governing my life.</td>
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<td>27.</td>
<td>I will age prematurely.</td>
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<td>28.</td>
<td>I will get relief from vomiting during my periods.</td>
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<td>29.</td>
<td>It will allow me to have a better quality of life.</td>
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<td>30.</td>
<td>I will have less time off work because of my periods.</td>
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<td>31.</td>
<td>It will stop me from feeling a whole woman again.</td>
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<td>32.</td>
<td>My life will be less disrupted by periods.</td>
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<td>33.</td>
<td>I will feel less faint.</td>
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<td>34.</td>
<td>My body will feel uncomfortable in the longterm.</td>
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<tr>
<td>35.</td>
<td>I will be able to have a better social life.</td>
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</table>
For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow your treatment. If any item does not apply to you, please tick (✓) ‘definitely won’t happen’. Remember, there are no right or wrong answers - what we need to know are your own views.

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<th>Definitely will happen</th>
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<tr>
<td>36. It will stop me from having a baby in the future.</td>
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<td>37. I will be freed from pre-menstrual or period headaches.</td>
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<td>38. I will have more interest in sex.</td>
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<td>39. My sex life will be more enjoyable.</td>
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<td>40. I will have more energy.</td>
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<td>41. My treatment may harm me physically.</td>
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<td>42. I will feel more depressed.</td>
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<td>43. It will stop me from having birth control problems.</td>
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<td>44. I will be less irritable.</td>
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<td>45. My breasts will be less painful or tender.</td>
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<td>46. I will be less depressed.</td>
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<td>47. It will make me less active at home or work.</td>
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<td>48. I will become less active socially.</td>
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</table>
For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow your treatment. If any item does not apply to you, please tick (✓) 'definitely won’t happen'. Remember, there are no right or wrong answers - what we need to know are your own views.

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<th>Don’t know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
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<tbody>
<tr>
<td>49. My body will feel more comfortable in the long-term.</td>
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<tr>
<td>50. I will feel more irritable.</td>
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<tr>
<td>51. I will be able to do things that I haven’t been able to do.</td>
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<td>52. I will be able to do my work/housework better.</td>
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<td>53. My family life will improve.</td>
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<td>54. I will feel less dizzy.</td>
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<td>55. It will improve my health in the long-term.</td>
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<td>56. I will get bladder problems.</td>
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<td>57. I will not feel so guilty about my menstrual problems.</td>
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<td>58. I will have less energy.</td>
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</table>
### Table I: Chi-square relationship between Age, complaint and duration (Study 1)

<table>
<thead>
<tr>
<th>AGE</th>
<th>PAIN N=21</th>
<th>BLEEDING N=62</th>
<th>PAIN &amp; BLEEDING DURATION N=117</th>
<th>DURATION (Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-35 years</td>
<td>N=11; 13.9%</td>
<td>N=20; 32.3%</td>
<td>N=48; 60.8%</td>
<td>N=29; 36.7%</td>
</tr>
<tr>
<td>N=70; 39.5%</td>
<td>[52.4%]</td>
<td>[32.3%]</td>
<td>[41%]</td>
<td>[46.5%]</td>
</tr>
<tr>
<td>36-50 years</td>
<td>N=10; 8.3%</td>
<td>N=42; 67.7%</td>
<td>N=69; 57%</td>
<td>N=34; 28.1%</td>
</tr>
<tr>
<td>N=121; 60.5%</td>
<td>[47.6%]</td>
<td>[67.7%]</td>
<td>[59%]</td>
<td>[54%]</td>
</tr>
<tr>
<td>Total: 200</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figures in [] refer to column %
Not significant: p>0.05

### Table II: Breakdown of Patient's Complaint (Study 1)

<table>
<thead>
<tr>
<th>COMPLAINT</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>21</td>
<td>10.5</td>
</tr>
<tr>
<td>Bleeding</td>
<td>62</td>
<td>31.0</td>
</tr>
<tr>
<td>Pain and Bleeding</td>
<td>117</td>
<td>58.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DURATION OF COMPLAINT</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months (1-11)</td>
<td>63</td>
<td>31.5</td>
</tr>
<tr>
<td>Years (1-5)</td>
<td>89</td>
<td>44.5</td>
</tr>
<tr>
<td>Years (6+)</td>
<td>48</td>
<td>24.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>COMPLAINT WORSENEDED</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weeks (1-4)</td>
<td>14</td>
<td>7.0</td>
</tr>
<tr>
<td>Months (1-11)</td>
<td>107</td>
<td>53.5</td>
</tr>
<tr>
<td>Years (1-5)</td>
<td>29</td>
<td>14.5</td>
</tr>
<tr>
<td>No worse</td>
<td>50</td>
<td>25.0</td>
</tr>
<tr>
<td>Total: 200</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table III: Breakdown of Patients' Contraceptives (Study 1)

<table>
<thead>
<tr>
<th>TYPE OF CONTRACEPTIVE USED</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill</td>
<td>19</td>
<td>9.5</td>
</tr>
<tr>
<td>IUD</td>
<td>7</td>
<td>3.5</td>
</tr>
<tr>
<td>Cap</td>
<td>6</td>
<td>3.0</td>
</tr>
<tr>
<td>Condom</td>
<td>43</td>
<td>21.5</td>
</tr>
<tr>
<td>Sterilized females</td>
<td>22</td>
<td>11.0</td>
</tr>
<tr>
<td>Not sterilized females</td>
<td>16</td>
<td>8.0</td>
</tr>
<tr>
<td>None</td>
<td>90</td>
<td>45.0</td>
</tr>
<tr>
<td>Total: 200</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix A:

Table IV: Duration of symptoms and treatment expectations (Study 1)

<table>
<thead>
<tr>
<th>Duration</th>
<th>Drugs N=42</th>
<th>Exploratory N=115</th>
<th>E.R. N=15</th>
<th>Hysterectomy N=30</th>
<th>N=200</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months</td>
<td>12 (6%)</td>
<td>42 (21%)</td>
<td>3 (3%)</td>
<td>6 (3%)</td>
<td>N=63 (31.5%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years</td>
<td>14 (12%)</td>
<td>48 (24%)</td>
<td>4 (3%)</td>
<td>14 (12%)</td>
<td>N=89 (44.5%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years</td>
<td>6 (3%)</td>
<td>23 (12.5%)</td>
<td>7 (3.5%)</td>
<td>10 (5%)</td>
<td>N=48 (24%)</td>
</tr>
</tbody>
</table>

Fig. 1: Scree test (Study 1)

Table V: Results of principal components analysis (Study 1)

Items that did not load on components

- It will stop me from feeling a whole woman again.
- It will stop my periods from governing my life.
- I will have less time off because of my periods.
- Sex will no longer be enjoyable.
- My partner will lose interest in our relationship.
- Reduce or stop bleeding in-between periods.
- I will get bladder problems.
- I will not feel so guilty about my menstrual problems.
- My periods will not last so long.
- I will need hormone replacement therapy (HRT).
- Men will no longer find me attractive.
- I will have less energy.
APPENDIX B: Study 2

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>VI</td>
<td>Patient information and consent form (<em>dilation and curettage and hysteroscopy</em>)</td>
<td>285</td>
</tr>
<tr>
<td></td>
<td>Patient information and consent form (<em>drugs</em>)</td>
<td>286</td>
</tr>
<tr>
<td></td>
<td>Patient information and consent form (<em>transcervical resection of the endometrium</em>)</td>
<td>287</td>
</tr>
<tr>
<td></td>
<td>Patient information and consent form (<em>hysterectomy</em>)</td>
<td>288</td>
</tr>
<tr>
<td></td>
<td>Demographic questionnaire</td>
<td>289</td>
</tr>
<tr>
<td></td>
<td>Health questionnaire</td>
<td>290</td>
</tr>
<tr>
<td></td>
<td>Expectations of treatment questionnaire (<em>ETQ</em>)</td>
<td>291</td>
</tr>
<tr>
<td>VI</td>
<td>Breakdown of patients’ complaints</td>
<td>295</td>
</tr>
<tr>
<td>VII</td>
<td>Breakdown of patients’ contraceptives</td>
<td>295</td>
</tr>
</tbody>
</table>
This study is designed to find out more about what patients expect from treatment. We will be looking at women who seek medical advice for menstrual problems (*heavy bleeding and/or pain*). We hope you will be happy to assist us with this study, because it will help to improve care of women in your position in the future.

We will require you to fill out some questionnaires about your symptoms and your expectations of treatment. You will remain ANONYMOUS on these questionnaires.

When filling out the Expectations of Treatment Questionnaire we would like you to imagine that you are going to have a DILATATION & CURETTAGE (D&C) (note, that this bears no reflection on the procedure you might be offered today).

D&C (*dilation and curettage*) is a small operation through the vagina where a gynaecologist scrapes sections of the endometrium (*lining of the womb*).

Sometimes the gynaecologist also inspects the womb (*uterus*) using a minute telescope with a small video camera attached (*hysteroscopy*), which is inserted in the vagina and cervix (*neck of the womb*). Precise inspection of the womb is carried out via monitoring on a television screen.

*Remember* you are under no obligation to participate in this study and whether or not you do, will not affect your own treatment. If you are willing to take part in the study, please sign the form below. Thank you for your cooperation.

Name: ............................................. Address: ..............................................................

I hereby consent to take part in the University College London and Watford General Hospital, Expectations of Treatment Study.

Signature: .................................................................................................................
Appendix B:

No: .......................  Date: ......................

UNIVERSITY COLLEGE LONDON
WATFORD GENERAL HOSPITAL
GYNAECOLOGICAL PATIENTS' EXPECTATIONS OF TREATMENT
STUDY 2
PATIENT INFORMATION AND CONSENT

This study is designed to find out more about what patients expect from treatment. We will be looking at women who seek medical advice for menstrual problems (heavy bleeding and/or pain). We hope you will be happy to assist us with this study, because it will help to improve care of women in your position in the future.

We will require you to fill out some questionnaires about your symptoms and your expectations of treatment. You will remain ANONYMOUS on these questionnaires.

When filling out the Expectations of Treatment Questionnaire we would like you to imagine that you are going to be given some PILLS (note, that this bears no reflection on the procedure you might be offered today).

Often 'the pill' (contraceptive pill) is given to women experiencing heavy menstrual bleeding. Like the contraceptive pill, other pills which may be prescribed for the same problems usually contain hormones.

Remember you are under no obligation to participate in this study and whether or not you do, will not affect your own treatment.

If you are willing to take part in the study, please sign the form below.

Thank you for your cooperation.

Name:...............................................Address:..............................................

I hereby consent to take part in the University College London and Watford General Hospital, Expectations of Treatment Study.
Signature:  ......................................................................................................................
This study is designed to find out more about what patients expect from treatment. We will be looking at women who seek medical advice for menstrual problems (heavy bleeding and/or pain). We hope you will be happy to assist us with this study, because it will help to improve care of women in your position in the future.

We will require you to fill out some questionnaires about your symptoms and your expectations of treatment. You will remain ANONYMOUS on these questionnaires.

When filling out the Expectations of Treatment Questionnaire we would like you to imagine that you are going to have a TRANSCERVICAL RESECTION OF THE ENDOMETRIUM (TCRE) (note, that this bears no reflection on the procedure you might be offered today).

Transcervical resection of the endometrium (TCRE) is a recently introduced treatment. It involves removing the endometrium (lining of the womb) either using a laser (laser ablation) or electrocoagulation (rollerball ablation). The lining may also be removed using an electrically heated loop (endometrial resection). The operation is performed through the vagina.

Remember you are under no obligation to participate in this study and whether or not you do, will not affect your own treatment. If you are willing to take part in the study, please sign the form below. Thank you for your cooperation.

Name: .................................................. Address: ...........................................................

I hereby consent to take part in the University College London and Watford General Hospital, Expectations of Treatment Study.
Signature: ..........................................................

UNIVERSITY COLLEGE LONDON
WATFORD GENERAL HOSPITAL
GYNAECOLOGICAL PATIENTS' EXPECTATIONS OF TREATMENT
STUDY 2
PATIENT INFORMATION AND CONSENT
This study is designed to find out more about what patients expect from treatment. We will be looking at women who seek medical advice for menstrual problems (*heavy bleeding and/or pain*). We hope you will be happy to assist us with this study, because it will help to improve care of women in your position in the future.

We will require you to fill out some questionnaires about your symptoms and your expectations of treatment. You will remain ANONYMOUS on these questionnaires.

When filling out the Expectations of Treatment Questionnaire we would like you to imagine that you are going to have a **HYSTERECTOMY** (note, that this bears no reflection on the procedure you might be offered today).

Hysterectomy is the surgical removal of a woman’s womb (*uterus*). The womb may be removed through an abdominal incision or through the vagina.

*Remember* you are under no obligation to participate in this study and whether or not you do, will not affect your own treatment.

If you are willing to take part in the study, please sign the form below.

Thank you for your cooperation.

Name:........................................Address:..........................................

I hereby consent to take part in the University College London and Watford General Hospital, Expectations of Treatment Study.

Signature:............................................................................................
UNIVERSITY COLLEGE LONDON
WATFORD GENERAL HOSPITAL
GYNAECOLOGICAL PATIENTS' EXPECTATIONS OF TREATMENT
STUDY 2

1. Date of birth: .... .... ....
   day  month  year

2. Please tick (√) one of the following:
   Single
   Married
   Living with a partner
   Divorced
   Widowed
   Other

3. How many children do you have? ....

4. Please tick one (√) of the following that best describes your employment:
   Employed
   Unemployed
   Self-employed
   Housewife
   Retired
   Student

5. If you do have a job tick (√) the one of the following that best describes it:
   Unskilled manual
   Skilled manual
   Shopwork/clerical/office work
   Skilled technical
   Professional/managerial

   (If you do not have a job tick (√) your partner's job)

6. Please tick (√) one of the following to show your religion:
   Church of England/Protestant
   Catholic
   Jewish
   Hindu
   Muslim
   Sikh
   Jehovah's Witness
   Other
   None
UNIVERSITY COLLEGE LONDON
WATFORD GENERAL HOSPITAL
Health Questionnaire

It would be helpful if you could now answer a few questions about your symptoms.

The questionnaire is anonymous: DO NOT WRITE YOUR NAME.

1. What is the main reason for your attendance at this clinic? (Please tick)
   Pain ( ) Bleeding ( ) Pain and Bleeding ( )

2. How long have you experienced these symptoms? Please specify length of time:
   ..... (1-4) Weeks (1-11) Months (1-5) Years (6+)

3. Have your symptoms become worse? If yes, please state when:
   ..... (1-7) Days (1-4) Weeks (1-11) Months (not worse)

4. Are you using any form of contraception? (Please tick)
   Yes ( ) No ( )

   If yes, please tick and say what type of contraception:

   Pill ( )
   I.U.D. ( )
   Cap ( )
   Creams ( )
   Condom ( )
   Sterilized ( ) Partner ( )

   If other, please specify..................................
## EXPECTATIONS OF TREATMENT QUESTIONNAIRE

Women coming to this clinic say they anticipate different things from the treatment they expect to receive. Below is a list of some of the changes that women may expect following their treatment.

For each statement, please tick (√) a box to show the extent to which you expect that outcome to follow the treatment which has been assigned to you. If any item does not apply to you, please tick (√) 'definitely won’t happen'. Remember, there are no right or wrong answers - what we need to know are your own views.

<table>
<thead>
<tr>
<th></th>
<th>Definitely won’t happen</th>
<th>Probably won’t happen</th>
<th>Don’t know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Relief from period pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Relief from pre-menstrual pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My stomach will be less swollen or bloated.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I will lose interest in sex.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. It will reduce or stop heavy bleeding after sex.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I will put on weight.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Relief from pain (other than pre-menstrually and during periods).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I will be less tired.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I will lose my femininity.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Less soiling of clothes because of periods.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow the treatment assigned to you. If any item does not apply to you, please tick (✓) ‘definitely won’t happen’. Remember, there are no right or wrong answers - what we need to know are your own views.

<table>
<thead>
<tr>
<th></th>
<th>Definitely won’t happen</th>
<th>Probably won’t happen</th>
<th>Don’t know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Reduce or stop blood clots during my periods.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. There will be less pain or discomfort after sex.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. It will stop my body from feeling ‘normal’ again.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. My stomach will be less tender.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. It will reduce or stop heavy period bleeding (flooding).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I will use fewer tampons or sanitary pads.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I will be more active.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. My bowels will be less loose pre-menstrually or during my periods.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I will be less constipated.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I will age prematurely.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I will get relief from vomiting during my periods.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. It will allow me to have a better quality of life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
For each statement, please tick (✓) a box to show the extent to which you expect that outcome to follow the treatment assigned to you. If any item does not apply to you, please tick (✓) 'definitely won't happen'. Remember, there are no right or wrong answers - what we need to know are your own views.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely won't happen</th>
<th>Probably won't happen</th>
<th>Don't know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
</tr>
</thead>
<tbody>
<tr>
<td>My life will be less disrupted by periods.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will feel less faint.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My body will feel uncomfortable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will be able to have a better social life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It will stop me from having a baby in the future.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will be freed from pre-menstrual or period headaches.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will have more interest in sex.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My sex life will be more enjoyable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will have more energy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My treatment may harm me physically.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will feel more depressed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It will stop me from having birth control problems.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
For each statement, please tick (√) a box to show the extent to which you expect that outcome to follow the treatment assigned to you. If any item does not apply to you, please tick (√) ‘definitely won’t happen’. Remember, there are no right or wrong answers - what we need to know are your own views.

<table>
<thead>
<tr>
<th>Definitely won’t happen</th>
<th>Probably won’t happen</th>
<th>Don’t know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
</tr>
</thead>
<tbody>
<tr>
<td>35. I will be less irritable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. My breasts will be less painful or tender.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. I will be less depressed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. It will make me less active at home or work.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. I will become less active socially.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. My body will feel more comfortable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. I will feel more irritable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. I will be able to do things that I haven’t been able to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. I will be able to do my work/house-work better.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. My family life will improve.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. I will feel less dizzy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46. It will improve my health in the long-term.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table VI: Breakdown of Patients’ Complaint (Study 2)

<table>
<thead>
<tr>
<th>COMPLAINT</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>9</td>
</tr>
<tr>
<td>Bleeding</td>
<td>41</td>
</tr>
<tr>
<td>Pain and Bleeding</td>
<td>50</td>
</tr>
</tbody>
</table>

**DURATION OF COMPLAINT**

<table>
<thead>
<tr>
<th>Duration</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weeks (1-4)</td>
<td>1</td>
</tr>
<tr>
<td>Months (1-11)</td>
<td>33</td>
</tr>
<tr>
<td>Years (1-5)</td>
<td>44</td>
</tr>
<tr>
<td>Years (6+)</td>
<td>22</td>
</tr>
</tbody>
</table>

**COMPLAINT WORSENED**

<table>
<thead>
<tr>
<th>Duration</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weeks</td>
<td>5</td>
</tr>
<tr>
<td>Months</td>
<td>60</td>
</tr>
<tr>
<td>No worse</td>
<td>35</td>
</tr>
</tbody>
</table>

Total: 100

### Table VII: Breakdown of Patients’ Contraceptives (Study 2)

<table>
<thead>
<tr>
<th>TYPE OF CONTRACEPTIVE USED</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill</td>
<td>11</td>
</tr>
<tr>
<td>I.U.D.</td>
<td>4</td>
</tr>
<tr>
<td>Cap</td>
<td>5</td>
</tr>
<tr>
<td>Condom</td>
<td>17</td>
</tr>
<tr>
<td>Sterilized (female)</td>
<td>25</td>
</tr>
<tr>
<td>Sterilized (male)</td>
<td>14</td>
</tr>
<tr>
<td>No contraception</td>
<td>24</td>
</tr>
</tbody>
</table>

Total: 100
APPENDIX C: Study 3

Patient information and consent form 297
Demographic questionnaire 298
Health questionnaire 299
Hospital anxiety and depression questionnaire (HAD) 301
Hopkins questionnaire 302
Hypochondriasis questionnaire 303
Abuse questionnaire 304
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UNIVERSITY COLLEGE LONDON
PATIENTS' VIEWS OF TREATMENT FOR MENSTRUAL
PROBLEMS

PATIENT INFORMATION AND CONSENT

This study is designed to find out more about what patients expect from treatment. We will be looking at women who seek medical advice for menstrual problems (heavy bleeding and/or pain).

By knowing more about women's attitudes to treatment, we hope to be able to improve care. Your help with this research will help us to meet the needs of future patients although it will in no way affect your own treatment.

This study will require you to fill out some questionnaires about your symptoms and your feelings about treatment and experiences that might affect these.

All the information that you give will be STRICTLY CONFIDENTIAL. It will not be given to any member of the hospital: i.e. the doctors and nurses. You will be identified by a code number only.

You are under no obligation to participate in this study and whether or not you do, will not affect your own treatment.

If you are willing to take part in the study, please sign the form below.

Thank you for your cooperation.

DETACH HERE

I hereby consent to take part in the study of Patients' Views of Treatment for Menstrual Problems.

Signature: ........................................................................................................................................
H/0  Rx1
UNIVERSITY COLLEGE LONDON
PATIENTS' VIEWS OF TREATMENT FOR MENSTRUAL PROBLEMS

1. Date of birth: ..... ..... ..... 
day month year

2. Please tick (√) one of the following:
   Single  ( )
   Married ( )
   Living with a partner ( )
   Divorced ( )
   Widowed ( )
   Other ( )

3. How many children do you have? ....

4. Please tick one (√) of the following that best describes your employment:
   Employed  ( )
   Unemployed ( )
   Self-employed ( )
   Housewife  ( )
   Retired  ( )
   Student  ( )

5. Please tick (√) one of the following that best describes your employment husband's/partner's job.
   Unskilled manual  ( )
   Skilled manual  ( )
   Shopwork/clerical/office work  ( )
   Skilled technical  ( )
   Professional/managerial  ( )

6. Please tick (√) one of the following to show your religion:
   Church of England/Protestant  ( )
   Catholic  ( )
   Jewish  ( )
   Hindu  ( )
   Muslim  ( )
   Sikh  ( )
   Jehovah's Witness  ( )
   Other  ( )
   None  ( )
UNIVERSITY COLLEGE LONDON
Health Questionnaire

Would you now kindly answer a few questions about your symptoms?

1. What is the main reason for your attendance at this clinic? Please tick (□).
   - Pain □
   - Bleeding □
   - Pain and Bleeding □
   - Other □

2. How long have you experienced these symptoms? Please tick (□) one of the following:
   - 1-4 weeks □
   - 1-11 months □
   - 1-5 years □
   - 6+ years □

3. At what age did you first experience the above menstrual symptoms? Please tick (□).
   - 8-10 years □
   - 11-13 years □
   - 14-16 years □
   - 18-20 years □
   - 21-30 years □
   - 31-40 years □
   - 41-50 years □

4. At what age did your periods start? .......

5. How would you describe your menstrual pain when your periods first began? Please tick (□).
   - none □
   - a little □
   - moderate □
   - quite painful □
   - very painful □

6. How would you describe your menstrual blood loss when your periods first began? Please tick (□).
   - very light □
   - quite light □
   - moderate □
   - heavy □
   - very heavy □

7. How would you now describe your menstrual blood loss? Please tick (□) one of the following boxes.
   - very light □
   - quite light □
   - moderate □
   - heavy □
   - very heavy □
Appendix C:

UNIVERSITY COLLEGE LONDON
Health Questionnaire

8. How would you now describe your menstrual pain? Please tick (□) one of the following boxes.

□ .................................................................
none   a little    moderate    quite painful    very painful

9. How would you rate your menstrual symptoms compared to other women? Please tick (□).

□ .................................................................
much better than    a little better than    the same as most    a little worse    much worse than
most women    most women    women    than most women    most women

10. Are you using any form of contraception? (Please tick)
    Yes ( )   No ( )

If yes, please tick one of the following:
Pill ( )
I.U.D. ( )
Cap ( )
Creams ( )
Condom ( )
Sterilized [me] ( ) Partner ( )
If other, please specify

11. What treatment do you think you will be offered today? Please tick (✓) one of the following:
    Drugs ( )    Endometrial resection ( )
    Hormones ( )    Hysterectomy ( )
    D&C ( )    Other

12. How many of your relatives or friends have had a hysterectomy?

None □   Three □
One □   Four □
Two □   Five + □
**UNIVERSITY COLLEGE LONDON**  
**HAD SCALE**

Read each item and tick (✓) in the box opposite the reply which comes closest to how you have been feeling in the last week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.  
*Tick only ONE box in each section*

<table>
<thead>
<tr>
<th>Item</th>
<th>Responses</th>
</tr>
</thead>
</table>
| 1. I feel tense or 'wound up': | Most of the time □  
A lot of the time □  
Time to time, occasionally □  
Not at all □ |
| 2. I still enjoy the things I used to enjoy: | Definitely as much □  
Not quite so much □  
Only a little □  
Hardly at all □ |
| 3. I get a sort of frightened feeling as if something awful is about to happen: | Very definitely and quite badly □  
Yes, but not too badly □  
A little, but it does not worry me □  
Not at all □ |
| 4. I can laugh and see the funny side of things: | As much as I always could □  
Not quite so much now □  
Definitely not so much now □  
Not at all □ |
| 5. Worrying thoughts go through my mind: | A great deal of the time □  
A lot of the time □  
From time to time, but not often □  
Only occasionally □ |
| 6. I feel cheerful: | Not at all □  
Not often □  
Sometimes □  
Most of the time □ |
| 7. I can sit at ease and feel relaxed: | Definitely □  
Usually □  
Not often □  
Not at all □ |
| 8. I feel if I am slowed down: | Nearly all the time □  
Very often □  
Sometimes □  
Not at all □ |
| 9. I get a sort of frightened feeling like ‘butterflies’ in the stomach: | Not at all □  
Occasionally □  
Quite often □  
Very often □ |
| 10. I have lost interest in my appearance: | Definitely □  
I don't take so much care as I should □  
I may not take quite as much care □  
I just take as much care as ever □ |
| 11. I feel restless as if I have to be on the move: | Very much indeed □  
Quite a lot □  
Not very much □  
Not at all □ |
| 12. I look forward with enjoyment to do things: | As much as I ever did □  
Rather less than I used to □  
Definitely less than I used to □  
Hardly at all □ |
| 13. I get sudden feelings of panic: | Very often indeed □  
Quite often □  
Not very often □  
Not at all □ |
| 14. I can enjoy a good book or radio or television programme: | Often □  
Sometimes □  
Not often □  
Very seldom □ |
UNIVERSITY COLLEGE LONDON
PATIENTS’ VIEWS OF TREATMENT FOR MENSTRUAL PROBLEMS
HOPKINS QUESTIONNAIRE

Read each statement and tick (✓) only one box which comes closest to how you have been feeling in the last week, including today.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Headaches.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Faintness or dizziness.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Pains in the heart or chest.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. Feeling low in energy or slowed down.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. Pains in the lower part of back.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>6. Soreness of muscles.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>7. Trouble getting your breath.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8. Hot or cold spells.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. Numbness or tingling in parts of your body</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>10. A lump in your throat.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>11. Weakness in parts of part of back.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>12. Heavy feelings in your arms or legs.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
**Appendix C:**

UNIVERSITY COLLEGE LONDON

PATIENTS' VIEWS OF TREATMENT FOR MENSTRUAL PROBLEMS

Below are some questions about you and your thoughts about illness. Please tick (√) either YES or NO to each statement.

<table>
<thead>
<tr>
<th>Question</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you think there is something seriously wrong with your body?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Does illness interfere with your life a great deal?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. If the doctor told you that he could find nothing wrong with you, would you believe him?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. If you feel ill and someone tells you that you are looking better, do you become annoyed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Do you find that you are often aware of various things happening in your body?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Are you more sensitive to pain than other people?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Are you afraid of illness?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Do you think that you worry about your health more than most people?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Do you find that you get jealous of other people’s good health?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Do you ever have silly thoughts about your health which you can’t get out of your mind, no matter how hard you try?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Are you upset by the way people take your illness?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Are you sleeping well?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Do you often think that you might suddenly fall ill?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. If a disease is brought to your attention (through the radio, radio, television, newspapers or someone you know), do you worry about getting it yourself?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Do you find that you are bothered by many different symptoms?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Many people may have unwanted sexual or violent experiences as children or adults. Some of these are with playmates, friends, relatives or acquaintances. These experiences may be so upsetting that they may never be discussed with anyone. Often they are forgotten for a long time, and sometimes they are frequently brought to mind.

We would like you to help us understand these experiences that people may have. Please try to remember whether any of the following happened to you. Tick (✓) either YES or NO for both age groups (when you were 13 years old or less, or after you were 14 years old.

<table>
<thead>
<tr>
<th>13 years</th>
<th>14 years+</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

1. Has anyone ever exposed their sex organs to you without your consent?
2. Has anyone ever threatened to have sex with you without your consent?
3. Has anyone ever touched your sex organs without your consent?
4. Has anyone made you touch their sex organs without your consent?
5. Has anyone tried forcefully or had sex with you without your consent?
6. Have you had any other unwanted sexual experiences not mentioned above?
   If yes, please specify, if you feel able to: ..........................................................
7. When you were a child, did an older person do the following: Tick (✓) a box for each statement.
   a. Insult or humiliate you, or try to make you feel guilty?
   b. Hit, kick or beat you?
8. Now, as an adult, does any other adult do the following: Tick (✓) a box for each statement.
   a. Insult or humiliate you, or try to make your feel guilty
   b. Hit, kick or beat you?
9. Have you ever discussed these experiences with anyone before? Please tick (✓) all that apply:
   Never   Family member   Friend(s)
   Occasionally  Minister/lay counsellor
   Often  Psychologist/doctor
10. Are you seeing a counsellor for these or any other emotional problems? Please tick (✓) YES or NO
    YES  NO
Many people have various feelings towards their womb. We are interested in finding out how you feel about your womb. Below are several words referring to feelings you may experience which are arranged in pairs.

Please tick (√) the box in each word pair which best shows how you feel about your womb.

<table>
<thead>
<tr>
<th>Beautiful</th>
<th>Ugly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Bad</td>
</tr>
<tr>
<td>Strong</td>
<td>Weak</td>
</tr>
<tr>
<td>Feminine</td>
<td>Masculine</td>
</tr>
<tr>
<td>Useful</td>
<td>Useless</td>
</tr>
<tr>
<td>Not Embarrassing</td>
<td>Embarrassing</td>
</tr>
<tr>
<td>Clean</td>
<td>Dirty</td>
</tr>
<tr>
<td>Safe</td>
<td>Dangerous</td>
</tr>
<tr>
<td>Pure</td>
<td>Polluted</td>
</tr>
<tr>
<td>Creative</td>
<td>Destructive</td>
</tr>
<tr>
<td>Attractive</td>
<td>Repulsive</td>
</tr>
<tr>
<td>Comfortable</td>
<td>Uncomfortable</td>
</tr>
<tr>
<td>Alive</td>
<td>Lifeless</td>
</tr>
<tr>
<td>Fertile</td>
<td>Sterile</td>
</tr>
</tbody>
</table>
EXPECTATIONS OF TREATMENT QUESTIONNAIRE

Women coming to this clinic expect different things from treatment. We are interested in finding out what treatment YOU think would help you most.

Please tick (✓) THE ONE treatment which YOU feel would help you most:

<table>
<thead>
<tr>
<th></th>
<th>Definately won't happen</th>
<th>Probably won't happen</th>
<th>Don't know</th>
<th>Probably will happen</th>
<th>Definitely will happen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormones</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D&amp;C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometrial resection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Now imagine you are going to have the treatment you want. For each of the statements below, please tick (✓) a box to indicate what changes you expect to follow the treatment. Remember, there are no right or wrong answers - what we need to know are your own views.

1. Relief from period pain.
2. Relief from pre-menstrual pain.
3. My stomach will be less swollen or bloated.
4. I will lose interest in sex.
5. It will reduce or stop heavy bleeding after sex.
6. I will put on weight.

NOTE THAT THE REST OF THIS QUESTIONNAIRE IS THE SAME AS IN STUDY 2.
### Table VIII: Breakdown of Patients' Contraceptives (Study 3)

<table>
<thead>
<tr>
<th>Type of Contraceptive Used</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill</td>
<td>17</td>
<td>10.9</td>
</tr>
<tr>
<td>I.U.D.</td>
<td>9</td>
<td>5.8</td>
</tr>
<tr>
<td>Condom</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>Sterile (Female)</td>
<td>23</td>
<td>14.7</td>
</tr>
<tr>
<td>Sterile (Male)</td>
<td>28</td>
<td>17.9</td>
</tr>
<tr>
<td>None</td>
<td>67</td>
<td>42.9</td>
</tr>
</tbody>
</table>

Total: 156

*(I.U.D. refers to intrauterine device)*

### Table IX: Results of Hysterectomy Operations (N=18) (Study 3)

<table>
<thead>
<tr>
<th>Patients</th>
<th>Pathology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Parity</td>
</tr>
<tr>
<td>37</td>
<td>3</td>
</tr>
<tr>
<td>45</td>
<td>3</td>
</tr>
<tr>
<td>31</td>
<td>4</td>
</tr>
<tr>
<td>33</td>
<td>1</td>
</tr>
<tr>
<td>38</td>
<td>3</td>
</tr>
<tr>
<td>46</td>
<td>3</td>
</tr>
<tr>
<td>40</td>
<td>0</td>
</tr>
<tr>
<td>33</td>
<td>2</td>
</tr>
<tr>
<td>39</td>
<td>1</td>
</tr>
<tr>
<td>45</td>
<td>0</td>
</tr>
<tr>
<td>34</td>
<td>3</td>
</tr>
<tr>
<td>47</td>
<td>3</td>
</tr>
<tr>
<td>41</td>
<td>0</td>
</tr>
<tr>
<td>47</td>
<td>3</td>
</tr>
<tr>
<td>39</td>
<td>3</td>
</tr>
<tr>
<td>49</td>
<td>4</td>
</tr>
<tr>
<td>39</td>
<td>2</td>
</tr>
<tr>
<td>46</td>
<td>0</td>
</tr>
</tbody>
</table>

### Table X: Reporting of abuse and other emotional problems

<table>
<thead>
<tr>
<th>Experience with anyone before?</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>96</td>
</tr>
<tr>
<td>Family member</td>
<td>31</td>
</tr>
<tr>
<td>Friend(s)</td>
<td>16</td>
</tr>
<tr>
<td>Minister/fay counsellor</td>
<td>5</td>
</tr>
<tr>
<td>Psychologist/doctor</td>
<td>8</td>
</tr>
</tbody>
</table>

Based on 156 patients
APPENDIX D: Study 4

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PATIENT INFORMATION AND CONSENT

This study is designed to find out more about what patients expect from consultations with gynaecologists. We will be tape-recording women who seek medical advice for menstrual problems (heavy bleeding and/or pain).

By knowing more about women’s expectations of gynaecological consultations, we hope to be able to improve the care of women suffering from menstrual problems. Your assistance with this research will help us to meet the needs of future patients although it will in no way affect your own treatment.

This study will require you to fill out some questionnaires about your symptoms and your comments about the consultation.

All the information that you give will be strictly confidential. It will not be given to any member of the hospital: i.e. the doctors and nurses. You will be identified by a code number only.

You are under no obligation to participate in this study and whether or not you do, will not affect your own treatment.

If you are willing to take part in the study, please sign the form below.

Thank you for your cooperation.

Name: .................................. Address: .................................................................

I hereby consent to take part in the University College London and Hillingdon Hospital, Uxbridge, Gynaecological Patients’ Consultation Study.

Signature:  ..............................................................................................................
UNIVERSITY COLLEGE LONDON
HILLINGDON HOSPITAL, UXBRIDGE
GYNAECOLOGICAL PATIENTS' CONSULTATION STUDY

1. Date of birth: ..... ..... ..... 
day month year

2. Please tick (√) one of the following:
   Single ( )
   Married ( )
   Living with a partner ( )
   Divorced ( )
   Widowed ( )
   Other ( )

3. How many children do you have? ....

4. Please tick one (√) of the following that best describes your employment:
   Employed ( )
   Unemployed ( )
   Self-employed ( )
   Housewife ( )
   Retired ( )
   Student ( )

5. If you do have a job tick (√) the one of the following that best describes it:
   Unskilled manual ( )
   Skilled manual ( )
   Shopwork/clerical/office work ( )
   Skilled technical ( )
   Professional/managerial ( )
   (If you do not have a job tick (√) your partner’s job)

6. Please tick (√) one of the following to show your religion:
   Church of England/Protestant ( )
   Catholic ( )
   Jewish ( )
   Hindu ( )
   Muslim ( )
   Sikh ( )
   Jehovah’s Witness ( )
   Other ( )
   None ( )
UNIVERSITY COLLEGE LONDON
HILLINGDON HOSPITAL, UXBRIDGE
Health Questionnaire

It would be helpful if you could now answer a few questions about your symptoms.

The questionnaire is anonymous: DO NOT WRITE YOUR NAME.

1. What is the main reason for your attendance at this clinic? (Please tick)
   - Pain
   - Bleeding
   - Pain and Bleeding

2. How long have you experienced these symptoms? Please tick one of the following:
   - (1-4) Weeks
   - (1-11) Months
   - (1-5) Years
   - (6+) Years

3. Have your symptoms become worse recently? If yes, please state when:
   - (1-7) Days
   - (1-4) Weeks
   - (1-11) Months
   - (not worse)

4. Are you using any form of contraception? (Please tick)
   - Yes
   - No

If yes, please tick one of the following:
   - Pill
   - I.U.D.
   - Cap
   - Creams
   - Condom
   - Sterilized [me] ( ) Partner ( )

If other, please specify..........................................................

FOR HAD QUESTIONNAIRE SEE APPENDIX C
UNIVERSITY COLLEGE LONDON
GYNAECOLOGICAL PATIENTS' CONSULTATION STUDY
POST-CONSULTATION QUESTIONNAIRE

**PATIENT'S FORM**

Code No:......... Doctor's Code No:............

Date:.........

For each statement, please tick (√) a box to show the extent to which you agree.

<table>
<thead>
<tr>
<th>Definitely No</th>
<th>Definitely Yes</th>
</tr>
</thead>
</table>

1. Overall were you satisfied with your consultation with the patient?
   - the doctor
   - the doctor and me equally
   - me

2. Who had the most influence on the outcome of the consultation?
**DOCTOR’S FORM**

<table>
<thead>
<tr>
<th>Code No:</th>
<th>Patient’s Code No:</th>
</tr>
</thead>
</table>

**Date:**

---

For each statement, please tick (✓) a box to show the extent to which you agree.

<table>
<thead>
<tr>
<th>Definitely No</th>
<th>Definitely Yes</th>
</tr>
</thead>
</table>

1. **Overall were you satisfied with your consultation with the patient?**

   - the patient
   - the patient and me equally
   - me

2. **Who had the most influence on the outcome of the consultation?**

   - the patient
   - the patient and me equally
   - me
UNIVERSITY COLLEGE LONDON
GYNAECOLOGICAL PATIENTS’ CONSULTATION STUDY

HOSPITAL: (Code No)........................................ Date: ...............

Time: Start: ............ Breaks: ............
Finish: ............

GYNAECOLOGIST (Code No) .............. Consultant ( ) Registrar ( )
Male: ............ Female: ............
Age: ............ Ethnic origin: ............

PATIENT: (Code No).................... Hospital No: ............
Age: ............ Ethnic origin: ............

Problem:
1. Pain ( )
2. Bleeding ( )
3. Pain & bleeding ( )

Length of problem(s): ............

Previous investigations and consultations: ..........................................
1. D&C ( )
2. Ultrasound ( )
3. Laparoscopy ( )
4. Blood tests ( )

Previous investigations and consultations: ..........................................
1. D&C ( )
2. Ultrasound ( )
3. Laparoscopy ( )
4. Blood tests ( )

Medical Treatment: RESULTS:..........................................
7. "pill"hormones ( )
8. Mefenamic acid ( )
9. Ethamsyalte acid ( )
10. Tranexamic acid ( )

Outcome: Another appointment? yes ( ) No ( ) When? ..................................
Referral? Where........................................ What for? ..................................

Action:
1. D&C ( )
2. Laparoscopy ( )
3. Hysteroscopy ( )
4. Scan ( )
5. Drugs (inc. hormones) ( )
6. Endometrial resection ( )
7. Hysterectomy ( )
8. Pain clinic ( )
9. No action ( )

Any other tests?........................................
GUIDANCE FOR SCORING TAPES

PATIENT STRATEGIES

(1) SYMPTOM PRESENTATION OF MENSTRUAL PROBLEMS

1. Pain. This applies to when the patient states her symptom and also when she responds to the doctor's prompts about her pain. This does not apply when the doctor verifies the patient's symptoms. Soreness is not interpreted as pain.
   Score whenever the patient affirms this symptom in different statements. Also score if the patient refers to pain in the recent past.

2. Bleeding. This also refers to blood clots. This applies to when the patient states her symptom and also when she responds to the doctor's prompts about her pain. This does not apply when the doctor verifies the patient's symptoms.
   Score whenever the patient affirms this symptom in different statements. Also score if the patient refers to menstrual blood loss in the recent past.

3. Extra symptom. Refers to non-menstrual physical symptom(s).
   Score once per statement.

(2) MANNER OF REPORT

1. Experience of symptoms. How bad or upsetting the pain or bleeding are. This includes patients conveying their suffering by emphasizing of the number of pads/tampons they have used.
   Score once per statement.

(3) PSYCHOSOCIAL DISRUPTION - reporting distress, tiredness, moodiness, tearfulness, fed-up.

1. Emotional effects
2. Social effects
   For each of the above: score once per statement.

(4) STATE OF SYMPTOMS

1. Improved/fine.
2. No change.
3. Worse.
4. Catastrophizing. Patient reporting that: I can't go on, can't carry on, end of my tether.
   For each of the above: score once per statement.
GUIDANCE FOR SCORING TAPES (2)

(5) CRITICISM OF PROCEDURES EXPERIENCED

1. Failure of treatment. Patient claims procedure administered as part of current referral has not worked.

2. Damage of treatment. Patient claims that the procedure has caused e.g. sickness, weight gain, fluid retention.

3. Previous episodes experienced with other doctors. Patient recounts past experiences encountered with doctors over her menstrual problems.

For each of the above: score once per statement and one per criticism within a statement.

(6) CRITICISM OF PROCEDURES ANTICIPATED

1. Failure of treatment. Patient reports that (treatment) does not work.

2. Damage of treatment. Patient claims it causes sickness and weight gain.

3. Fear of damage. Patient fears side effects of (treatment) e.g. thrombosis.

For each of the above: score once per statement.

(7) PATIENT INTRODUCES MEDICAL/PHYSICAL EXPLANATION FOR HER GYNAECOLOGICAL SYMPTOMS - explanations such as: cysts, fibroids, adhesions, ovary attaching itself to bowel.

Score per statement.

(8) PATIENT USES LAY PHYSICAL EXPLANATION FOR HER GYNAECOLOGICAL SYMPTOMS e.g. weak womb

Score each time the patient uses different explanation(s) for her symptoms.

(9) PATIENT EXPLAINS HER SYMPTOMS BY USING MEDICAL PSYCHOLOGICAL TERMS - such terms as: anxiety.

Score each time the patient explains her symptoms in such a way.

(10) PATIENT USES LAY PSYCHOLOGICAL TERMS TO DESCRIBE HER SYMPTOMS - such terms as: nerves.

Score each time the patient uses these terms to describe her symptoms.
GUIDANCE FOR SCORING TAPES (3)

(11) **PATIENT SUGGESTS/RECOMMENDS MEDICAL/SURGICAL TREATMENT FOR HER SYMPTOMS**

1. **Non-specific.** Patient states: something has to be done/do something.
2. **Medical.** Drugs. HRT.
3. **Scrape.**
4. **Have a look and see what’s going on.**
5. **Endometrial resection.**
6. **Hysterectomy** e.g. patient states: get rid of it/it’s no use to me.

For each of the above score every time the patient makes the suggestion.

(12) **PATIENT INTRODUCES ANOTHER EXPERT** - to justify her symptoms or her preference for a particular treatment.

1. GP or other professional.
2. Relatives, friends.

For each of the above score every time the patient refers to that ‘expert.’

(13) **PATIENT ASKS FOR TREATMENT OPTIONS**

1. Score once per option. If patient asks for additional treatment options score again.

2. Patient asks doctor what s/he would recommend.
   Score each time it is asked.

(14) **REQUEST FOR INFORMATION ABOUT TREATMENT**

1. Operation and drugs.
2. Waiting list. *When the operation will be carried out.*
3. **Short-term impact** e.g. length of stay, speed of recovery, side-effects of drugs.
4. **Long-term impact.** No more menstruation, infertility, possible HRT.

For each of the above score once per statement.
GUIDANCE FOR SCORING TAPES (4)

GYNAECOLOGIST'S STRATEGIES

(15) **STATEMENT ABOUT INVESTIGATIONS CARRIED OUT** (of a gynaecological nature)

1. **Objective report** of results. *Reporting for example that a scan is negative or any mention of a gynaecological investigation.*
2. **Personalized report.** *Doctor reports that: taken a look/seen inside - this could be referring to a hysteroscopy or laparoscopy. The name of the operation does not have to be mentioned.*
   
   For each of the above score every time the doctor refers to an investigation or a 'look'.

(16) **STATEMENT ABOUT PATHOLOGY**

1. **No pathology** *(a score for each item that is normal: e.g. ovaries, womb, no infection).*
2. **Normal/completely normal.**
3. **Fairly/essentially normal** *(to be used when doctor has indicated any abnormality in concrete, anatomical or physiological terms, including reference to, e.g. womb being slightly enlarged).*
4. **Possible pathology** *(not confirmed).*
5. **Pathology** *(fibroids, cysts, endometriosis).*
   
   For each of the above score once per statement.

(17) **EXPLANATION OF SYMPTOMS**

1. **Mystery.** *Doctor states he cannot offer an explanation or reason for symptoms.*
2. **Something going on but within what is normal** *(e.g. aches and pain/or to do with fine tuning in the body. The aim of the doctor is to try and normalize the patient’s symptoms).*
3. **Gynaecological problem** *(fibroids, cysts, endometriosis).*
4. **Non-gynaecological problem.**
   
   For each of the above score once per statement.

(18) **DOCTOR RAISES PSYCHOSOCIAL AGENDA.** *Doctor asks patient how her periods are affecting her life/reflects to the patient that she looks or feels fed up. It could also relate to issues more remote from gynaecological problem. For example the doctor might ask: Is intercourse alright? How are you getting on with your partner?*

   Score per statement when the doctor raises these questions.
GUIDANCE FOR SCORING TAPES (5)

(19) TREATMENT RECOMMENDATIONS
1. Stated. Doctor advises the best course of action (one treatment) for patient’s problem. This refers to actual treatments not to aspects of treatment (e.g. ovariectomy)
   Score once and name the treatment recommended.

2. Alternative treatment/options. Patient informed of other treatments which are available for her symptoms.
   Score once for the range of treatments offered.

   Score once per statement.

4. Treatment patient got. Name the treatment patient got.

5. Possible future treatment if no improvement in condition.
   Score once per statement.

6. Further investigations. This statement implies invasive investigation and/or blood tests.
   Score once for each statement.

   Score once for each statement.

(20) TREATMENT OUTCOME
1. Uncertainty. Doctor states: I can't guarantee the results.
   Score once per statement.
GUIDANCE FOR SCORING TAPES (6)

(21) **INFORMATION**
1. Side effects mentioned. Relating to: e.g. operations and drugs. Specific side-effects have to be mentioned by the doctor. Score once per side effect.

2. Information offered about treatment. This can relate to specific details about an operation. For example: vaginal/abdominal hysterectomy; ovaries remain; remove lining of the womb. It can also relate to information about drugs. Score per each piece of information provided. If the details are repeated do not score again since this may give the impression of numerous different details being offered. The aim is to note that information is forthcoming about treatment.

3. Waiting list. When the operation is to be done. Only score once.

4. Short-term impact of operation. Length of stay, speed of recovery. Score once per statement.

5. Booklet/leaflet offered about treatment. Only score once, even if a range of material is given to the patient.
### SCORING SHEET

#### PATIENT STRATEGIES

<table>
<thead>
<tr>
<th>Patient Code No:</th>
<th>Treatment Outcome</th>
</tr>
</thead>
</table>

#### (1) SYMPTOM PRESENTATION OF MENSTRUAL PROBLEMS

*patient volunteers symptoms/responds to doctor’s question*

- 1. Pain
- 2. Bleeding *(including clots)*
- 3. Extra symptom *(non-menstrual physical symptom)*

#### (2) MANNER OF REPORT

- 1. Experience of symptoms *(e.g. how bad or upsetting the pain or bleeding are)*

#### (3) PSYCHOSOCIAL DISRUPTION

- 1. Emotional effects *(e.g. reporting distress, tiredness, moodiness, tearfulness, fed-up)*
- 2. Social effects

#### (4) STATE OF SYMPTOMS

- 1. Improved/fine
- 2. No change
- 3. Worse
- 4. Catastrophizing *(e.g. I cannot go on, cannot carry on, end of my tether)*

#### (5) CRITICISM OF PROCEDURES EXPERIENCED

- 1. Failure of treatment *(it did not work)*
- 2. Damage of treatment *(got sick, got fat, fluid retention)*
- 3. Previous episodes experienced with other doctors

#### (6) CRITICISM OF PROCEDURES EXPERIENCED

- 1. Failure of treatment *(does not work)*
- 2. Damage of treatment *(causes sickness, weight gain)*
- 3. Fear of damage *(through side effects)*

#### (7) PATIENT INTRODUCES MEDICAL/PHYSICAL EXPLANATION FOR HER GYNAECOLOGICAL SYMPTOMS *(e.g. cysts, fibroids, adhesions, ovary attaching itself to bowel)*

- 1. Yes
SCORING SHEET (2)

(8) **PATIENT USES **LAY PHYSICAL EXPLANATIONS  
FOR HER GYNAECOLOGICAL SYMPTOMS *(e.g. weak womb)*  
1. Yes □

(9) **PATIENT EXPLAINS HER SYMPTOMS BY USING**  
MEDICAL PSYCHOLOGICAL TERMS *(e.g. anxiety)*  
1. Yes □

(10) **PATIENT USES **LAY PSYCHOLOGICAL TERMS  
TO DESCRIBE HER SYMPTOMS *(e.g. nerves)*  
1. Yes □

(11) **PATIENT SUGGESTS/RECOMMENDS MEDICAL/**  
SURGICAL TREATMENT FOR HER SYMPTOMS  
1. Non-specific *(e.g. something has to be done/do something)* □  
2. Medical *(drugs, HRT)* □  
3. Scrape □  
4. Have a look and see what’s going on □  
5. ER □  
6. Hysterectomy *(e.g. get rid of it)* □

(12) **PATIENT INTRODUCES ANOTHER EXPERT** *(to justify a diagnosis)*

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP or other professional</td>
<td>□</td>
</tr>
<tr>
<td>Relatives, friends</td>
<td>□</td>
</tr>
<tr>
<td>Media</td>
<td>□</td>
</tr>
</tbody>
</table>

(13) **PATIENT ASKS DOCTOR WHAT S/HE RECOMMENDS**
1. Yes □

(14) **REQUEST FOR INFORMATION ABOUT TREATMENT**  
1. Operation and drugs □  
2. Waiting list *(when to be done)* □  
3. Short-term impact *(length of stay, speed of recovery, side-effects of drugs)* □  
4. Long-term impact *(end of menstruation, infertility, possible HRT)* □
SCORING SHEET (3)

GYNAECOLOGIST'S STRATEGIES

(15) STATEMENT ABOUT INVESTIGATIONS CARRIED OUT
1. Objective report of results (e.g. scan negative or any mention of a gynaecological investigation)
2. Personalized report (e.g. taken a look/seen inside)

(16) STATEMENT ABOUT PATHOLOGY
1. No pathology
2. Normal/completely normal
3. Fairly/essentially normal (to be used when doctor has indicated any abnormality in concrete, anatomical or physiological terms, including reference to, e.g. womb being slightly enlarged)
4. Possible pathology (not confirmed)
5. Pathology (e.g. fibroids, cysts, endometriosis)

(17) EXPLANATION OF SYMPTOMS
1. Mystery (doctor says he can't explain, no reason)
2. Something going on but within what is normal: (e.g. aches and pains, fine tuning, weight)

(18) DOCTOR RAISES PSYCHOSOCIAL AGENDA (asks patient how periods are affecting her life/reflects to the patient that she looks or feels fed up)
1. Yes

(19) TREATMENT RECOMMENDATIONS
1. Stated (best course of action for patient's problem)
2. Alternative treatment/options (patient informed of other treatments which are available for her symptoms)
3. Preference/choice of treatment (patient prompted for their preference/choice of treatment)
4. Treatment patient got
5. Possible future treatment
6. Further investigations
7. No treatment (we'll leave well alone)
Appendix D:

SCORING SHEET (4)

(20) TREATMENT OUTCOME
   1. Uncertainty (*cannot guarantee the results*)

(21) INFORMATION
   1. Side effects mentioned (*specific side-effects have to be mentioned*)
   2. Information offered about treatment (*vaginal/abdominal hysterectomy; ovaries remain; remove lining of the womb, effects of drugs*)
   3. Waiting list (*when operation is to be done*)
   4. Short-term impact of operation (*length of stay, speed of recovery*)
   5. Booklet/leaflet offered about treatment
### Appendix D:

#### Table XI: Breakdown of Patients' Contraceptives (Study 4)

<table>
<thead>
<tr>
<th>TYPE OF CONTRACEPTIVE USED</th>
<th>N=88</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill</td>
<td>6</td>
<td>6.8</td>
</tr>
<tr>
<td>Cap</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Condom</td>
<td>16</td>
<td>18.2</td>
</tr>
<tr>
<td>Sterilized (female)</td>
<td>25</td>
<td>28.4</td>
</tr>
<tr>
<td>Sterilized (male)</td>
<td>14</td>
<td>15.9</td>
</tr>
<tr>
<td>None</td>
<td>25</td>
<td>28.4</td>
</tr>
</tbody>
</table>

#### Table XII: Patient and doctor strategies (Study 4)

<table>
<thead>
<tr>
<th>STRATEGIES</th>
<th>NON. Hysterectomy</th>
<th>Hysterectomy</th>
<th>F.E. p&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENT STRATEGIES (N=88)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient asks doctor what s/he recommends for treatment</td>
<td>5 (6.8%)</td>
<td>1 (6.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Patient asks about operation/drugs</td>
<td>28 (38.4%)</td>
<td>6 (40.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>Patient asks about waiting list</td>
<td>3 (4.1%)</td>
<td>3 (20.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>Patients asks about short-term impact of treatment</td>
<td>15 (20.5%)</td>
<td>-</td>
<td>ns</td>
</tr>
<tr>
<td>Patients asks about long-term impact of treatment</td>
<td>2 (2.7%)</td>
<td>3 (20.0%)</td>
<td>6.92 0.03</td>
</tr>
<tr>
<td><strong>GYNAECOLOGIST'S STRATEGIES (N=11)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor states best course of action for patient's problem</td>
<td>28 (38.4%)</td>
<td>6 (40.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor suggests alternative treatment options</td>
<td>26 (35.6%)</td>
<td>9 (60.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor asks patient for their preference/choice of treatment</td>
<td>20 (27.4%)</td>
<td>8 (53.3%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor informs patient of possible future treatment</td>
<td>2 (2.7%)</td>
<td>1 (6.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor informs patient of further investigations</td>
<td>11 (15.1%)</td>
<td>1 (6.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor informs patient that no treatment is necessary</td>
<td>19 (26.0%)</td>
<td>-</td>
<td>4.98 0.03</td>
</tr>
<tr>
<td>Doctor informs patient that there is some uncertainty about treatment outcome</td>
<td>12 (16.4%)</td>
<td>5 (33.3%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor informs patient about the side-effects of treatment</td>
<td>29 (39.7%)</td>
<td>7 (46.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor offers information about treatment</td>
<td>49 (67.1%)</td>
<td>13 (86.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Doctor informs patient about waiting list for the operation</td>
<td>7 (9.6%)</td>
<td>8 (53.3%)</td>
<td>16.84 0.0001</td>
</tr>
<tr>
<td>Doctor informs patient about the short-term impact of treatment</td>
<td>9 (12.3%)</td>
<td>10 (66.7%)</td>
<td>21.70 0.0001</td>
</tr>
<tr>
<td>Doctor gives patient booklet/leaflet about treatment</td>
<td>6 (8.2%)</td>
<td>1 (6.7%)</td>
<td>ns</td>
</tr>
</tbody>
</table>

F.E.=Fisher's Exact Test  ns=not significant
PATIENTS’ AND DOCTORS’ STRATEGIES IN CONSULTATIONS WITH UNEXPLAINED SYMPTOMS:

INTERACTIONS OF GYNAECOLOGISTS WITH WOMEN PRESENTING MENSTRUAL PROBLEMS

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Abstract

Patients commonly receive invasive investigation and treatment in response to entirely subjective symptoms, but little is known about how this decision is reached. We therefore audiotaped the interactions of gynaecologists with 88 patients presenting menstrual problems without confirmed physical pathology. From these, 8 interviews that led to hysterectomy were chosen for detailed qualitative analysis, together with 8 chosen from those leading to conservative responses. Dialogues leading to hysterectomy were characterized by a framework dictated by the patient. Typically, the patient presented psychosocial distress in a way that gave responsibility for managing it to the gynaecologist and she imposed a biomedical model on the dialogue: components of this included the presentation of an anatomical cause and a surgical solution and criticism of conservative treatments. In interviews leading to conservative responses, by contrast, the typical strategy whereby gynaecologists established their influence was to attest to the normality of a patient’s condition by confirming, in a personalized way, their ability to ‘look inside’ the woman’s uterus and see that it was normal. This established the gynaecologist’s control of such interactions, but a complication of this strategy was that it disregarded the symptoms presented. The theory we propose, that these strategies help to explain whether or not hysterectomy is chosen as a response to menstrual problems in the absence of pathology, can be tested by future quantitative analysis.

Key words- doctor-patient communication, menstrual problems, somatization
Appendix D:

Introduction

Medical and surgical treatment is often provided in the absence of objective signs or symptoms: that is, where the patients' complaints are entirely subjective [1-3]. Examples include many instances of back pain, pelvic pain, gastrointestinal problems, menstrual dysfunction and fatigue. This presents a dilemma for medicine, which is based on the provision of physical treatments for physical problems, and for health services because of growing concern that many patients may not be helped - and may even be harmed - by expensive somatic treatment. It is therefore important to understand how decisions are made about the physical treatment of subjective symptoms. Previous work has tended to emphasize the influence on consultation exerted by the doctor rather than the patient. For instance, the somatic diagnosis, investigation and treatment of patients with unexplained subjective symptoms has been attributed to doctors' misdiagnosis of a putative underlying emotional disorder [3]. A crucial limitation of this approach is to neglect the influence that patients exert on the process.

Traditionally, patients' influence on consultation has been viewed in terms of compliance with doctor's requests [5,6]; however, patients' ability to influence those requests is central to the consumer-orientation of health care, established in the USA and other countries and increasing in the UK [7]. Although recent work has begun to study the intentions that patients have when consulting their doctor [8,9], the ways that they pursue these intentions have received less investigation. A recent report described the strategies deployed by a single patient who constrained the surgeon to offer mastectomy in response to purely subjective complaints [10]. However, the relevance of this analysis of an extreme case to routine cases is not established, and we are aware of no study that has yet addressed this problem by examining in detail the interactions of doctors and patients.

The present study therefore focused on the interactions with gynaecologists of patients who routinely consult in large numbers, in the absence of detectable
organic pathology, with symptoms of menstrual dysfunction. These interactions are of particular interest. First, many lead to hysterectomy; in fact, a large proportion of hysterectomies are carried out as a result of such interactions (estimates range from 20-35%; [11,12]). Secondly, geographical variability in levels of hysterectomy and disagreement between gynaecologists on whether hysterectomy is indicated in specific cases [11,12] suggest that the decision reflects criteria other than 'hard' medical signs and symptoms. Thirdly, opposing views of the reason for the high level of surgical responses have been asserted strongly, but without appreciable empirical support. One is that it reflects physicians' influence, motivated by concern to minimize the risks of uterine cancer [13], by a desire to earn their patient's fee [12] or by a masculine need to assault their female patients [13,14]. Another view, frequently voiced by gynaecologists, is that it results from their inability to withstand the insistence of their patients.

To approach this problem quantitatively would require the assumption that existing conceptualizations of doctor-patient interaction provide an adequate framework for understanding and measuring these interactions. We have argued above, however, that existing frameworks are incomplete. Our study was therefore qualitative, with aims that correspond to the two key functions of such an approach: description and theory generation [15]. The first aim was to add to existing frameworks by delineating components of patient presentation and surgical response whereby either party might influence the other. The second aim was to propose a theory, grounded in an account of such interactions, which could explain why patients receive one clinical response or another and which could be amenable to subsequent quantitative investigation. We therefore contrasted consultations which led to hysterectomy with those that led to conservative treatment.

Our data provide no indication as to the appropriateness of the decisions that were made. Instead, our concern is the way that the different decisions come about. Given that none of our patients had confirmed pathology, the principal
way in which differing needs could influence the decision was by the dialogue that we observed.

SUBJECTS AND METHOD

Subjects

The sampling combined consecutive, purposive and random components. An initial pool of 88 consecutive patients were approached who (i) were referred with menorrhagia or dysmenorrhoea (ii) were attending one of 9 gynaecologists who had previously agreed to take part (Table 1) (iii) had received one previous consultation as part of the present referral (iv) had undergone an exploratory procedure as part of the present referral: dilation and curettage (D&C), laparoscopy, hysteroscopy (v) had no evidence of organic pathology (vi) provided informed consent. No patient declined to participate. To provide contrasting groups for analysis, audiotapes of 8 of the 15 consultations leading to hysterectomy were chosen at random for transcription. Additionally, consultations were chosen at random for transcription from those leading to endometrial resection (2 of 5), pharmacotherapy (2 of 28) and no treatment or further investigation (2 of 34).

TABLES 1 & 2 ABOUT HERE

Method

The female researcher sought the patient’s informed consent and then was present during the consultation to operate the audio tape-recorder. Transcripts were later prepared, anonymized for both patient and gynaecologist.

Parts of the transcribed interaction were not considered in detail. These included, principally, the gynaecologists’ attempts to clarify the history of prior consultations and tests. The approach to analysis of the remainder conformed to an ‘editing-analysis’ style [16], in which the aim is to allow theory to arise from a thematic analysis of the transcripts. In this way, the theory is grounded in the
data rather than preexisting conceptualizations [17]. The initial analysis was based on a set of 6 transcripts. From repeated reading of these, a preliminary account was constructed which was 'tested' by (i) rereading and coding the transcripts in the light of the account and (ii) discussion with a colleague who had read the same transcripts. After further 'cycling' between account and these transcripts [18], the resulting account was further tested and developed by reading and coding of further transcripts until this became unfruitful. The categorization of patients' and gynaecologists' strategies that we provide is the conclusion of this final analysis. Dialogue is presented to illustrate each type of strategy. Interviews are detailed in Table 2 and interview numbers are indicated in the text by superscripts. The final transcript is presented in detail to illustrate the sequencing and interaction of the strategies described. 'Turns' in this dialogue are numbered successively.

Results

Different strategies arose from analysis of consultations which led to hysterectomy and those which led to conservative responses. These are summarized in Table 3 and detailed separately below.

TABLE 3 ABOUT HERE

Consultations leading to conservative responses

Gynaecologist's confirmation of normality

Symptom presentation was not a salient feature of these interactions. Early in case dialogue, however, the gynaecologist stated the normality of the woman's uterus. Although some statements were made in objective terms

G2 The D&C is normal. It did not show anything. We have the pathology report and that's OK.

designations of normality were more commonly tied to the gynaecologist's ability to 'see' or 'look' inside the patient's body.
OK. All the swabs I did back in March were normal. X is the senior registrar, had a good look round inside. There's nothing wrong inside.

Now what you are here for today is mainly to have a chat to you because recently you have come in where we had a look inside you. Didn't we? Is that right?

Yeah.

Now we agree on that. Did we tell you what we saw when we had a look inside you?

Gynaecologists' models of normality

Categorical vs ambiguous models of normality. Despite the categorical nature of statements such as that above, many were ambiguous in implying both normality and a small degree of abnormality:

Your womb is perfectly normal. Very slightly enlarged. We've had a look inside.

You know, you're quite alright inside. Endometriosis was only spots of endometriosis. Alright, it's not as if there's any major problem down there.

A second difficulty is the discordance that exists between the patient's experience of symptoms and the doctor's statement that all is well. In one instance, the doctor herself acknowledged this:

So I can't explain that pain. Alright?

Right.

But we often find in similar situations we do find ladies come up to clinic with genuine pain. We do laparoscopies, we do find that reassurance helps.

Yeah.

Whether its reassurance or a laparoscopy itself, I don't know.

Reference to 'genuine pain' implies a distinction between real and unreal pain, and the gynaecologist's appeal to the effects of laparoscopy or reassurance
appeared to identify this patient’s presentation with unreal pain. In another instance, the patient’s attempt to explain reduction in her symptoms since investigation highlighted the discordance between the reality of her experience of her symptoms and the gynaecologist’s use of a model in which symptoms (and changes in their intensity, cannot be explained.

\[P^6\] Have you, is that because what you’ve scraped away?

\[G\] Not really. No.

\[P\] Is there some kind of block or something? Why is the bleeding much better now? Or like what you’d expect it to be in a normal period.

\[G\] It’s not something we scrape away really, I mean, that’s really certainly relevant to the lining to the womb, to your health, to yourself, really in many ways. So not what I scrape away as such, ah, I mean, that may, or may not.

\[P\] I thought you unblocked something. I mean, opened the flood gates.

\[G\] I mean, it may, may not be. I don’t think we’re that clever.

Gynaecologists’ use of lay models of normality. These ambiguities exist because the gynaecologist’s model of normality was based on a rigid separation of normality and abnormality. There were however other, less rigid models presented in which normality was consistent with the presence of symptoms. In one instance the gynaecologist appealed to a lay notion of meaningless aches and pains:

\[G^3\] We all get aches and pains. It doesn’t particularly mean anything.

A second gynaecologist used a machine-based model in which medically unimportant problems could be understood as arising from normal function:

\[G^4\] Which means that the problem with your periods is one of the sort of finer control of the way your womb is working.

\[P\] Right.

\[G\] And we know that, that, there is a very fine hormonal control on how your womb is working and how heavy your periods are.

\[P\] Mm.

\[G\] And unfortunately at some stage it tends to give up and that’s when your
periods tend to get too heavy.

Whereas the 'aches and pains' model assumes a gynaecologist with authority to separate meaningful from meaningless pains and, by implication, to treat the former, the latter model gives the doctor much less responsibility. The symptoms have been acknowledged as real and physically based - and therefore in principal amenable to treatment. However, the effects of that treatment cannot be predicted. Therefore treatment becomes 'trial and error' as was explained to a second patient:

G^8 What you need to know about medical treatment is that nothing comes with any guarantees. All women are different. All women are different. Some things work for one woman and don't work for another. So medical treatment is all a little bit of trial and error.

and again when discussing treatment options:

G^5 So there is, there are other medical choices. And, you know, we are quite happy to do whatever you want to do. We are quite happy to fiddle and trial and error - and try one thing and try another thing - if you feel you can handle that.

Patients' reference to external authority

In no instance did a gynaecologist cite literature or another person as authority for his/her statements. Patients' recourse to external authority included written literature, but also lay individuals. In opting for endometrial resection, one patient cited her mother in addition to literature:

G^8 Okay, that's fair enough. I think an endometrial resection might be worth your while thinking about. I think it's an option.

P That's the option I've been thinking about mostly 'cos like I talked to me mum. 'Cos she's, she's like had a few problems as well.

G Right, right.

P In her eyes as well, she, she thought this would be better than hormone.

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G You've decided.
P I mean, even, like because I read a bit about it before I'd seen you anyway, the first time.
G Right, so really you had more or less decided about it.
P Um, since you, like told me if I had anyway been thinking about it and listened to what my mum says.

Treatment decision
For most patients the elimination of pathology by the gynaecologist led naturally to a decision for no treatment or continued medication only. Generally this was proposed by the gynaecologist but, on occasion, by the patient:
P^ I mean, there is nothing you can do, is there? I mean you've done that, and there's nothing there.

One setting, in which a research trial of endometrial resection was being conducted, was distinctive in that patients were explicitly invited to consider treatment
G^ Let's talk about all the different options that there are.

even in the face of initial reluctance.
G^ The question is are you happy with this?
P Yes.
G Or do you want to do something more?
P Ah, right, um. I suppose I'm happy if.
G She says, I'm not happy.
P Yes. I know. Oh it just means more palaver really. You know, it means going into hospital and, and, what sort of options are there anyway? I mean, I have to ask you that.

This dialogue continued with the presentation by the gynaecologist of a cafeteria of options, including endometrial resection, and with a decision-making process in which the gynaecologist explicitly gave her patient the responsibility for choosing treatment:
Um. What are your expectations?

Well, I just hope that it will improve matters. I know there's might be a slim chance that I won't get any more periods. But I know it's possible that hopefully they will be a lot lighter.

Right. Okay. Yeah. This is what I thought important to clarify, because there are some women who feel that the operation stops their periods and that's it and you end up with a tiny amount of bleeding which is very disappointing.

Oh no, I'm hoping for no more.

Oh yes. Sure.

But I'm prepared for

Absolutely. Yeah. That's what I wanted to make clear that our aim is to improve the degree of loss. But if you are lucky it may stop altogether.

But

M'm.

That's not the aim. We

That's what I'm hoping for, but I know it's not, not definite.

Consultations leading to hysterectomy

Symptom presentation

By contrast with the previous dialogues, a number of distinct components to symptom presentation were salient.

Deterioration. The emphasis in patients' symptom presentation was on failure to improve since the previous consultation. Indeed, the interviews typically began in these terms:

How are you?

Not too bad.
Good.

Still suffering.

How’s things?

No better.

In general, however, the presentation did not stop at the failure of symptoms to improve, but went on to emphasize continued deterioration since the previous visit. Central to this picture of deterioration was the extension of pain to a wider area:

How are you?

Rapidly going downhill Mr X. I’m afraid.

I’ve had the most horrendous pains.

Where are the pains?

Well it’s all over, it’s the whole of my abdomen this time where I get this thing.

What have your periods been like?

They are just the same, only I’m getting more pain in my back now, then I did have before.

Psychosocial distress. Every patient who presented deteriorating symptoms went on to describe the negative effects of the symptoms on their lives. Accounts included the immediate effects of symptoms,

I’m still getting up in the night at least three times for the first three days.

and emotional distress:

I feel very fed up at the moment.

but they extended to the complication of social and employment activities. In the following dialogue, the patient responds to an enquiry about severity of periods by presenting, not information about the level of symptoms, but details about their effects on her working life:

You say your periods are that bad?
Appendix D:

P  Well I'm a lollipop lady for a start and I can get myself change just before I go out in the morning you can guarantee in three quarters of an hour I'm rushing back into the toilets to get changed.

G  They're that bad?

P  Because

G  Yes.

P  I'm wearing two sanitary towels.

G  Yes.

P  A tampax,

G  Yes.

P  and I don't feel comfortable and I'm working with children all day

G  Yes.

P  And I feel so uncomfortable. I can't see myself saying to the children 'I've got to go to the toilet.' Ha ha.

Threat. The picture of recent deterioration extended to the prediction of future deterioration to a dangerous level. The danger was usually diffuse and unspecified and described as an inability to 'go on':

P  I don't think I can go on. I've been like it for 5 year now and I don't want to, you know, sort of wait any longer.

G  They are not likely to get much better before you get the menopause.

P  Yeah. I don't think I can last that long really.

This patient later specified a danger: the risk of damage through overdosing on analgesia:

G  What have you tried for your periods?

P  Well, I just take panadol-extra. But it worries me because I have to take the maximum of 8 tablets a day nearly every 4 hours.

Patients' biomedical explanatory model

No model of the patients' symptoms was apparent in the gynaecologists' responses. By contrast, patients commonly presented the gynaecologist with a
clear model that attributed their problems to an anatomically localized cause, i.e. the uterus, and invited their surgical removal.

*P* 11  Um, we, I feel really that the main solution to my problem would be hysterectomy.

*G* 10  What do you think we should do?

*P*  Just stop it. I can't be done with them.

*G*  How do you categorize 'stop it?'

*P*  Hysterectomy, or whatever you, or whatever you suggest.

**Criticism of available treatments**

Patients commonly criticized previous treatment by the gynaecologist. For one patient, this involved simply the failure of symptoms to respond to previous interventions (even diagnostic ones).

*P* 13  Could I really have a hysterectomy if I wanted to?

*G*  Mm, mm.

*P*  Because I had this scrape. And that didn't help.

*G*  That is really for diagnosis really. To make sure there's no desperate need to do a hysterectomy.

*P*  Yeah. And ah, you know I've had all the hormone tablets and the other.

In all other instances, however, further deterioration was dated to those interventions.

*G* 10  Recently we got you in and ah to look at you didn't we?

*P*  That's right, yes.

*G*  Ah, we were wondering whether you may have you know some problems because you still have heavy periods?

*P*  Mm, I have since I've had that [D&C] done as well. It's even got worse since then.

Additionally, new symptoms were attributed to prior interventions.

*P* 12  That [drug treatment] was horrendous, I put on half a stone just like that. It was so depressing after I'd starved myself again.

Other patients criticized previous gynaecological procedures unrelated to the
current referral (such as insertion or removal of a contraceptive coil). Criticism of a previous specific treatment cast doubt on the value of conservative treatments generally.

\[G\] You don't want any other form of treatment. Don't want to be cauterized or whatever? Sometimes we cauterize the womb instead. Ah

\[P\] Well, what I had before, did absolutely nothing for me. It's actually worse than I was before.

Similarly, patients merely anticipated the failure or negative effects of alternative treatments

\[P\] I worry about the side effects with tablets.

\[G\] Right.

\[P\] 'Cos, I take that many. And me stomach's off, isn't it, you know. Can't win.

\[G\] We've not tried you on any medicines or tablets or anything like that?

\[P\] Are they going to work? Cos if they're not I don't think I'll want them.

\[G\] I don't think they will probably either.

\[P\] Mm.

\[G\] It's a hysterectomy.

\[P\] Mm.

\[P\] Yeah, fine, yeah.

Patients' reference to external authority

This was apparent in one patient's comments:

\[P\] I mean, my daughter actually says to me if you don’t get it [hysterectomy] done soon she'll wheel me to the theatre and do it herself.

Gynaecologist's statement of normality

This strategy was rare in this series of interviews. Only one gynaecologist attempted to normalize a patient's symptoms:

\[G\] You had a D&C not so long ago. It shows a fairly normal uterus. The histology on the lining is OK.
Treatment decision

It is clear from many of the above statements that the request for hysterectomy was often the patient's and that, in other cases, the decision reflected the elimination of alternative treatments. An exception was a single case in which hysterectomy was pressed by the doctor against obvious reluctance on the patient’s part.

G

Um, we've got two options, you know. We can either operate on you or we can try different tablets. The operation will be the hysterectomy which will take away Um.. the womb and that will be the end of the bleeding.

...........

P

A big decision isn't it? I don't feel like no operation. Can I try some more tablets?

...........

G

Yeah. I was rather hoping that you were going to say you wanted a hysterectomy.

...........

P

Will this be after Christmas?

G

Yeah. It can be. I mean

P

M'm.

G

Let's put it. I mean we're doing this operation not for a life threatening condition. We are doing something because for social aspects - for the quality of your life. So I mean, you know, you can pick when you want it really.

P

Yeah.

...........

G

What you got planned for January?

P

Not a lot. Can we leave it 'til February?

Case study'

Extracts from this interview are presented, taking account of the order in which
they occurred, to illustrate how the separate strategies that we have described interacted during the course of the interview.

**Symptom presentation: deterioration, psychosocial distress and threat**

Symptoms were deteriorating and expanding in place and time. The patient introduced the psychosocial dimension early in the interview, with the implication of disastrous consequences should she remain untreated.

\[ \text{G1 Good afternoon. Dr. X. How are you? Right. How are you doing?} \]
\[ \text{P Oh. Not doing very good.} \]
\[ \text{P8 I'm getting ever such a lot of pain in between as well.} \]
\[ \text{G That's when you are not bleeding at all?} \]
\[ \text{P Even when I'm not bleeding. Yeah. And it's all, you know, down on the left hand side. That's getting worse than what it was before.} \]

At this point, the gynaecologist moved to objectify symptoms by referring to the menstrual chart completed by the patient. However, the patient re-established her control over the dialogue by introducing psychosocial problems and threats to her ability to continue coping:

\[ \text{P50 The, the thing is that, I'm, I'm just getting to the end of my tether because I've, I've, um. You get dirty looks at work.} \]
\[ \text{G Yes.} \]
\[ \text{P And, um, I just feel as though I'm going to lose my job. If this carried on.} \]
\[ \text{G Yes.} \]
\[ \text{P I can't carry on.} \]

Psychosocial material was not confined to the start of the interview. It recurred periodically: for instance, when the gynaecologist and patient discussed the anatomical basis of the symptoms (see below):

\[ \text{P78 But I mean. As I say, what, what's worrying me is that um. I mean if I lose my job, I've lost everything.} \]
\[ \text{G Oh yeah, yeah.} \]
\[ \text{P You know, I mean. I, I just. Well, it's getting me down.} \]

The same strategy recurred when the gynaecologist suggested a conservative
approach, to investigate the source of the pain (see below). She added new material concerning disruptive effects of her symptoms on her sexual relationship.

G139 The other thing to do is to put a scope in your tummy and have a look first before we do anything.

P M’m.

G If, if it is the pain that is the main bother.

P Well, I mean, it is both obviously.

G Right,

P When I am bleeding, I mean, that, that is bad because sometimes I can’t go to work from bleeding. But

G Right.

P I mean, I’m also having to have time off with the pain as well.

G M’m.

P And sometimes, the, the, worse pain is coming sort of, I’m getting it a week before I start.

G M’m.

P And, and, then I’m having a bad bleed after.

G Mm.

P So I mean this is why it’s getting so

G Mm

P Bad at work

G Mm Mm

P And um, I mean, I’ve got the pain all the time. So I mean, that is getting me down. I’m not sleeping sometimes

G Mm.

P Through it. And, I mean, the friend who I go out with, we are not having a proper relationship because half the time it’s too painful.

Patient’s explanatory model

The stimulus to the patient’s presentation of her model was the gynaecologist’s doubt as to the gynaecological basis of the inter-menstrual pain.
G59 Yeah. But there is something I have to tell you. Pain usually due to gynaecological causes gets worse during the periods.

In contrast to the gynaecologist's failure to provide a model, the patient provided an explanation for her symptoms which located them firmly within the gynaecologist's domain.

P68 But, but the one on the left hand side. Years ago I had an op, um, and it was my left ovary

G Mm.

P That was causing the problem. I needed, it had attached itself to the bowel.

G Yeah.

P Well, the pain I'm getting on my left hand side

G Mm, is similar to what you

P It feels like

G Like what you had before.

P I had years ago.

The model had clear implications for intervention:

P96 Is this hysterectomy, would they check up on the left ovary as well?

The gynaecologist worked within this model in his own attempts to dissuade the patient of a gynaecological basis to the pain:

G83 But the pain. Because your left ovary was attached to your bowel, for all you care the pain could be coming from the bowel.

Soon after, however, he acquiesced to the patient's model and to its treatment implications.

G113 I think on balance if we have to do any medical intervention for you, then probably an abdominal hysterectomy would be in order um, because then we have the chance of looking at your ovaries and if there are any adhesions, we can divide them. But what I am saying is that, if after your operation you still have your pain then I mean, it is probably, it's very probable that pain is not gynaecologically um, related.

The patient's model was sufficiently flexible to respond to the gynaecologist's
continued attempt to reopen the area of non-gynaecological pain. Clearly, at this point, the patient had control of the medical model which underpinned the interaction and which set the agenda for the gynaecologist as well as the patient.

G127 It is very difficult to imagine the ovary attaching itself to the bowel and causing you that much pain. Unless there are very tough adhesions there which we'll divide in any case.

P I'm not saying that's what its attached itself to this time.

G Mm.

P Um. I mean that's what it was attached to last time.

Treatment decision
It was possible to identify a single point in the interview at which the decision was made to proceed to hysterectomy. The two salient points were where, above, the gynaecologist introduced hysterectomy as a response which was valid in terms of the patient’s model and, subsequently, where the patient expressed her preference for surgery:

P191 I think can I say yes to that, I think, the hysterectomy?

G Right, fine.

P As I say I, I've just come to the end of it.

Reaffirmation of threat
Even this statement was not, however, final. It was followed immediately by psychosocial material and, later, by the danger which resulted from her current treatment:

P245 The problem is just lately I've gone on such a lot of tablets and I, I don't. I mean, you know what I mean, sort of before this, before I started this episode.

G Yes.

P I didn't take any tablets at all.

G Mm.

P Um. You, you know what I mean. It sort of, it fair worries me the fact
that I'm chucking everything down. But, I need them, you know for the pains, sort of thing. But, um, it fair worries me that I'm taking all these tablets.

Appeal to external authority
This occurred at the end of the interview, when the gynaecologist continued to warn that pain originating in the bowel would not be helped by the hysterectomy. The patient's response was to refer to a previous consultation with a gastroenterologist and to reassert the gynaecological basis of the pain on this doctor's authority.

P267 They thought I had an irritable bowel syndrome.
G Mm.
P Well, I have. He said I have got irritable bowel syndrome.
G Right, right.
P But he has says that the pain you are getting is gynae, gynae
G Gynaecological.
P Gynaecology, yeah.
G Mm.
P Ah.
G So that is what he said?
P Yeah.
G M'm. I hope so.

Discussion
Dialogues leading to hysterectomy and to conservative responses were similar in an important respect: the objective characteristics of patients' symptoms rarely featured. In part this reflected our study of the second interaction in the sequence: symptoms had been detailed previously. However, it also became clear that, in both sets of interviews, the clinical decision was typically negotiated by material other than symptoms. Beyond this, our analysis of dialogues leading to conservative and surgical management yielded different strategies, for both
patients and gynaecologists.

Conservative responses followed dialogues in which the gynaecologist typically stated the normality of the patient on the basis of objective investigations. That is, normality was defined in terms of locations that were inaccessible to the patient who was therefore unable to disagree. A striking feature of these statements was the gynaecologists’ reference to 'seeing' and 'looking around' inside the patient. So personalizing the authority for the statements is likely to strengthen a gynaecologist’s position in the dialogue that follows. Such responses were clearly successful in the limited sense that conservative decisions were made which disposed of the referral. However, the success of the strategy was less clear when judged as an attempt to establish a common understanding between doctor and patient. First, these statements of normality refer to a state that is qualitatively distinct from, and opposite to, abnormality, and which indicates a symptom-free state. That is, the gynaecologists’ approach to normalization denies or disregards their patients’ symptoms. This discordance was made explicit by the gynaecologist in interview 1 who admitted her inability to explain her patient’s pain. Her subsequent reference to ‘genuine’ pain and to the ability of reassurance to relieve pain betrayed the dualist view of pain that this view of normality entails. Similarly gynaecologist 4 had no reply to a patient who proposed a model to explain, not her symptoms, but their improvement since her D&C.

Gynaecologists’ ambiguous designations of normality might have been a response to their awareness of these problems. However, references to the womb being ‘slightly enlarged’ or having ‘nothing major’ are likely to be problematic for a patient: they are made in a framework in which normality is not graded, so that any absence of normality must be a cause for concern. Despite the evidence that menstrual bleeding in the general population varies widely and continuously [19], no gynaecologist presented a picture of normality as a continuum. However, two gynaecologists attempted to normalize patients’ symptoms in terms of lay rather
than medical understanding, and using frameworks within which real symptoms can exist but not signify abnormality: one referred to 'meaningless aches and pains'; the other likened the womb to a finely tuned machine.

It was in interviews that led to hysterectomy that the patients' ability to shape the interaction became apparent. Patients presented psychosocial material rather than symptoms, and used psychosocial disruption and distress to indicate the severity of their need. Tuckett et al [19] have observed how patients add details of their problems that extend beyond the narrow presentation of their symptoms. Our results extend this view by suggesting that psychosocial material is strategically presented so as to engage the doctor. The effect is that the doctor is given the responsibility for the patient's psychosocial suffering as much as for their medical needs. Given that doctors accept this kind of responsibility [10], patients can reinforce this process by threatening continued deterioration towards the limit of their tolerance. The implication of this strategy is that the doctor would become responsible for the unspecified consequences of their failure to arrest the decline.

Patients did not, however, seek psychological support to deal with their psychosocial needs. On the contrary, it was patients rather than the doctors that imposed a biomedical model of their problems onto the dialogue. The most obvious component of this was an anatomical attribution, in one case highly detailed, which indicated hysterectomy. The testimony of experts - medical or familial - was cited in support. This observation is evidence of the process that Shorter [19] has suggested: that medicine loses control of models that pass into lay discourse about health and illness.

Intrinsic to the model was that it located the patient's needs within the domain of the gynaecologist. Patients went on to work within the model by highlighting the failure of conservative procedures (even exploratory ones) and often went beyond this to attribute deterioration or harm to gynaecologists' recent or
previous actions. In this way, the gynaecologist was given responsibility to the point of culpability: that is, s/he was bound into a moral obligation to help the patient as well as a professional responsibility. In this context, the model provided by one gynaecologist who likened the womb to a 'finely balanced machine' was significant: it formed the basis for a restriction of the gynaecologist's responsibility to actions rather than results: i.e. 'trial and error'.

Our observations with patients who went on to hysterectomy converge in important respects on key strategies described previously whereby a single patient secured surgical intervention in the absence of pathology [9]. In addition, we have identified strategies with which the gynaecologists responded to the patients' presentation. That these were detected in dialogues leading to conservative responses implicates them in the avoidance of surgical intervention. Our theory is therefore that, in the absence of organic signs, patients and doctors use the strategies that we have described to exert their influence towards opposite ends: disposal and disengagement (sought by the doctor) or engagement, even to the point of surgery (sought by the patient). The strategies of each serve to establish a basis for the dialogue of which they alone have knowledge: the view from inside the uterus (by the doctor) and the subjective experience of symptoms and their effects (by the patient). Paradoxically, it is the patient who increases her influence by introducing aspects of a medical formulation.

In isolation, some of the strategies that we have described have been reported in previous accounts of interactions of patients with general practitioners [20,21]. However, their possible influence on the course of the interaction has not been considered, perhaps because of the assumption that doctor-patient communication is essentially collaborative. The view of doctor-patient interaction that emerges from the present transcripts is therefore of an activity between opponents: one aiming to give responsibility to the other for her distress, the other aiming to resist that responsibility. It may be this property of the interactions which explains the apparently unfocused and unstable nature of some doctor-patient
dialogues described by Stewart [22], which weave back and forth between medical and psychosocial agendas. On the basis of our model, to regard the interview as unfocused would be mistaken: the apparently meandering course can be the result of each party's use of strategies towards opposite goals.

The importance of this report is, firstly, to have described strategies in doctor-patient communication which, because clearly able to exert leverage in the negotiation of a response to unexplained symptoms, should be incorporated in theoretical accounts of doctor-patient communication if these are to be realistic. Secondly, we have proposed a theory as to specific patient and doctor strategies that influence the decision for surgery in the absence of pathology. The quantitative test of this theory, by coding of the larger pool of consultations on the basis of the strategies identified in the present report, will be the subject of further analysis and report.
Table 1. Details of participating gynaecologists.

<table>
<thead>
<tr>
<th>Gynaecologist</th>
<th>Grade</th>
<th>Sex</th>
<th>Race</th>
<th>Age</th>
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<td>White</td>
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<td>5</td>
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<td>White</td>
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<tr>
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<tr>
<td>8</td>
<td>Consultant</td>
<td>M</td>
<td>White</td>
<td>47</td>
</tr>
<tr>
<td>9</td>
<td>Registrar</td>
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Table 2: Details of patients and interviews.

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<th>Interview duration (mins)</th>
<th>Treatment decision</th>
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<td>2</td>
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<td>Hysterectomy</td>
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Appendix D:

Table 3: Summary of strategies detected in patients’ and gynaecologists’ parts of dialogues leading to hysterectomy or conservative responses.

### Consultations leading to conservative responses

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<th>Patient</th>
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<td>Report of normality</td>
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<tr>
<td></td>
<td>Objective report</td>
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<tr>
<td></td>
<td>Personalized report</td>
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<td></td>
<td>Model of normality</td>
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<tr>
<td></td>
<td>Categorical normality</td>
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<tr>
<td></td>
<td>Ambiguous normality</td>
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<td></td>
<td>Lay normality</td>
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### Consultations leading to hysterectomy

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<th>Gynaecologist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom presentation</td>
<td>Normalization</td>
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<tr>
<td>Deterioration</td>
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</tr>
<tr>
<td>Psychosocial distress</td>
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<tr>
<td>Threat</td>
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<tr>
<td>Biomedical explanatory model</td>
<td></td>
</tr>
<tr>
<td>Criticism of conservative treatment</td>
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<tr>
<td>Failure of past treatment</td>
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<td>Harmful effects of treatment</td>
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<td>Reference to external authority</td>
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</table>
References


