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The illness experiences of women with fibroids. An exploratory study using interpretative phenomenological analysis

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ABSTRACT

This was an exploratory qualitative study investigating the illness experiences of women with the gynaecological condition of fibroids. Previous research reported that women with fibroids attending a central London gynaecology outpatient service had high levels of distress. Eighteen women with fibroids completed the Hospital Anxiety and Depression Scale and were interviewed using a semi-structured interview. The content of the interview was guided by Leventhal's self-regulation model. The main aim was to explore how women with a diagnosis of fibroids experience and think about their condition, with a further aim of developing an understanding of how their gynaecological problems influence their emotional state. The interview transcripts were qualitatively analysed using Interpretative Phenomenological Analysis. The analysis revealed eight themes: 'what is normal?', 'seeking knowledge', 'the doctor's viewpoint and the woman's viewpoint', 'it's going on and on', 'thinking about fibroids', 'not leading the life I aim to lead', 'effects on self and others' and 'gaining control'. These themes were drawn into two higher-order themes: 'managing uncertainty' and 'struggling between defeat and optimism'. These themes attempt to capture the experience and understanding of having fibroids for the eighteen women in this study and provide a framework for understanding their levels of distress. The findings are discussed in relation to the literature on distress among gynaecology patients and the illness representation literature. The implications for medical and clinical psychology service provision to gynaecology patients are considered.

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CHAPTER ONE: INTRODUCTION

Overview of the Study

This is an exploratory qualitative study investigating the illness experiences of women with the gynaecological condition of fibroids. Research has consistently shown that women attending gynaecology outpatient services have high levels of anxiety and depression. Although a number of theories have been proposed to account for this, it is poorly understood. The study is informed by the illness representation literature, in particular Leventhal's self-regulation model (Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitailee,1997).

This study was initiated following a recent study at a central London hospital that found that women with fibroids have especially high levels of psychological distress (Glover, Novakovic & Hunter, unpublished; O'Donovan, Glover, Hunter & Novakovic, 2001). There is currently no literature looking at the illness experiences of women with fibroids, which could aid understanding of why these patients appear to be particularly vulnerable to experiencing distress. Qualitative methodology was employed as it has previously proved useful in health psychology research looking at illness representations (Leventhal & Nerenz, 1985) and this approach is particularly suitable for researching areas in which there is a lack of previous research.

Background to the Research

It is only within the last few decades that the lack of information and research on women's health and well-being has been highlighted (Ussher, 2000). Increased attention to women's health issues across a wide range of disciplines has resulted in more research investigating the biomedical and psychosocial factors that contribute towards the diseases and conditions that affect women (Gallant, Coons & Morokoff, 1994). Within the field of clinical psychology, researchers are interested in looking at the psychological health of women with health problems and developing psychological interventions aimed at reducing their distress.

Interest in the psychological distress among gynaecology patients has been expressed since the early 1940s. At this time a special edition of the medical journal 'Bulletin of the Menninger Clinic' was devoted to gynaecology and psychiatry in order to promote *'co-operation and respectful attention'* between these two specialities (Bulletin of the Menninger Clinic, 1943 p.2). Since then a number of studies have reported that women attending gynaecology clinics experience particularly high rates of psychological distress and psychiatric morbidity as measured by standard psychological instruments and compared with general population surveys or control groups (Hunter & Walker, 1998; Hodgkiss & Watson, 1994; Low, Edelman & Sutton, 1993; Agrawal, Malik & Padubidri, 1990; Byrne, 1984; Ballinger, 1977; Worsley, Walter & Wood, 1977). However, within obstetric and gynaecology services, referral rates to liaison psychiatric services are low (Phillps, Dennerstein & Farish, 1996; Hrasky & Morice, 1986) or non-existent (Abiodun, Adetoro & Ogunbode, 1992). Thus, although it has been established that these women are distressed, little research has been conducted into identifying the reasons for these high levels of anxiety and depression.

The onset of illness can result in a range of problems, which can vary greatly from patient to patient, even amongst individuals with the same condition. Within the field of health psychology, it is becoming clear that in order to understand these difficulties, it is necessary to find ways of accessing the models or representations that patients create to make sense of their illness (Leventhal & Nerenz, 1985). Studies in the field of illness representations have provided a model for understanding how people think about their health status and how this influences their emotional reactions and behavioural coping strategies in response to real or potential health threats. A number of different illnesses and conditions, including diabetes, breast cancer and myocardial infarction have been investigated (Petrie & Weinman, 1997). However, few studies have asked women about how they appraise and understand their gynaecological conditions. Research in this area could inform our understanding of the possible factors contributing towards women's distress, which would be beneficial for the women themselves and those involved in their care.

As previously stated, referral rates to psychiatric services are low. However, clinical interest in working psychologically with gynaecology patients is increasing. A few psychological interventions, for example cognitive-behavioural treatment for menopausal hot flushes (Hunter & Liao, 1996), have been designed and positively evaluated. Hunter and Walker (1998) have outlined a number of ways in which clinical health psychologists may work with gynaecology patients. These include direct assessment and treatment work with women either individually or in groups; working within a teaching, supportive and research orientated approach with medical staff; and advising service providers about psychological considerations in the development and provision of gynaecology services. Given the high levels of distress evidenced among gynaecology clinic attenders, it is clear that clinical psychology has an important role to play in the treatment of these women. However, whilst psychological interventions have been shown to be beneficial for women with a variety of gynaecological and concomitant psychological problems, more research is needed to inform and develop their clinical application in order to optimise service provision (Hunter & Walker, 1998).

Context of the Current Study

The current study is part of a larger study looking at the provision of psychological services to women attending gynaecology services at a central London hospital. Previous research at this hospital involving a questionnaire survey of 200 gynaecology outpatients found that 35% of women scored in the clinical range for depression and 60% in the clinical range for anxiety.

Furthermore, when asked whether they considered themselves to be distressed, 49% said yes (Glover, Novakovic & Hunter, unpublished; O'Donovan, Glover, Hunter & Novakovic, 2001). The results showed that one of the groups that seemed to be especially distressed were women with fibroids. Of these 22 women 73% were in the clinical range for anxiety and 36% were in the clinical range for depression. In addition, 68% of these women described themselves as 'distressed'. Furthermore, eight (36%) of these women had sought help in the past for psychological or emotional problems (O'Donovan et al, 2001). Despite these high levels of clinically significant distress, there is a lack of research looking specifically at the psychological aspects of having fibroids. This study proposed to investigate the illness experiences of women with fibroids.

Overview of Chapter One

The chapter will begin by providing some information on fibroids, the gynaecological condition investigated in this study. This will be followed by a brief overview of the general findings in the literature on distress in gynaecology patients. The various theories proposed to account for this robust finding will then be presented. The next section will provide a review of the illness representation literature relevant to this study, with particular emphasis on the Self-Regulation Model developed by Leventhal and colleagues (Leventhal et al, 1997). This section will also outline some of the ways in which this model has aided our understanding of how lay people understand and cope with illness. A brief rationale for the choice of qualitative methodology will then be presented and the chapter concludes with the aims of the current study and the main research questions.

Much of the research presented in this chapter has been conducted on general samples of gynaecology clinic out-patients, usually first time attenders who present with a variety of complaints. Other studies have looked only at certain conditions. Where studies have limited their focus to specific gynaecological conditions this will be indicated to the reader, so that it is clear that the conclusions of the researchers relate only to this condition.

Fibroids

Fibroids are a common condition in which there are one or usually more benign growths of the uterine muscle. Fibroids consist mainly of muscle cells and of fibrous tissue, which start as small knots of muscle within the wall of the uterus. They then continue increasing in size either into the uterine cavity or outwardly into the peritoneal cavity of the pelvis and abdomen. How and why fibroids begin to grow is not known. However, oestrogen is known to promote their growth and menopause causes them to shrink (McKay Hart & Norman, 2000; Wilson, 1999; Rees, 1998; March, 1994).

Research suggests that fibroids are present in around a fifth of all women over 30 years and are most common in women over 40 years, who are towards the end of their reproductive years. They are more common in obese women, Afro-Caribbean and African women and women who have had no children. They are less common in women who are smokers (March, 1994). Fibroids are commonly discovered before the woman has noticed any symptoms, through routine gynaecological examinations, such as those conducted during pregnancy or regular smear tests. Otherwise they may be diagnosed following referral to a gynaecologist for heavy bleeding, pelvic pressure or fertility problems.

Some women may have asymptomatic fibroids, whilst other women may experience symptoms, which they find extremely disruptive, distressing and difficult to manage. The most common complaints of women with fibroids are pressure symptoms and menorrhagia (heavy bleeding). Pressure symptoms occur when the fibroids increase in size, causing them to press against the internal organs. This may cause a variety of physical symptoms including increased urination, backache, lower abdominal discomfort and pain during intercourse. Furthermore, about a quarter of women with fibroids have fertility problems. A possible complication with fibroids is that they can outgrow their blood supply and become ischaemic, meaning that the blood flow is reduced. This means they are subject to various forms of degeneration. This may cause bleeding and severe pain, which may require emergency surgery. In very rare cases, the fibroid may become malignant (McKay Hart & Norman, 2000).

Treatment options for fibroids are limited. Medical textbooks suggest that treatment is guided primarily by the size and location of the fibroids, the presence of symptoms such as menorrhagia, and the woman's age and desire for future pregnancies (e.g. Wilson, 1999). If the fibroids are not causing any symptoms and are relatively small (5cm or less), they may initially just be observed and reviewed at regular intervals. West & Lumsden (1989) suggest that even large asymptomatic fibroids can be conservatively managed if adequate monitoring facilities are available. Also, women who are close to menopause may not need treatment as the fibroids will shrink naturally once the level of the hormone oestrogen has declined. Women may be offered treatment for the heavy bleeding, such as tablets and insertion of a coil. A medicinal treatment is available which prevents the ovary producing hormones in order to shrink the fibroids. However, this makes the woman menopausal (with all the menopausal symptoms) and the fibroids revert to their previous size when treatment is stopped. Also, if the treatment is continued for more than 6 months, there are further side effects of heart disease and osteoporosis. This treatment approach is usually only used with women close to menopause or as a treatment prior to surgery in order to shrink the fibroids and make them easier to remove surgically (McKay Hart & Norman, 2000; Wilson, 1999; Rees, 1998; March, 1994).

Surgical options include myomectomy and hysterectomy. A myomectomy is the removal of the fibroids under general anaesthetic without removing the uterus and a hysterectomy is the removal of the uterus. However, there is a risk of haemorrhage during a myomectomy and some women may then require an immediate hysterectomy in order to control the bleeding. Both of these procedures are major operations and require recovery periods of several weeks. Depending upon their size and location, some fibroids may be cut up and removed laparoscopically (Wilson, 1999; West & Lumsden, 1989). As West & Lumsden (1989) highlight, there is considerable demand from patients for an alternative to surgery.

There is no literature looking specifically at the psychological morbidity of women with fibroids. The existing literature on distress in women with gynaecological conditions will be summarised in the following section.

Distress in Gynaecology Patients

A variety of approaches have been used to study the psychological morbidity in gynaecology patients. These include: general psychiatric screening of all first-time attenders at gynaecology clinics (Agrawal et al, 1990; Salter, 1985; Byrne, 1984; Worsley et al, 1977; Munro, 1969); screening of all women attending clinics over a particular time period (Abiodun et al, 1992; Worsley, Walters & Wood, 1978); screening of all women on a general practice list (Balinger, Smith & Hobbs, 1985); and screening of women admitted to gynaecology hospital wards (Wancata, Windhaber, Bach & Meise, 2000; Phillips et al, 1996). Other researchers have investigated the prevalence of psychiatric symptoms among particular groups of women, such as women having gynaecological surgery (Hrasky & Morice, 1986; Gath & Cooper, 1981; Steiner & Aleksandrowicz, 1970), women with chronic pelvic pain (Hodgkiss & Watson, 1994) and women experiencing the menopause (Montero, Ruiz & Hernandez, 1993; Ballinger, 1990). In addition, the prevalence of gynaecological problems among particular groups of women such as psychiatric patients (Coppen, 1965) or nursing students (Hain, Lindon, Eber & Chapman, 1970) has been measured.

Studies typically report higher levels of anxiety than depression in women attending gynaecology clinics. For example, Slade, Anderton & Faragher (1988) reported that 33% of their British clinic sample (n=248) had clinically significant anxiety scores and 21% had clinically significant depression scores. They compared these findings with a community sample control group of whom only 6% were clinically anxious and 5% clinically depressed. Similarly high findings have been reported in non-Western countries. Abiodun et al (1992) reported psychiatric morbidity rates of 35% among women attending a clinic in Nigeria and Agrawal et al (1990) found a psychiatric prevalence rate of 49% among clinic attenders in India compared with 26% among women accompanying them to the clinic. Particular conditions, such as chronic pelvic pain (Hodgkiss & Watson, 1994), the menopause (Montero et al, 1993; Ballinger, 1990), and menstrual problems (Abiodun et al, 1992; Agrawal et al, 1990; Ballinger et al, 1985; Salter, 1985; Gath & Cooper, 1981; Hain et al, 1970; Munro, 1969; Coppen, 1965; Dutton, 1965), seem to be associated with increased psychiatric morbidity.

Treatment Implications

Research suggests that having elevated distress scores may have treatment implications for women with gynaecological problems. There is some evidence that distressed women may present their symptoms in a way that may affect the subsequent course of their treatment. Greenberg (1983) reported that there was a tendency for women with higher scores on the General Health Questionnaire (GHQ) to describe their symptoms in less specific terms than women scoring below the GHQ cut-off point of twelve. This supported earlier findings by Munro (1969) who noted a similar tendency in his survey of first-time clinic attenders. The possible implications of this were outlined by Worsley et al (1977), who found that women with higher GHQ scores had received less orthodox gynaecological treatment than low scorers. The authors also hypothesised that the high scorers may have presented their symptoms in a different manner from the low scorers which may have led the gynaecologists to stop investigating possible organic causes. This may in turn have reduced their chances of being given a specific diagnosis. There is considerable variation in how medical practitioners respond to women presenting with gynaecological problems and referral rates vary considerably, suggesting that many factors are involved in the process (McColl, Newton & Hutchinson, 1994). GPs have called for guidelines on this issue (Coulter, Bradlow, Agass, Martin-Bates & Tulloch, 1991).

An investigation of how GPs respond to women with menstrual problems found that women were more likely to be referred to a gynaecologist if the doctor perceived them as having a preference for surgery, if they had a history of previous surgery and if their GP was male. Furthermore, women with less education were more likely to express a preference for surgery, which again increased the likelihood of referral (Coulter, Peto, & Doll, 1994). However, whilst the GPs in this study reported that they tried to take the woman's perspective into consideration, they were unaware of patient preferences in 45% of cases and correct about patient's strong treatment preferences in only 34% of cases. Another study looking at how GPs respond to women with chronic pelvic pain also concluded that medical factors were not the only influence upon whether a woman was referred or not (McGowan, Pitts and Clark Carter, 1999). They found that other more subjective factors were involved, particularly in cases where there was no identifiable organic pathology. Marshall's (1998) qualitative study of the experiences of women with menorrhagia found that there was considerable variation in how the women had been treated by their GP. She highlighted that the GP has to evaluate the validity and seriousness of the woman's presenting symptoms and then decide whether to offer reassurance, information, primary care treatment or refer onto specialist services.

The social context of the consultation is also important. Marshall (1998) reported that the concerns of women with menorrhagia were influenced by their perceptions of 'acceptable' reasons to consult a doctor, citing the example of one woman who only discussed her menstrual problems having initially presented to her GP with a more 'acceptable' sore throat. Laws (1992) conducted interviews with men to find out their attitudes to menstruation and found that 'social etiquette rules' exist that place restrictions on a woman's ability to discuss her menstrual problems. Laws suggests that these rules influence the way in which the medical profession, wider society and women themselves think and talk about menstruation. In addition, Ussher (2000) highlights that the way in which women think about and experience their bodies and health care has to be considered within a cultural and social framework.

The doctor-patient relationship is important and there are a number of factors influencing the consultation. Good communication and a patient-centred model of care have been shown to enhance treatment efficacy and optimise patient satisfaction. Research has shown that doctors who only attend to the biomedical details may easily miss patient clues about psychological issues relevant to their care and that failure to attend to these may adversely affect the doctor-patient relationship (Levinson, Gorawara-Bhat & Lamb, 2000).

Models of distress in gynaecology patients

The causal relationship between gynaecological disorders and psychiatric disorders is recognised to be complex (Oates & Gath, 1989; Worsley et al, 1977; Hain et al, 1970). Hunter and Walker (1998) note that it has proved difficult for one theoretical model to account adequately for the different problems presented in gynaecology clinics. Furthermore, endorsement of these different theoretical models may also impact upon the treatment and management of women attending these clinics. There is a need for work investigating both the medical practitioners' and the women's perspectives and understanding of the conditions.

Biomedical Explanations of Women's Distress

The biomedical model explains women's distress from a biological perspective and has concentrated upon identifying organic pathology and hormonal imbalances in women presenting with gynaecological problems. Within this model, much of women's distress is thought to be the result of hormonal dysfunction. Biomedical theories have especially been used to explain mood changes associated with the menstrual cycle, such as pre-menstrual syndrome and menopause symptoms. Both professionals and women themselves have endorsed this argument, although there is little research to support it (Hunter & Walker, 1998; Sampson, 1989). From a feminist perspective, Ussher (1991) argues that menstruation is socially constructed as something unnatural and indecent, which is used as evidence of women's biological weakness. Women's 'biological weakness' is then used to explain women's higher levels of psychiatric morbidity, therefore anxiety and depression are attributed to hormonal causes rather than psychosocial factors.

Biomedical explanations propose that both physical and psychosocial distress can be attributed to specific organs and relief is achieved through modification or removal of the organ (Marchant-Haycox, Liu, Nicholas and Salmon, 1998). Thus, procedures such as dilatation and curettage (D&C) may be offered for a variety of conditions, despite limited evidence of efficacy either in diagnosis or treatment (Coulter et al, 1994). One of the most common gynaecological operations is hysterectomy It is a major surgical procedure requiring several weeks of post-operative recovery (Hunter & Walker, 1998). It is often used as a final solution for long-standing gynaecological problems, even in the absence of organic pathology. Although there is evidence that hysterectomy can alleviate women's distress (Gath and Cooper, 1981), there is great variation in the rates of hysterectomy both between countries and between hospitals within the same country (Hunter & Walker, 1998). This suggests that organic pathology is not the only factor influencing treatment choice and the biomedical explanation cannot adequately account for these discrepancies.

The association between physical disease and psychological disorder is recognised to occur more frequently than can be attributed to chance alone. A review of the evidence concluded that much of this association can be attributed to the individual's illness behaviour as shown in complaints of symptoms and consultation frequency rather than organic pathology (Benjamin, Barnes, Falconer & Hoare, 1984). This concurs with studies in the gynaecology field, which have consistently reported no difference in distress levels between women who have an organic explanation for their physical symptoms and women for whom no organic cause can be identified (Worsley et al, 1977; Gath and Cooper, 1981; Greenberg, 1983). This suggests that a straightforward relationship between the medical condition and distress levels does not exist and other factors need to be considered.

Psychosocial and Socio-Cultural Explanations

Psychosocial and socio-cultural explanations propose that the distress experienced by women may be a response to social, cultural or psychological factors. It is argued that some women with gynaecological disorders may be more at risk of developing psychological problems, which may influence their concerns about and reactions to their gynaecological symptoms. As Ussher (2000) highlights, women have very different subjective experiences of illness that will influence illness prevention and treatment and also how the woman thinks about her condition and symptoms over time.

A number of practitioners and researchers have commented upon the large number of women presenting to their doctors with ambiguous symptoms and unknown aetiology of their gynaecological condition (Benjamin et al, 1984; Worsley et al, 1977). This has led to the suggestion that the women attending the clinic may be so distressed about other events in their lives that their medical problems provide a 'safer' focus or outlet for their distress. Greenberg (1983) proposes that there may be prior personal or family gynaecological history for these women involving a previous focus on gynaecological problems and the women are expressing their distress through presentation of their physical symptoms (Hrasky & Morice, 1986). Researchers have attempted to investigate whether there are identifiable factors that place a woman attending a gynaecology clinic at greater risk of psychiatric or psychological morbidity.

Slade et al (1988) found that women attending a gynaecology clinic who had a previous psychiatric history or had consulted their GP in the past twelve months for 'nerves' had significantly higher levels of distress than other outpatients at the same clinic. Also, the experience of multiple traumas and a diagnosis of borderline personality disorder is associated with higher utilisation of gynaecology services (Sansone, Wiederman & Sansone, 1998). Greenberg (1983) found that first time attenders with high distress scores on the General Health Questionnaire (GHQ) had experienced significantly more stressful life events in the two years prior to referral, than low scorers. Additional factors were identified by Montero et al (1993) who compared women seeking help for menopause symptoms with a control group of women from the general population. They reported that the women attending clinics for menopausal symptoms were mainly those who lacked social support and who were significantly more dissatisfied with their social contacts, their marital relationships and their sexual life. There is reported to be a high prevalence of sexual concerns among women attending gynaecological clinics (Nusbaum, Gamble, Skinner & Heiman, 2000). Another study reported that patients scoring highly on the GHQ had significantly more marital problems and difficulties with money, accommodation, children and other relatives than low scorers (Worsley et al, 1977). Byrne (1984) interviewed a random sub-sample of 35 women with psychiatric difficulties from a larger sample of 211 gynaecology outpatients and compared them with a matched community sample of women. He identified that these women were more likely to be below 35 years of age, have no children and have a history of divorce, separation or widowhood. Childlessness, young age and being single were also reported by Phillips et al (1996) and Agrawal et al (1990) as risk factors for psychiatric morbidity among gynaecology clinic attenders.

Summary of the Findings

There are a number of consistent findings from the gynaecology literature showing that women attending gynaecology clinics are at increased risk of psychological distress. These suggest that women with a past history of psychiatric disorders and recent experience of life events or current psychosocial problems, particularly in their sexual relationships, appear to have a decreased capacity to cope with gynaecological symptoms and are more likely to score in the clinical range for anxiety and depression. In addition, there is support for the finding that prior psychiatric disorder is associated with distress following gynaecological surgery and undetected and untreated psychiatric problems may interfere with treatment decisions and treatment outcomes (Oates & Gath, 1989).

Methodological Considerations

Several researchers have noted that the large and conflicting literature on the frequency and nature of psychological problems in women with gynaecological conditions makes it difficult to interpret and compare the findings of different studies (Savidge & Slade, 1997; Phillips et al, 1996; Slade et al, 1988; Cooper & Gath, 1983). Studies have used a variety of measurement instruments and diagnostic criteria, and have sampled from different populations. Phillips et al (1996) point out that psychiatric classification systems are usually based upon research conducted with psychiatric patients. Thus they suggest that this makes it particularly difficult to differentiate between 'appropriate distress' in the context of a physical illness and affective disorder. Furthermore, Mayou and Hawton (1986) highlight the importance of establishing the degree to which the psychological problems reflect long-standing psychiatric problems or reflect current social difficulties or if in fact they relate to the physical condition or hospital admission.

Further difficulties are highlighted by Slade et al (1988) who only found a significant association of higher depression scores in women with amenorrhoea (absence of menstruation) and could not support the common finding of increased depression in women with menorrhagia. The authors suggest that this is because previous findings have used a general 'menstrual disorders' category, which has failed to discriminate between the different types of menstrual disorders and therefore masked the specific associations. They also caution against some studies making interpretations based upon small sample sizes. Thus it is difficult to have a clear picture of the extent and nature of the psychological distress seen in gynaecology clinics or of how this is related to the different types of condition.

Despite these methodological considerations, it is clear that women with gynaecological problems do have elevated levels of distress. Although there are a number of different models to account for this, it is poorly understood. Furthermore, there is also an absence in the literature of the woman's perspective, either of her condition or her distress. It highlights the need for more research to clarify the issue. The use of biopsychosocial models in health psychology is an attempt to overcome these limitations.

Biopsychosocial Models

The research to date clearly suggests that the distress found among women attending gynaecology clinics cannot be directly attributable to their gynaecological condition. Using a biopsychosocial model allows a broader research approach to be adopted (Hunter & Walker, 1998; Gallant et al, 1994). It recognises that there are biological, social and psychological influences on an individual, which will affect all aspects of the illness experience. As Hunter and Walker (1998) highlight, these models take account of the woman's psychosocial and cultural contexts in addition to her physical symptoms, which allows a more complete understanding of her experience of having gynaecological problems. It also helps clarify if there is a mismatch between the patient's and the doctor's expectations and models (Fry, Crisp & Beard, 1991). Biopsychosocial models have the advantage of being able to encompass cognitive factors, such as attributions about symptoms and treatment and individuals' illness representations (Hunter & Walker, 1998). This approach encourages a more individual understanding of women, who despite having the same diagnosis, may have very different illness representations and experiences.

The following section will present current knowledge about illness behaviour and how it is influenced by people's illness representations. This is explained using the Self-Regulation model (Leventhal et al, 1997), which was used as a framework in this study to guide exploration of women's understanding of having fibroids.

Models of Illness Behaviour

There are various psychological, social and cultural factors that may influence gynaecology patients' vulnerability to psychological distress. However, whilst more is known about the factors that place women at increased risk of experiencing clinically significant levels of anxiety and depression, the reasons for their distress remain little explored. As the previous section has highlighted, research has shown that there is often a discrepancy between the symptoms patients present with and their underlying pathology. This is not restricted to gynaecology patients, but has been reported across the health psychology literature, where patients with the same condition or symptoms may present very differently (Lacroix, 1991).

Illness behaviour has been defined as the ways in which patients differentially perceive, evaluate and act or fail to act upon symptoms (Mechanic, 1962). The relationship between illness behaviour and disease may be regarded as a continuum, ranging from gross displays of distress to denial of illness, which is independent of physical disease status (Benjamin et al, 1984). This has resulted in increased interest in investigating how people think about their health status and the concepts of 'illness' or 'disease' and in turn how these mental representations influence patients' health-related behaviour or coping responses (Skelton & Croyle, 1991).

Traditional health psychology approaches have attempted to catalogue the internal and external factors affecting health behaviours. These are conceptualised in terms of a uni-directional cause and effect relationship (Bishop, 1991). However, these models cannot adequately account for the irrational decisions that people often make about their health and cannot account for the wide variety of behaviours seen in people with the same symptoms or condition. For example, they do not specify those conditions under which people will ignore serious symptoms at the risk of endangering their lives. A further difficulty is that the models assume that the patient has knowledge of the potential risks of various illnesses or behaviours and has thought these through in a detailed way (Bishop, 1991). Bishop (1991) has suggested that the traditional approach of investigating the factors affecting health behaviours is somewhat simplistic. Hence, models of health behaviour that lack constructs such as the individual's cognitive and emotional representations of their illness are incomplete (Leventhal et al, 1997). This has led to the development of illness representation models.

Illness Representations

Leventhal and colleagues define illness representations as 'a person's own, implicit, common-sense beliefs about illness' (Leventhal, Meyer & Nerenz, 1980). The individual's behaviour is determined by their cognitive and emotional responses to their subjective illness experiences. The illness representation model allows health-related behaviour to be viewed as the product of a dynamic interaction of several factors. These health-related behaviours are also conceptualised as goal-directed and the individual is constantly evaluating them to determine whether the goal has been achieved. This on-going evaluation process may then lead to changes in future behaviour and changes in the original illness interpretations. The mechanisms by which this happens are conceptualised within the framework of the Self-Regulation Model (Leventhal et al, 1997).

The Self-Regulation Model - theoretical foundations

The self-regulation model developed from work looking at how lay people perceive illness as a threat (Leventhal, Nerenz & Steele, 1984). It arose from work which aimed to understand why health information in the form of fear messages, failed to produce long-term attitudinal and behavioural change. Following various empirical studies in this area, Leventhal hypothesised that it was the individual's cognitive representation of the disease threat which influenced their health related behaviour (Leventhal et al, 1997). As previously outlined, existing models of health behaviour could not adequately account for his findings, because they attempted to explain the decision making process without knowledge of all the different factors contributing to the choice process (Leventhal et al, 1997). In other words, "*knowing what to do and when to do it did not lead to action if a clear view of specific attributes of the health threat was lacking*" (Leventhal & Nerenz, 1985, pp. 522).

Leventhal's self-regulation model can be applied both to the initial identification of a disease and to the subsequent monitoring of changes as it progresses, is managed or cured (Hampson, 1997). The processing system consists of three recursive stages: representation, coping and appraisal (Scharloo & Kaptein, 1997). Thus the individual forms a representation of the health threat and their emotional reaction to it. They then identify the procedures they will use to cope with this threat. This process is constantly appraised and altered if the evaluation changes the original representation.

There will obviously be a wide variety in the models used by individuals, as they necessarily reflect unique situational and individual factors (Leventhal & Nerenz, 1985).

The theoretical assumptions underlying the model are that people interpret and cope with current and potential health events by having an active information processing system, through which they generate both a representation of the illness and an emotional reaction to this illness. People's illness behaviour reflects an interaction of environmental events and their cognitive and emotional knowledge base. Much of this process cannot be directly observed. The content of illness representations is accessible through verbal reports, actual behaviour and physiological responses (Leventhal & Nerenz, 1985).

Attributes of Illness Representations

Research interviews with patients have been conducted to establish the content of people's illness representations. Research to date, has identified five attributes: disease identity (symptoms and label); time-line (time to develop and duration); consequences (beliefs about the severity and likely impact on physical, social and psychological functioning); causes (ideas about likely causation) and controllability (likelihood of the condition being cured or controllable) (Leventhal et al, 1997). These attributes have been described as "*the individual's common-sense perceptions and conceptions of* *what is there, what it feels like, what makes it happen, how long it will last, what it has done and will do yet, whether it can be controlled; and of the various procedures that can be used to clarify and control various features of the health problem and its somatic expression."*(Leventhal et al, 1997, p40).

Overviews of the research in this area have confirmed the consistency and validity of the five identified components (Scharloo & Kaptein, 1997; Skelton & Croyle, 1991). Studies have also shown that the individual's perceptions across these five dimensions regulate their health-related behaviour, such as treatment compliance, and evaluation of treatment efficacy (Scharloo & Kaptein, 1997). Research suggests that the structure of illness representations seems to be constant across demographic and illness groups, but the content varies between individuals and between patients and health practitioners (Bishop, 1991).

Leventhal et al (1997) describe how within the framework of the self-regulation model, the illness representations shape the selection and performance of the coping procedures. They identify how these procedures also have 'common-sense' attributes that are similar to the illnesses they aim to alleviate or cure. Certain procedures, such as taking a pain-killer, have specified target symptoms, duration to work, means of administration and expected outcome. These attributes influence patient adherence and beliefs about their efficacy or suitability of the treatment.

Sources of Disease Representations

The self-regulation model proposes that illness cognitions are formed from an implicit model of illness based upon a number of different factors. These include illness related beliefs, knowledge of the illness and the individual's own personal experience of the illness. Their knowledge and experience will be drawn from cultural factors, information from medical professionals and lay people, such as friends and family (Leventhal et al, 1980).

People appear to have prototype models of disease against which they compare symptoms in order to interpret and evaluate the disease threat. Research suggests that people have implicit illness models of everyday illnesses (Lau, Bernard & Hartman, 1989). It appears that these disease categories are often not rigidly defined, so a perfect fit between the symptoms and prototype is not always necessary in order for a diagnosis to be made. People will assign a label on the basis of a 'family resemblance' (Rosch & Mervis, 1975). Thus, an illness experience that cannot be easily identified encourages the individual to actively seek to understand their symptoms. The self-regulation model proposes that they will continue attempting to make sense of their symptoms in order to construct a meaningful illness representation (Bishop, 1991).

Illness Models in Gynaecology

Although there has been no research specifically comparing the illness representations of doctors and gynaecology patients, separate studies have looked at how these two groups understand certain conditions. In the case of chronic pelvic pain, McGowan et al (1999) showed that GPs as a group generally had a shared understanding of this condition and how they would treat it. Treatment usually consisted of investigating organic causes and only if no organic pathology was found, were psychosocial factors explored. However, Fry et al (1991) used a questionnaire study to elicit the illness concepts of 64 women with chronic pelvic pain and demonstrated that the women themselves had more flexible and 'incomplete' representations of their condition. The women often gave concurrent biomedical and psychosocial explanations of their pain. In terms of their illness representations, it appears that the timeline and consequences appeared to be particularly salient. For most of these women, it was fears about the interminability of their condition and the effects upon their lives that predominated. In terms of the effects on their lives, they were most concerned about their sexual lives and ability to work. There were also fears about the symptoms being indicative of cancer. Fry et al (1991) suggest that knowledge of how women think about their condition can be utilised to aid in providing appropriate medical information and treatment. It is possible that women with other gynaecological conditions also have flexible and incomplete models of their illness, which may help explain their emotional responses.

Other Qualitative Studies of Women with Gynaecological Conditions

A few studies have used qualitative methodology to explore women's experiences or understanding of gynaecological conditions. Zadinsky and Boyle (1996) investigated the illness experiences and coping behaviour of women with chronic pelvic pain. They found that women's experiences could be described as a process of self-care, in which women used a variety of self-care practices to enable them to function in their everyday lives and different social roles following numerous, unsuccessful medical investigations and interventions. The authors concluded that medical care for these patients could be enhanced by working within a framework that helps medical professionals understand the woman's perspective.

A qualitative interview study of women's understanding of abnormal smear test results concluded that women wanted to participate in decisions about their care, but found it difficult to get the information they wanted. They tried to make sense of the information, but it appeared that for some women their medical care was not compatible with their understanding of their condition. The authors concluded that this was due to the *"inherent power structure of medical practice combined with time pressures"* which made it difficult for doctors to give information and reassurance to patients (Kavanagh & Broom, 1997, pp. 1388). Again this study highlights the importance of the women's experience of the medical consultation.

Marshall (1998) conducted semi-structured interviews with women with menorrhagia in order to examine the women's concerns about heavy blood loss and their expectations regarding treatment. The results were analysed using a grounded theory approach and identified a number of significant factors that impacted upon the women's experiences, including the importance of doctor/patient communication. Marshall highlights the need for greater understanding of the psychological aspects of health care within gynaecological services in order to ensure that the treatment offered to women is appropriate to their previous psychological and gynaecological experiences, expressed concerns and treatment expectations.

Aims and rationale of the current study

Previous research has shown that many different factors affect both women's vulnerability to distress, their experience of having a gynaecological condition and their feelings about all aspects of the treatment process. Although the existing literature on gynaecology patients has shown that women have significant levels of anxiety and depression, there is little work that aims to understand or explore the nature of their distress. In addition, few researchers have asked the women themselves about how they understand their gynaecological conditions and illness experiences. This is important since illness representation research suggests that individual differences in people's perceptions of their condition may help to explain differences in emotional distress, levels of self-care behaviours and even health outcomes (Leventhal et al, 1997).

The primary aim of this study was to provide a description of women's understanding and experiences of having fibroids in order to gain an understanding of the meaning this condition has for them and how this influences their emotional responses. Fibroids are a common gynaecological condition, yet research on the psychological aspects is lacking. The goal was to increase understanding of the psychological factors contributing towards the high levels of distress among these women.

Rationale for using Qualitative Research Methodology

Murray and Chamberlain (1999) highlight that the increasing use of qualitative methods represents a radically different view of the research process. Instead of seeking accurate measurement of hypothetically related variables and assessing their relationship statistically, qualitative approaches seek detailed complex interpretations of specifically socially and historically located phenomena. Qualitative methodologies have been used in women's health research as they allow analysis of the power and gender issues considered to be central to women's illness experiences (Murray & Chamberlain, 2000).

Qualitative methodology was considered appropriate for this study as the emphasis was on discovery and description. This is beneficial in an area in which *'existing theory is incomplete, inappropriate or entirely absent'* (Henwood & Pidgeon, 1992, pp. 102). Leventhal and Nerenz (1985) also discuss how the choice of research methodology is influenced by the state of knowledge at the time the research is initiated. Where knowledge is lacking, they endorse a more discovery orientated approach which aims to uncover and define the important variables of the topic under investigation. Smith (1996) also suggests that idiographic approaches are especially useful in health psychology research. Within the study of women with gynaecological conditions, Savidge and Slade (1997, pp.442) advise that *'the use of idiographic methods could expand information regarding women's appraisals, beliefs and adjustment'.* Furthermore, a greater understanding of gynaecological problems from the women's perspective can facilitate services in providing appropriate health care (Zadinsky & Boyle, 1996). Therefore, a qualitative approach was adopted to meet the aims of the study and the method of Interpretative Phenomenological Analysis (IPA) was employed (Smith, Jarman & Osborn, 1999; Smith, Flowers & Osborn, 1997; Smith, 1996).

Interpretative Phenomenological Analysis (IPA)

IPA is a form of qualitative analysis which aims to explore in detail the participant's view of the topic under investigation (Smith et al, 1999). It does not attempt to provide an objective account of the topic as it is concerned with the individual's perception and personal understanding. Rather than testing a preconceived hypothesis on a large sample, the aim is to understand a small number of participants' own frames of reference. Thus it is a phenomenological approach to analysis (Smith et al, 1997). IPA also recognises that the research exercise is a dynamic process in which the researcher is an active participant. That is, the researcher's personal views and expectations are likely to exert an influence at all stages of the research, including the data collection stages and the analysis. For this reason, IPA is also interpretative, since it recognises that the analysis involves the researcher's attempts to understand the individual's perspective through careful interpretative work. This interpretation aims to elucidate something of the participant's feelings and cognitions about the topic under investigation (Smith et al, 1997).

IPA is increasingly being used in a number of health psychology settings. Smith et al (1997) argue that IPA and health psychology can *"form a useful alliance"* (pp.71), since health psychology is *"premised on the assumption that people think about their bodies and that what they have to say about their bodies in some way relates to their thoughts"* (pp.71). Thus it is argued that the use of IPA allows the researcher to access some of the individual's perceptions about their experience of their body and health status. Furthermore, the analytic process recognises and attempts to understand the gap between the individual's account of their illness and the underlying cognitions (Smith et al, 1997). The use of IPA in the field of health psychology allows for an exploration of the personal meaning of the illness experience and how the individual participants make sense of it. It is particularly valuable when studying areas of health psychology in which psychological phenomena have not previously been extensively researched (Smith et al, 1997). It can add to the literature on medical conditions and illuminate relevant issues for the individuals with the conditions and the professionals involved in their care.

Research Questions

The research considered the experiences of women with fibroids. There were three research questions:

1. How do women with a diagnosis of fibroids experience their gynaecological problems?

2. How do they understand the condition of fibroids?

3. To what extent do their illness representations seem to influence their levels of distress?

These questions were addressed using a qualitative approach that explored participants own descriptions of their experiences and understanding of their condition. Eighteen women with fibroids were interviewed using semi-structured interviews guided by the self-regulation model.

CHAPTER 2: METHOD

Overview

This is a qualitative study of the illness experiences of women with the gynaecological condition of fibroids. Semi-structured interviews were conducted with eighteen women with fibroids. All interviews were fully transcribed. All participants also completed a measure of their current levels of anxiety and depression. All women were receiving gynaecology outpatient treatment at a central London hospital.

Ethical Approval

Ethical approval was obtained from the Joint University College London and University College London Hospitals (UCL/UCLH) Committees on the Ethics of Human Research. (Appendix A)

Recruitment Procedure

Participants in this study were recruited by two different methods. It had been hoped to recruit all participants by invitation letter. The initial arrangement was that the medical staff would supply the names and addresses of all the women attending the clinic over the period of data collection who met the inclusion criteria. However, due to the busy nature of the clinics and the high number of different staff working there, it proved difficult for this procedure to be followed consistently. Thus, following consultation with the medical staff, the researcher also arranged to attend the clinics and approach women in person.

The two methods of recruitment are detailed below:

Invitation letter

Participants were recruited from the general gynaecology outpatient clinics of three consultant gynaecologists at a central London hospital. A letter detailing the study (Appendix B) was sent to all women meeting the inclusion criteria, who were on the surgery waiting lists of the three consultants. As detailed above, some letters were also sent to women meeting the criteria who had attended the weekly outpatient clinics. This was done over the six months of data collection.

The invitation letter asked the women to return the tear-off slip if they were interested in taking part in the research or wanted to find out more information. A stamped addressed envelope was enclosed with the letter. Upon receipt of the returned slip, the researcher contacted the woman directly by telephone and in one case by letter. Further information about the study was then given and any questions about the study were answered. If the woman agreed to take part, an appointment was then made to meet with the researcher at a location convenient for the participant.

Response rate for invitation letters

Sixty-seven invitation letters were sent out over the six months of data collection. Seventeen women (25%) returned the slip. Fifteen of these women were then contacted by telephone and all agreed to participate, thus giving a response rate of 22% for invitation letter recruitment. One woman did not have a contact telephone number and was contacted by letter with a suggested appointment date. She subsequently did not attend this appointment and made no further contact with the researcher. One woman could not be contacted at all, despite returning the slip. Of the fifteen women interviewed, three had a diagnosis of menorrhagia. Thus twelve women who eventually took part in the study were recruited via invitation letters.

Direct Recruitment in the Clinics

The researcher attended ten separate weekly outpatient clinics over the course of three months. Women who fulfilled the inclusion criteria were approached directly and asked if they would be willing to hear about an on-going research project. A few women declined at this point, all saying that they could not spare the time. If a woman agreed, the study was explained and the invitation letter and information sheet (Appendix B) were given to them. It was emphasised that there was no obligation to take part in the study and that they could contact the researcher at a later date if they wanted time to consider it or if they had any questions about the study.

Response rate for clinic recruitment

Fifteen women who met the inclusion criteria and who were attending the clinic agreed to discuss participating in the study. Two women said that they did not have time to hear about the study. Twelve women then agreed to take part. Three women subsequently did not attend their appointments. Unsuccessful attempts were made to contact them. Two other women rearranged their appointment twice and then subsequently said that they could not participate due to work and home commitments. Thus six women who eventually took part in the study were recruited directly from the clinic, giving a response rate of 35% for clinic recruitment.

Participants

Eighteen women with a diagnosis of fibroids participated in the study. A further three women with a diagnosis of menorrhagia also participated, but in the interests of having a more homogeneous group, they were not included in the analysis.

Inclusion Criteria

The inclusion criteria were that women were 18 years of age or over, conversant in English and had a diagnosis of fibroids or menorrhagia. It had been hoped to compare women with fibroids and women with menorrhagia, so women with menorrhagia were initially included in the study. However, their data was subsequently excluded from the analysis.

Characteristics of the Sample

Participants' mean age was 42 years (range 33 to 53 years). Eight women were married or living with a partner, 4 were single, 3 were divorced or separated and 3 described themselves as in a relationship, but not living with their partner. Ten (56%) of the women had children. All the women except one were in full or part-time work. Five women were educated up to O' levels, one woman up to A' levels and 12 women had higher college or university qualifications. Nine (50%) of the women had seen a counsellor or psychologist in the past. Ten (56%) of the women had had one or more previous referrals to a gynaecologist. Reasons included previous referrals for fibroids (6 women), abnormal smear results (2 women), endometriosis (1 woman), miscarriage (2 women) and pregnancy termination (2 women). Women were asked to define their own ethnic background. The ethnic background of the sample was one Asian woman, four black women (1 African, 1 Afro-Caribbean, 1 Afro-European, 1 Black British) and thirteen white women.

Procedure

The interviews took place at a location convenient for each participant. Eight women were interviewed at the hospital, three women were interviewed at University College London and seven were interviewed in their own homes. All interviews took place in a quiet room with just the researcher and the participant present. All interviews followed the same procedure.

The participant was first given the information sheet (Appendix B) to read through. Any questions or concerns that the woman had about the study were then discussed before she completed and signed the consent form (Appendix B). It was emphasised that participation in the study was under conditions of confidentiality. The researcher also explained that participation in the study was voluntary and they could withdraw at any time. Following this the researcher completed the demographics questionnaire with the participant (Appendix C). Participants were then interviewed. Following the interview, women completed the Hospital Anxiety and Depression Scale (Appendix C). Finally, women were given the opportunity to ask any further questions about the research project. They were also informed that they would receive a summary of the study's conclusions upon completion of the project.

Measures

Semi-Structured Interview

Participants were interviewed using a semi-structured interview format. This approach to interviewing is recommended for gaining a detailed picture of a respondent's beliefs and account of a particular topic. It allows the researcher more flexibility to pursue areas that arise during the course of the interview, which perhaps were not initially anticipated (Smith, 1996).

The aim of the interviews was to elicit how the women conceptualised their illness experience and its impact on their lives. The interviews aimed to cover the five components of illness representations. At the end of each interview, the participant was also asked if she wanted to expand upon anything discussed or if she had anything else she felt it was important to mention about her experiences.

During the design of the interview protocol, the questions were discussed with two women who had had gynaecological outpatient treatment to check for face validity and relevance. Following these discussions, some minor changes were made to the format and content of the interview. A final interview schedule is provided in Appendix C.

The interviews lasted between forty and ninety minutes. All interviews were audio-taped.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983).

This is a brief self-report scale designed to detect anxiety and depression in general medical outpatient populations. The questionnaire consists of two separate scales for Anxiety and Depression, each consisting of seven items. The questionnaire has been designed so that anxiety and depression symptoms that could be attributed to physical illness are excluded. Thus the anxiety scale concentrates upon generalised anxiety symptoms rather than somatic complaints and the depression scale provides an indication of the person's depressed mood by focusing upon the degree of interest and pleasure they are able to show during usual activities. Each item is rated on a four-point scale ranging from 0 (absence of a symptom) to 3 (maximum symptomatology). There is a maximum score of 21 for each sub-scale. Respondents are asked to complete the questionnaire according to how they have felt over the past week. Using this measure it is possible to obtain a score of psychological distress. Both sub-scales use the same cut-off score of 8. Respondents scoring above the cut off score are considered to be within the clinical range for anxiety and/or depression. Scores between 8 and 10 indicate mild anxiety / depression, scores of 11 to 14 indicate moderate anxiety / depression, and scores of 15 to 21 indicate severe anxiety / depression (Zigmond & Snaith, 1983).

This questionnaire was included in the study because it has been shown to have good psychometric properties and is quickly and easily administered. Furthermore it had been used in the previous investigation of gynaecological outpatients at the same hospital and so provided the opportunity for comparison data. Previous research has shown the HADS to be a valid instrument for assessing anxiety and depression in general outpatient populations and for estimating the severity of their mood disorder (Zigmond and Snaith, 1983). It has also been validated for use in gynaecology clinics (Abiodun, 1994). The HADS demonstrates satisfactory internal consistency with Cronbach's alpha scores of 0.93 for the anxiety scale and 0.90 for the depression scale, together with satisfactory construct and concurrent validity (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991; Zigmond & Snaith, 1983). In addition it has acceptable face validity with patients.

Analysis of the Qualitative Data

This section provides an overview of the method of qualitative analysis used in this study with a description of the stages of analysis.

Stages of the Analysis

Data analysis followed the methods outlined by Smith et al (1996; 1999). This begins with the initial data preparation stage and the process of identifying initial themes in the transcripts, eventually leading to more general categorisations of the themes into a few higher-order themes that describe the experiences of the participants. At all times analysis involves going back to the original transcripts to check that the themes are based in the data. An interview transcripts is provided in Appendix E.

Data Preparation

All interviews were transcribed verbatim. Care was taken to omit or change any details that might either identify participants or the medical staff involved in their care. Transcripts were printed with double spacing and wide margins on either side of the text, to allow for comments and emerging themes to be noted down each side during the initial analytic stages when the transcript is read in great detail. Following this preparation, the 18 transcripts of women with fibroids were analysed using IPA.

Identifying Themes

Given the large number of transcripts, initial analysis focused upon five transcripts and then broadened out to include the other transcripts in the analysis. The first transcript of participant P17 (see Appendix D) was chosen because it was considered to be especially rich. This was then read and re-read several times. During this process anything of interest was noted down in the left-hand margin. As Smith et al (1999) advise, this may include attempts at summarising what the participant has said, associations that come to mind and connections with other parts of the text or psychological concepts. Particularly evocative quotes from the participant may also be underlined. Following this process, emerging themes are noted down in the right-hand margin. This is an attempt to use a few key words to describe the essence of what the participant is describing. This process was then repeated with four more transcripts.

Development of the Themes

Once the first five transcripts had been annotated and several emerging themes identified, these were noted down on a separate sheet. At this stage, the aim was to be over-inclusive in order to ensure that themes were not dropped from the analysis prematurely. Thus the initial list of themes included many that were subsequently incorporated into higher level themes or omitted later on in the analysis.

The next stage involved looking for connections between these themes, to see whether some of them clustered together and explained one or more of the themes. Eventually a final list of higher-order themes was developed which incorporated the sub-themes and which reflected all the transcripts. Once this had been achieved, the remaining thirteen transcripts were analysed using the themes identified in the first wave of analysis as a basis. When new themes arose in these subsequent transcripts, the original five interviews were re-examined to look for instances of the newly identified theme. This sometimes resulted in changes being made to the list of themes originally drawn up. Throughout the qualitative analytic process, checks were made with the original transcripts to ensure that the themes and clusters of themes were illustrated in the comments of the participants. This was an iterative process. Once all 18 transcripts had been analysed, a final list of higher-order themes and sub-themes was drawn up.

Themes dropped from the analysis

Qualitative analysis of the transcripts revealed many different themes. However, some themes were dropped during the final stages of analysis. These included a few themes that occurred infrequently and which appeared to be relevant to the individual, rather than the experience of having fibroids. An example of this was one woman's concerns about Hormone Replacement Therapy following surgery. Another particularly interesting example of a theme that was dropped, was the theme of cultural influences on a woman's ability to speak about being ill. One Afro-Caribbean woman and one African woman discussed this at some length in their interviews. Although it would have been interesting to include this theme, their understanding indicated that this was a taboo relating to all medical conditions and was not specifically related to having fibroids. Other issues that were dropped were related to general concerns about medical treatment and the National Health Service and were thus again not particularly representative of the experience of having fibroids.

Credibility Checks

A number of procedures recommended in qualitative research, were followed to check the credibility of the themes identified during the various stages of analysis (Elliott et al, 1999). As detailed above, the researcher continually returned to the original transcripts at all stages of the analysis to ensure that the interpretations were grounded in the data. In addition, over the course of the analytic process, four other researchers, all experienced in qualitative research methods, checked the findings at different stages. Initially the transcripts were read by two of these researchers, who then engaged in discussion of the themes arising from these transcripts with the researcher. Once the initial list of themes had been drawn up, these were presented with examples from the raw data to the other two researchers to check the interpretations being made. This process was repeated once a draft report had been written up.

CHAPTER 3: RESULTS

Overview

This chapter presents the analysis of the data collected from the women's interviews. Firstly, the quantitative data for each woman from the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) is presented. This is followed by a summary list providing an overview of the higher-order themes and the sub-themes that emerged from the women's interviews during the IPA analysis. The remainder of the chapter then presents and describes these themes.

The qualitative data collected from the women's interviews was organised into eight themes. These themes were subsumed within two higher-order themes, 'Managing uncertainty' and 'Struggling between defeat and optimism'. An overview is given of each higher-order theme, followed by presentation of the sub-themes within it. For each theme, direct quotes from the participants' interviews are provided to illustrate the theme and show how women thought about it and described it in their own words. At the end of each quote is the identify number of the participant cited. Within each theme any variations between the eighteen participants are highlighted and discussed.

Hospital Anxiety and Depression Scale (HADS) Scores

Scores for all eighteen women on the HADS are provided in Table 1. As can be seen, nine (50%) of the women had scores indicative of clinical levels of anxiety and four (22%) had scores indicative of clinical levels of depression. Four women had mild anxiety scores and five had moderate anxiety scores. Three women had mild depression scores and one woman had a moderate depression score.

Table 1: Individual HADS scores for participants

Identity No.	Age	HADS - Anxiety Scale	HADS - Depression Scale
P10	33	14 **	5
P11	36	11**	11**
P12	35	7	6
P13	49	13**	3
P15	43	11**	4
P17	46	10*	3
P18	53	7	9*
P19	41	7	2
P20	40	5	0
P21	34	14**	9*
P22	46	4	0
P23	44	9*	7
P24	40	2	4
P25	45	5	6
P26	49	3	1
P27	48	4	7
P28	38	10*	6
P30	42	9*	10*

Key:
*	= Mild Anxiety / Depression
**	= Moderate Anxiety / Depression
***	= Severe Anxiety / Depression

Table 2: Overview of the Higher-Order Themes

Higher-order Theme: Managing Uncertainty
Theme one: What is normal? (includes: 'It's a natural thing that a woman should bleed every month'; Symptoms as a sign of normal ageing'; 'Am I ill?')
Theme two: Seeking knowledge (includes: 'Doing your own research'; 'Doctors as source of information'; 'Knowledge of treatment options')
Theme three: The Doctor's Viewpoint and the Woman's Viewpoint (includes: 'The challenge of their skill against what I want with my body'; 'How women's bodies are viewed')
Theme four: It's going on and on (includes: 'Waiting for treatment')
Higher-order Theme: Struggling Between Defeat and Optimism
Theme one: Thinking about fibroids (includes: 'Fibroids as something *other*'; 'Fibroids as *part of me*')
Theme two: Not leading the life I aim to live (includes: 'Limited impact'; 'One day at a time'; Restricting activities')
Theme three: Effects on the self and others (includes: 'Body image'; 'Effects on relationships')
Theme four: Gaining control (Includes: 'Determination'; 'Determination in the pursuit of treatment')

Overview of Higher-order Theme 1: Managing Uncertainty

The higher-order theme of managing uncertainty was evident throughout the interviews with the women. It was clear that most of the women were currently in the process of managing their uncertainty about many aspects of their illness experience. Two women had successfully resolved this stage.

For some women the process of managing uncertainty began before they received a diagnosis. At this time they were trying to make sense of various physical symptoms in order to understand whether they were normal changes or signs of something being wrong. Even once they had received a diagnosis of fibroids, this process was ongoing. Their uncertainty focused upon their condition, how they thought about it and the possible treatment options available to them. It was compounded by the apparent lack of clear information available to the women.

Many of the women interviewed were also uncertain about whether they identified themselves as being ill or not. Consequently, it was frequently difficult to reach a shared understanding with the doctors about what having fibroids meant and how best to treat it. The women found it difficult to understand the rationale for some of the treatments being offered to them. Some felt that they struggled to have their experiences and opinions heard and respected by the doctors. This then had the potential to create a situation in which they found it difficult to agree on the best way to alleviate or treat their symptoms.

Theme one: What is normal?

The theme of identifying whether something is normal or not arose in several different contexts for the women in this study. Some women discovered that they had fibroids without experiencing any symptoms, whereas other women noticed changes in their bodies that eventually prompted them to obtain medical advice. It was not always straightforward for these women to recognise that these physical changes were evidence of illness. This was particularly difficult for the women who were approaching the age of menopause at the time they first noticed their symptoms. These different factors created much uncertainty and some anxiety for the women. Most women had to rely upon and trust their own body awareness and knowledge of what was 'normal' for them. This is set within the context of how society views women's gynaecological problems.

"It's a natural thing that a woman should bleed every month"

For most of the women interviewed, the first symptoms they noticed were changes in their menstrual bleeding patterns. Their periods became much heavier and in some cases more frequent. The women were all aware of what a normal period was like for them and consequently noticed when this changed:

> *"And also in January last year, I noticed that my flow, my period flow was getting very heavy, which was quite confusing because I was on the pill and everything, and it was very abnormal."* (P21)

> *"I started getting very, very heavy periods which didn't last the normal five, seven days. Went on and I had a few days off and then start up again and it got quite horrendous." (P17)*

> *"Um, about eighteen months ago my periods, which had always been extremely regular and pain-free and light... became heavier and more painful for a few months. Then I moved on to having bleeding between periods and finally um, the bleeding became continuous and at that point I went to see my GP." (P20)*

This awareness of what a 'normal' period was like for them as individuals, also extended to their awareness of heavy periods. Most women indicated that they had an idea of what a 'normal' heavy period was like. They therefore became frightened when their experiences exceeded this:

> *"But uh, and that's very frightening to bleed that heavy. It's more than just a heavy period. A normal heavy period is clotty. This was just pouring." (P22)*

> *"Because it's quite frightening when you've not had, when you've had a sort of normal period and then suddenly you have this horrendous bleed, it is very frightening. And you start thinking the most awful things and you know, ok, if it goes on for a day or so, that's fine, but you know, to go on for, you know, non-stop and have a couple of days off and you think that's it and then you start up again, it's frightening." (P17)*

Other factors also contributed towards the women's awareness that their experiences were not 'normal'. For many the changes in their use of sanitary protection also provided a signal that something had changed:

> *"... now I just buy dozens of packets. I buy absolutely masses of them, and I use them all. I use masses of them." (P24)*

> *"And that then during the night, when you have your period, you have to get up a few times because it's not enough, nothing is enough to, for the whole night." (P25)*

> *"And I need a mega tampon and a towel and I might get twenty five minutes out of it." (P22)*

However, despite recognising that their periods were not 'normal' for them as individuals, women found it difficult to know if their symptoms were 'normal' for women generally or whether they should be considered as a sign that something was medically wrong with them. This is particularly difficult since as one woman said *'it's a natural thing that a woman should bleed every month....a woman in theory can cope with it'* (P17). Thus women struggled with identifying the point at which it was acceptable to say they could not cope. As one woman said:

> *"I think the thing that would help me is, it's difficult, none of the doctors will commit themselves as to what's a normal amount of bleeding, and what's normal to try and manage. And I feel I'm on the edge of what I can manage though, just in terms of wanting to go out and do things." (P24)*

Symptoms as a sign of normal ageing

Recognising whether physical changes were a sign of illness was particularly difficult for the women who were approaching the age of menopause at the time that they first noticed the symptoms. They initially attributed their symptoms to the normal ageing process as these quotes illustrate:

> *"I assumed at first that it was my age. That it was inevitable for, you know, as I got older that was what happened. It was only when they became continuous that I realised that I had something that didn't happen to every woman as she got older." (P20)*

> *"I know it's normal in, in your forties maybe to have more blood, but there seems to be an awful lot more." (P24)*

Two women in the study had found out that they had fibroids during routine medical examinations some years prior to the onset of any symptoms. Despite this prior knowledge, they both still attributed their heavy bleeding a few years later to the menopause. As one woman put it:

> *"And I thought well you're coming up to the change, believe me. These just show you the change. Not knowing still that the fibroids might be getting... larger and other things." (P13)*

However, it was not just women approaching the menopause who had difficulty distinguishing normal ageing from abnormal physical symptoms. A younger woman in the study became aware of a lump in her abdomen and described her thoughts in the following way:

> *"I'm in my mid-thirties and I thought it, it seems a bit strange, but ok, maybe this is what happens to our bodies, you know." (P11)*

Am I ill?

Within the theme of recognising whether something is normal or not is the concern that several women expressed about whether they were ill. Specifically, some of them found it difficult to make sense of their experiences of generally not feeling ill whilst at the same time having physical changes, distressing symptoms and eventually a medical diagnosis. It was clear that this dilemma continues even once they have got a diagnosis of fibroids:

> *"Um, three weeks of the month I feel that oh, like today you know, I was running for missing the buses and rushing there and rushing there and then, you know, I thought I haven't got fibroids. What are they talking about? (laughs) I'm fine." (P13))*

> *"I'm not, I'm not ill. I haven't got a life-threatening condition. I'm not confined to bed. I've you know, I do, um, although at, at times it, it does slow me down and I feel unwell. Um, um, I don't feel too bad. (laughs) You know, it does just depend, um... yeah no I don't feel ill, yeah. It depends how you define it all really." (P15)*

Some women struggled with understanding the difference between having an illness and having a condition. Several had the feeling that *'I'm not ill. I'm quite healthy and fit'* (P26). This meant that they did not always view fibroids as an illness. Generally women who thought that their fibroids would be cured described it in terms of a problem that would eventually be solved, as shown in the quote below:

> *"I don't really view fibroids as a serious, it's not serious and in time it should go away." (P15)*

However, despite usually not considering themselves to have an illness, most of the women expressed the fear that their symptoms or their condition could be more serious. Many of the women interviewed had at some point feared that they had cancer. For some women this was an ongoing fear, despite reassurances from the doctors.

> *"And obviously you, you do start thinking oh have you got cancer? Have you got this? Have you got that? Have you got a tumour?" (P17)*
>
> *"And I thought oh, is it going to be cancer? And that's my main problem, is it going to be cancerous? Is it cancer or is it something else? Or is it a fibroid or is it a cancer?" (P13)*

Attempts to define what is 'normal' represented one way in which the women tried to manage their uncertainty about changes in their bodies. Despite receiving medical attention, they continued to show considerable uncertainty regarding how to think about their condition. Again these appraisals focused upon the question of normality, namely whether they identify themselves as being ill in addition to concerns that apparent normality masks serious illness.

Theme two: Seeking knowledge

Many women felt that they had not received enough information about their condition and had found it difficult to get information. Most of them had little or no knowledge of fibroids prior to their diagnosis. Following diagnosis, they were also concerned to be informed about the different treatments available so that they could be sure of making the right choices. They seemed to want more information and this caused most of them great uncertainty.

Doing your own research

Women generally felt that they had to do their own research in order to find out information on their condition. For some this assumed great importance as they were so uncertain about what was wrong with them. However, doing their own research was generally felt to be unsatisfactory, with some women worrying that they could not understand the information properly:

> *"Reading stuff off the internet which is written by doctors for doctors isn't good enough for someone like myself who's not studied medicine, you know. But that's the only way I could get information." (P21)*

A few women were also concerned that other medical practitioners, such as GPs or in one case the doctors at the family planning clinic seemed ignorant of the condition:

> *"... the family planning clinic, didn't know anything about it, couldn't help me, they, they told me to go to the wrong place for an ultrasound. Um, I felt I had to rely very much on, on doing homework myself." (P30)*

A number of the women wondered whether other women in their situation would be as proactive in seeking out knowledge:

> *"I haven't received enough information about the operation, no. But I have... done my own research. You know, but for women who can't do their own research, then they're going to be unaware aren't they? There's not every women gonna go out there and do their own research, is there?" (P12)*

The women had different experiences of the availability and utility of the information. Most felt uninformed and said that it had been difficult to access adequate information. This seemed to be specific to having fibroids, as several made unfavourable comparisons with researching other conditions. The following quotes were typical:

> *"If you go into that, um waiting area, there's no literature which talks about fibroids... They talk about chlamydia. They talk about smear tests and they talk about all these other things, sexually transmitted diseases and they don't talk about fibroids. I never even knew what fibroids was." (P12)*

> *"Um, I think the main thing was feeling scared, uh, in that I knew I had a, a condition and it was so hard um, to find information out about it. Uh, and it's very hard to distract yourself from that and just get on with thinking about other things." (P30)*

A minority of women felt that information was available, so long as they were persistent in their search for knowledge and actually asked questions of the medical staff:

> *"Information. I, I just go and seek out information. Some of it terrifies you, some of it's useful. You just have to go and seek out information. And people that you trust should give you a good overview. It's about being persistent." (P22)*

> *"They're always willing to tell you, you know, if you ask. Or if you have a prob, a concern, they're always... people always seem to have time to tell you, no matter how late it is, or how late they're running or. They always seem to have time to explain something to you or sort something out." (P18)*

The women who had not done their own research generally did not feel well informed:

> *"I haven't really found out more. I don't know I would say much more than I did before the whole thing started." (P20)*

Doctors as sources of information

All the women had expectations that the doctors would have provided them with information about their condition. When this had happened, they tended to be very appreciative of the efforts of the doctor to explain it, but felt that *'it's very easy to forget what you've been told'* (P15). Another woman felt that anxiety around the consultation increased the likelihood of forgetting the information because:

> *"You're seriously not listening, 'cause you've worked yourself up probably before you went in." (P17)*

Several of the women had been treated at other hospitals and had been referred to the current hospital because they were dissatisfied with their previous treatment. Almost all the women felt that their experiences with regard to receiving an explanation at this hospital compared very favourably with the other hospitals. However, despite their general enthusiasm for the hospital, some women felt that they still did not know 'the whole story'. One woman said:

> *"I know what they, what they told me, and um, at [name of hospital] I got a lot more explanation than I had at [name of previous hospital]. Um, I had a proper explanation, which was good. Um, but no, I don't know that much about it." (P24)*

However, for some of the women there was a concern that they had to be extremely persistent to access further information. Even having done their own research, there was an expectation that the doctors should be able to tell them more and enhance their understanding. Most women doubted their ability to be well informed without assistance from the medical profession and almost all still felt there were gaps in their knowledge, as these women's quotes illustrate:

> *"I understand a little bit about lots of different people's opinions about why this happens, how you can deal with it, um but you know, I'm, I'm, I'm not a doctor and so I still have questions." (P30)*

> *"I'm still sort of in a fog about it. Um, I would still like to know a lot more." (P13)*

Yet, for other women there was also a sense that even the medical profession do not know much about fibroids, which added to their own uncertainty. They doubted whether anybody could tell them about their condition, particularly about the causes. They acknowledged that they wanted more information and continued to be hopeful that "someone might know". Some women managed their anxiety about this by constantly asking the doctors:

> *Um, they do try to explain, but I still haven't, I still can't get why you, why there are fibroids growing inside you, because no one seems to know… which fascinates me. They seem to know about other things." (P17)*

> *"I do sometimes wonder and, but everybody I talk to, every doctor that I talk to says we don't know why women get them." (P11)*

A minority of women accepted the fact that nobody could tell them and instead concentrated on finding out how to help their symptoms, rather than dwelling on the causes. This can be seen in the quote below:

> *"I've never actually asked would I like to know what it was, but I suppose I would. I never, because you think well no one knows, so you don't, you don't. You sort of think well I'm not going down that route, because there's no answer to that one." (P22)*

Knowledge of treatment options

Once diagnosed with fibroids, the knowledge that having fibroids is a common condition amongst women also aroused uncertainty, rather than reassurance. This knowledge made some women confused about the lack of knowledge available to them about the condition. It also made it difficult for women to understand why there were such limited treatment choices available, which increased their feeling of uncertainty. Concern about limited treatment choice was typically voiced by those women who had been advised by their doctors to have a hysterectomy. One woman described her attempts to seek knowledge about the different treatment options in this way:

> *"And I tried to find out if there were any groups that will help women, so you can talk to people who've had this experience, had surgery, how they dealt with stuff, couldn't get any information. Er, looked on the internet, asked my GP, asked someone's secretary. No one knew. But isn't this really, really common this fibroid thing?" (P30)*

Another factor related to the general lack of knowledge that women had about their condition, was the concern that they would make the right choices about treatment. One woman described how she spent a lot of time thinking about the different options:

> *"Which one should I go for and which sounds better? And which one would suit me, this operation? Should I do something about it, or should I leave it, you know?" (P13)*

Some women also said that they wanted to have somebody with whom they could discuss the different options. One woman said she wanted the doctors as 'specialists' to explain the different options to her so that she could make a decision about treatment. Her feelings were *'I go to them hoping they can tell me that'* (P30). For some women the way in which they resolved their uncertainty about treatment choices was through deferring to the expert knowledge of their doctors:

> *"I think when the doctors and the consultants tell you it's probably a good idea, then it's not as if they're short of work." (P18)*
>
> *"Maybe I should leave well alone? And then I think well, if it does grow, then it's harder to remove, so if, if the surgeon thinks it should come out now, er, then maybe that's the best thing to do." (P30)*

Other women felt unable to rely upon their doctors' advice and were consequently very undecided about which treatment to pursue. This was particularly so for women who had been advised to have treatments which they regarded as extreme, such as a hysterectomy. It was noticeable that the few women who had been scheduled to have a myomectomy operation did not express concerns about their treatment. These women were also the youngest women in the sample. They generally were not preoccupied with whether myomectomy was the right treatment, but were more worried that they did not know what to expect from treatment. This uncertainty caused them distress. As one woman said:

> *"Well you're frightened for a start, you know. You don't know what the outcome's going to be... and you don't know how you're gonna feel afterwards." (P21)*

As this quote shows, the uncertainty was focused upon knowing what to expect when they began treatment. As the treatment also involved three months of hormonal treatment to reduce the size of their fibroids, they were concerned about adverse hormonal effects on their mood. The women were also concerned that the operation would be a success and that the fibroids would not return.

Theme three: The Doctor's Viewpoint and the Woman's Viewpoint

The many factors that contributed towards the women's sense of uncertainty were further compounded by the search for a shared understanding with their doctors of their condition. This was complicated for many women because of differences of opinion between themselves and their doctors, both about the causes of their gynaecological symptoms and the best course of treatment. These difficulties led some women to view the consultation as a conflict, in which they had to approach the doctor forearmed with knowledge and determination to be heard. One woman who was dissatisfied with the choice of treatments offered to her felt angry and distressed about the way in which she was treated during consultations. She felt she had to be forceful to find out about alternatives and said:

> *"I don't think you should feel as though you're going to have conflict or, or not to be feeling at your ease when you go into, for your consultation." (P15)*

For these participants, it seemed to be difficult to have a shared understanding of their problems with the doctors. Some expressed the opinion that the doctors did not seem to listen to their perspective as a woman or respect their understanding of their own bodies. Although one women felt *'very naïve about how the body works'* (P13), others felt more informed and wanted this taken into consideration. Another woman felt she had a lot of understanding of her condition and remarked *'it's my body. I live in it. They're only seeing it for twenty minutes.'* (P22). However, she had struggled to get the doctors to accept her perspective that she did not want surgery to remove her very large fibroid. A number of women thought that being heard and understood was especially difficult when they were treated by male doctors, who could not understand and empathise with their experiences as a woman could. The quotes below are typical of the women in this study:

> *"... Especially if you go to see, especially a lot of men doctors, they're not sympathetic, because they don't have, they've not experienced it. And it doesn't, I don't care what they've said, they don't experience what a woman goes through every month, so they can't be that sympathetic." (P17)*

> *"... and I think generally women know about themselves and therefore um, perhaps the doctor should listen a little more." (P15)*

> *"because, I just feel as though they don't really listen sometimes, especially um, if it's a man, they don't really understand" (P23)*

This suggests that gender issues within the consultation may be viewed by female patients as having an adverse influence upon their search for understanding. However, some women also recognised that their own approach to consultations limited the doctors' ability to understand them. One woman described it as *'a barrier that you put up because he's a man...you just say what you have to say and get out'* (P17). Furthermore, it was notable that despite expressing these feelings in the interview, none of the women who said they would prefer not to be seen by a man had actually ever specifically requested to see a female doctor. They cited reasons such as the doctors being 'so busy' and felt that other women had more reason to request it, perhaps due to cultural or language issues.

"The challenge of their skill against what I want with my body"

Within the theme of having a shared understanding between the doctors and the patients was an issue around what both parties expect from the consultations and the treatment. There did not appear to be an agreed agenda for how consultations were conducted. A couple of women expressed the view that sometimes attending their appointments *'was a complete waste of time'* (P19) and they thought ' *oh, why did I bother coming?'* (P17) Especially for those women who were awaiting treatment or had made a decision to delay treatment, it was not clear what role was served by 'just a little chat' at outpatient appointments every few months. Although women were generally clear that they were seeking reassurance from the doctor that they were not seriously ill or that their condition was not worsening, this reassurance was often not achieved. They continued to be uncertain about the progress of their condition, wanting someone to *'actually look inside of you and each time you go in and say everything's fine'* (P17). Other women also mentioned the lack of monitoring of their condition through regular scans and/or internal examinations. This increased their fears about the fibroids growing. As one woman said:

> *"I want to ask the, the consultant if it's, if my fears, if he can just assure me that there's no danger. Because I know that this fibroid's growing and that it's getting bigger, and I just want to ask him if it's ok that the fact that I haven't had a scan since August." (P23)*

However, some women had different views of the consultation. Two of these women felt that having fibroids had had some positive effect upon their lives. They were both sure about what treatment they wanted and to some extent had resolved their uncertainty:

> *"I mean I'm sure if I ever walked through that door, you know and said look you know, I just know you'd get, just some support." (P22)*

> *"When I saw a gynaecologist in the hospital, she was extremely kind, supportive, giving information. It's, it's excellent." (P25)*

Another woman who expressed satisfaction with the consultations had previously been diagnosed and successfully treated at the same hospital for a serious illness. She felt that fibroids comparatively were 'nothing to worry about' and felt very grateful to the medical staff for all their help. Again it was noticeable that the women who were having a myomectomy operation were more satisfied with their consultations.

For a number of reasons it seemed difficult for some of the women to reach a consensus with their doctors about the best course of treatment during the consultations. One of the main reasons for this seemed to be the perceived mismatch between the offered treatment and the women's subjective illness experiences. Several women described having fibroids as a '*nuisance*' (P20) or '*just another little niggle....in the daily niggles of life*' (P18). So for them it was difficult to understand that major surgery such as a hysterectomy was an appropriate response. It seemed too extreme given their current way of thinking about their symptoms. This is illustrated in the quotes below:

> *"They were a bit, they were very pro surgery, which in the early stages seemed to me to be a bad decision, because I had no symptoms and it didn't seem to me any reason to undergo major surgery if you're having no symptoms." (P19)*

> *"I'm thinking I'm not having any symptoms. Why should I have a hysterectomy? And why can't they do something else?" (P13)*

> *"And er, basically the advice that I was given, er, it was implied that a hysterectomy would be the best thing. Er, even though I wasn't having a lot of pain, I wasn't having heavy periods..." (P30)*

The women could understand that major surgery would be appropriate if their fibroids began breaking down or were cancerous, in which *case "well go ahead, remove everything straightaway, but if it's fibroids, then I'm not having that drastic a problem"* (P13).

For most women there was a belief that the doctors had a preferred treatment which they would try and persuade the woman to accept. One woman felt that the message she received from the doctors was *'this is what we offer and we can't go down any other road'* (P15). She described herself as a *'whiney old thing'* because she continued to ask her doctors to tell her about alternative treatments to hysterectomy. Like her, women who disagreed with the treatment offered felt that they had to be persistent to be heard and have their opinion respected. The following quote is from a woman who had lived with a large fibroid for over ten years:

> *"When I first came, I mean I have been... persuaded if you like, I mean they desperately tried to persuade me into surgery. And that was every single um, consultant gynaecologist I see has always said oh you've gotta have this out. Why are you walking around with this inside you? And eventually I say, well you know, actually it isn't a problem. And when I explain from my point of view, they hear me. When I was younger they would never have heard me. You know it would have been yes, yes, yes, but you've gotta have this taken out. Because they, you know, it's almost like I've gotta take this thing out. It's almost like it's the challenge of their skill against what I want with my body. And now they listen to you." (P22)*

As the above quote clearly shows, there is a belief that the doctors have a need to demonstrate their surgical skills by removing the fibroid, rather than considering whether the woman herself wants it removed. Furthermore, several women appeared to think that treatment decisions are dictated by what is easiest for the doctor, rather than what is in the best interests of the woman:

> *"It sounds like it's, it's easier for the consultant, the doctor to remove everything for himself." (P13)*

> *"I think he kind of thought, you know, well you're just gonna make my job easier, which in the end will affect you. From his point of view it's the best thing to do, and I'm not saying it isn't, but I, I, wouldn't have minded knowing a bit more about how um, it affects you." (P30)*

> *"I felt as though they thought of me as a bit of a crank. That's, you know, she's really not fitting into what we wanted, she's a bit of a pain or something." (P15)*

One woman who had decided that hysterectomy was the best option had a different experience of the consultation. She felt that the way in which she was treated by the doctors showed respect for her opinions and allowed her to reach her own conclusions. She felt that the decision was not forced upon her and the way in which it was discussed allowed her to suggest hysterectomy as an option, rather than feeling that the doctor was imposing the treatment upon her. She said:

> *"He asked me what do I know about the innards? And what solutions? .... and it's a very good, psychologically it's a very good way of leading someone to this solution, that she brings it up. And not I attacked her with that solution." (P25)*

How women's bodies are viewed

Part of the difficulty appeared to be differences in the way in which the doctors and women viewed their bodies, particularly their uterus. One woman felt that it was *'as though any bits of your body don't matter'* (P15). Another woman who had previously had other gynaecological problems was scheduled to have a myomectomy operation, which she herself was satisfied was the right option. However, she described how when she told her GP about this, the response was:

> *"if I were you, when you go to the hospital to have your surgery, you should just tell them to take the whole thing out, because it's diseased....You've had this and you've had that done and if I were you I'd just have the whole thing taken out." (P21).*

Situations such as this create a conflict situation over who makes decisions about women's bodies and what they need. It was also notable that women who had already had children or who did not want children felt more pressured to have a hysterectomy, because *'you don't need your uterus anymore'* (P13). The following quotes illustrate this further:

> *"I don't like other people saying things to me like 'oh you don't need that'. (laughs) And I thought well no, I still do. It's mine. Why should it be removed?" (P13)*

> *"my GP as well, she's you know, it was kind of like, well if you don't want children just have it out, which um really surprised me." (P30)*

Thus there appears to be a lack of recognition of women's views of surgery and their bodies. They feel that their opinions are neglected about wanting to avoid major surgery with the removal of their *'healthy uterus'* (P15) when as one woman said *'the fibroid is the sick part of me'* (P13). Furthermore, women felt they had to justify reasons for keeping parts of their body they were not going to 'use'. This was also evident in a more subtle way among women who had agreed with their doctors that hysterectomy was the best option. One woman described giving a lot of thought to the type of hysterectomy she wanted to have. She had decided that she did not want her cervix removed because she was concerned that this would affect her future ability to enjoy sexual intercourse. However, she felt that the doctors would prefer to perform a full hysterectomy to eliminate the risk of any future gynaecological problems. She described it in the following way:

> *"I sort of got the impression that it would be more convenient... I think I can imagine that medically it would probably be more convenient to take the whole lot out. I mean you can see that. It's quite logical. But from a sort of female point of view, one hesitates to er, to lose one's cervix because of, you know, the um, the element of that, that it contributes towards intercourse and I wouldn't really like to particularly miss out on that." (P26)*

This quote shows how some women felt that there was a difference between the doctor's 'logical' medical viewpoint and the woman's viewpoint.

Theme four: It's going on and on

Many women felt that the situation had been continuing for an unanticipated length of time, which contributed to their feelings of distress and uncertainty. It appeared that they had not anticipated that they would be seeking treatment and suffering from their symptoms for so long. Furthermore, for many of them, an end to their situation was not easy to envisage and they longed to "*get it over and done with*" (P11). The following quotes illustrate how many of the participants felt:

> *"It's just been going on so long, you know. And it's still got to go on." (P11)*

> *"I don't know what I expected, but it just seems to have gone on and on and on. And I'm still no further on now." (P24)*

When contemplating how long their condition would endure, some women found it difficult to envisage an end to their problems without surgery. They felt they had no control over the outcome unless they had an operation:

> *"Um yes, I don't want it there, but yes I can't do anything about it because it's inside of me. There isn't nothing I can do until I have an operation to remove it." (P13)*

> *"If I had surgery, yeah, but that's like an if first, isn't it? No, I can't or if I had the menopause, but I'm only forty so yeah, there will be eventually, but it may be ten years or so." (P24)*

However, for some women even surgery did not promise an end to their problems. This contributed to their feelings of uncertainty about making the right choices for treatment and their general feelings of uncertainty about their current situation and future health:

> *"I suppose that's really the only thing I have, just at the back of my mind is this the beginning of a long period of gynaecological problems or not." (P20)*

> *"After this operation I've been made to understand or I've read it some places as well, that it could grow back. So I can't say how long I expect it to last. It's lasted all these years now you know, I could have the operation and it could come back in under five years time. I don't know. You know, it could be that's the end of it, I don't know." (P10)*

Some women accepted that their condition had been going on for a long time because they had deliberately decided against treatment. Usually this was for personal reasons, such as conflicting demands on their time or because the offered treatments were unacceptable to them. However, some women seemed to manage their uncertainty about choosing treatments by delaying treatment. This was particularly so if they felt they could manage their symptoms or felt very strongly that they did not want surgery. Some women expressed the belief that new treatments were imminent and that if they waited long enough, they would benefit from them. As one woman said:

> *"I'm probably convinced that in the next three, five, seven years there will be something which will avoid me having to have to go through major surgery, because I really don't want it." (P22)*

Alternatively, the knowledge that fibroids usually shrink after menopause, encouraged some women to delay treatment in the hope that they would experience the menopause before having to go through what they viewed as potentially unnecessary medical procedures. One woman who had delayed treatment for over five years due to her uncertainty explained that *'knowing that my menopause is coming has given me this little bit of hope'* (P13). For other women, their menopause was considered too far off and only served to reinforce the idea that it would 'g*o on and on'* (P24).

Waiting for treatment

For a few women, the reason for the enduring nature of their condition was mostly attributed to having had to wait for treatment or diagnosis. Some felt that there had been an unnecessary delay in investigating the cause of their symptoms. This is shown in the quotes below:

> *"It shouldn't take this long to find out." (P15)*
>
> *"...cause at the moment, for the last, almost a year now, I've been thinking, when's this appointment gonna be? When's the scan gonna be?" (P23)*

These women felt that their feelings of distress or frustration were mostly due to uncertainty about when their next appointment would be or when their initial treatment to prepare them for surgery would begin. They blamed the delays on the inefficiencies of the health service, as shown by the following quotes:

> *"I know there are waiting lists and I understand that it's, I'm not an emergency and I don't have a problem with waiting as such, but the process overall has some real in-built inefficiency that I think could be addressed and I could have been treated a bit more quickly." (P20)*

> *"I lost six weeks on the waiting list because um I was misinformed by someone." (P30)*

Several women were very uncertain about how long their condition would last and expressed frustration that it had already endured as long as it had. They had to find different ways of managing their uncertainty regarding this. This was especially relevant for those women who were several years away from the menopause and who were delaying treatment, because they did not want a hysterectomy.

Overview of Higher-order Theme 2: Struggling between defeat and optimism

Analysis identified a second higher-order theme relating to control and how women have to learn to live with having fibroids. One woman called this 'struggling between feeling defeated and feeling optimistic'. For some women this was easier than for others. The degree to which they felt in control of their situation impacted upon how they thought about both the condition and themselves. There were differences between the women in how they thought about and visualised their fibroids. For some they were viewed as part of themselves, whilst other women saw them as separate and 'alien'. These different views influenced how much control they felt they had over it.

All participants had made some adaptations to living with this condition. As a minimum this involved certain practical considerations, usually around the heavy menstrual bleeding. At most it came to dominate much of the woman's life, so that they felt the condition was at times controlling them. For some women it had a negative effect upon personal relationships, their self-image and their ability to choose how to lead their lives. However, the personal emotional impact and individual interpretation of these restrictions varied among the respondents. Thus the way in which they live and think about it influences whether they feel defeated by the condition or optimistic about their present and future ability to cope.

One way in which they gained control of the condition was by being determined that the condition wouldn't control them and the way they lead their lives. This determination also showed itself in the way in which they related to the medical profession and their pursuit of treatment. Most of the women interviewed had also tried various 'self-help' treatments, which increased their feeling of being in control to varying degrees. Thus a number of factors contributed towards the amount of control they perceived themselves to have.

Theme one: Thinking about fibroids

The women in this study differed in how they thought about their condition and this appeared to affect the degree of control they felt they had over it. A few women said that they did not really think about their condition a great deal. One woman described her thoughts as *'oh well I've got fibroids and that's that' (P26).* She had not spent time thinking about what the fibroids were like. In common with other women who also had not considered this, she described having fibroids as *'a nuisance'*, but did not describe any particular images or thoughts about them.

Fibroids as something 'other'

Women who did have images of their fibroids as something 'other' were much more distressed and frightened by their experiences. They seemed to think of them as having a malevolent individual identity, with one woman saying *'I don't like them' (P21)* and describing her largest fibroid as *'evil'.* These women became quite preoccupied with the unpleasant images of what was growing inside them, often drawing upon vivid images such as *'creepy crawlies inside of me' (P17)* and *'this is a little monster' (P13).* The image of something that continues growing dominated their thinking as shown in the following quote:

> *"you start thinking you've got these huge things growing inside you. And obviously you've seen these films on TV where things start. It does, it makes you think and you think you've got these things inside you and they're gonna get bigger and bigger and bigger and it is frightening." (P17)*

This preoccupation with something growing inside them was also reinforced by physical changes that caused several of them to comment that they both looked and felt *'permanently pregnant' (P23).* This was possibly reinforced by the practice of the medical profession to describe the size of their fibroids in terms of weeks of gestation. One woman was told that she had a fibroid *'the size of a three months foetus' (P21)*, whilst another said *'the doctor that ultimately referred me here described me as looking four or five months pregnant' (P11).* Another woman wondered *'maybe it's my second baby' (P13).*

How doctors described fibroids to the women had an influence upon the way in which they thought about them. In particular, being told that they had a 'tumour' increased their fears of serious illness. As one woman said, *'to me a tumour is cancer' (P11).* She told how she *'panicked for the rest of the day'* until she was able to look up fibroids in a dictionary, which reassured her that *'it wasn't a scary thing'.*

What women were told about their fibroids also either increased or decreased their feelings of control. Having been told of the possible dangers of not removing the fibroid, one woman with no current symptoms was left with the feeling that it was *'like an unexploded time-bomb' that 'could go at any time' (P19).* Another woman was told that her womb was *'covered'* in fibroids. She found this image quite alarming. The way in which she described her thoughts shows the preoccupation with something growing inside them:

> *"Yes, I think actually that probably was the worst bit hearing that, because I mean, I don't know, I was trying to think how big a womb is. How many can you get on the womb? You know, how can it be? But I think that's probably my main, just the fact that what happens when they do get bigger?" (P28)*

These women also described how having fibroids had caused them to become 'burdened' by all their thoughts. They focused upon what might have caused them and the effects, both now and in the future. The following quote is illustrative of how a number of the women became fearful that they could not survive the amount of blood loss they were experiencing. This woman described the effects upon her:

> *"Um it did, it affected you not just physically, mentally as well. Because you are, I was becoming like, I've spoken to other women that have had the problem, you become so obsessed by the fact you're always bleeding and you get this sort of thing, you're going to bleed to death." (P17)*

Thus as this quote shows, women worried that the fibroid had the potential to cause their deaths through heavy blood loss, over which they often felt they had little or no control.

Fibroids as 'part of me'

In contrast, two women in this study felt that having the condition had actually had some positive effects upon their lives, despite both suffering quite severe symptoms. The way in which they talked about their fibroids indicated that they viewed their fibroids as 'par*t of me (P22)'*, which they had created in some way. One woman thought the cause was hormonal, whilst the other felt that stressful events in her life had caused it to grow. In response to being asked what her feelings were about her fibroid, one of these women replied:

> *"Well it's along for the ride. (laughs) It's just there. It's part of me. I don't, I don't... I think you're asking me whether I have a bond with it or whether I hate it, or whether I sort of feel like it's an alien or, and it's just, it's part of me. It's, it's, it's an idiosyncrasy of my hormonal functioning. Fine. Ok. Well let's get on with it. Let's get on, let's get on with the journey together." (P22)*

The second woman who felt she had gained something from having the fibroid, felt more open to different perspectives on life. She said that she had *'gone on these thinking paths'* and she *'wouldn't have gone through it without this fibroid' (P25)*, which had prompted her to examine painful events in her past, which she felt had contributed towards the growth of the fibroid. However these two women were in the minority.

Theme two: Not leading the life I aim to live

All the women interviewed acknowledged that having fibroids had affected their lives to some degree. However, there was a great variation in how much impact this had had on them and this did not appear to be related to the perceived severity of their symptoms. The degree to which their condition influenced their lives and the way they wanted to live, was related to how they thought about it and what difficulties they perceived to be a result of having fibroids.

Limited impact

A few women felt that having fibroids had had little impact upon their lives. They typically said things such as:

> *"...it's not a major... it's not a major problem, you know. I just live with it." (P18)*

> *"It's, I mean I don't find it massively inconvenient. It doesn't hugely affect my life, but it's a bit of a nuisance." (P20)*

Although these women often experienced similar symptoms to the other women, they were not as aware of having had to make adjustments to their everyday lives. Furthermore, one of these women had previously had a serious disease and comparatively she felt that fibroids were not like *'the terrible things people have'*.

Only one woman felt that learning to live with fibroids had actually helped her find *'the recipe to a lifestyle'* which was beneficial to her. She said *'I'm probably healthier at forty five than I was at twenty five, minus the fibroid' (P22)*. She had found a lifestyle incorporating diet, exercise and various self-help strategies that she reflected has *'sustained my working career, my family life and everything else in a much better way.'* Although in the past she had felt *'I can't cope with this anymore'*, she now felt that through her lifestyle she had *'complete control'* over her condition.

'One day at a time'

Some women described the adjustments they had made to living with the condition. They felt that it was difficult to control certain symptoms, particularly if they had irregular heavy bleeding. This unpredictability obviously had an impact upon how they were able to lead their lives. They had to find a way of living with the possibility that sometimes they would have to change their plans. This meant that for some of them it was easier to live in the present. The following quotes illustrate how women approached their everyday commitments:

> *"There's loads of clichés for this, you know, one day at a time, take it as it comes, you know, er... I can't plan ahead. I can't, I can't accept invitations for things. I can't, I mean I didn't know this morning whether after meeting you, I would go for a swim, go talk to my friend to you know, kind of work things out or go home and be quiet." (P11)*
>
> *"I think only just and then just I do the next most urgent thing, whatever that is." (P24)*

Living in this way also means that they have to be prepared for difficulties. The women described planning ahead and anticipating that the bleeding could start at any time. This is clearly shown by the quotes below:

> *"I always do have a bag in the car with clothes in it. You know I think it's becoming worse, you know, it's part of my life to have a bag in the boot. This is for changing or something. Even in my car seat, I have towels in there." (P10)*
>
> *"I've always gotta know that if I'm going somewhere, there's gotta be a toilet." (P28)*
>
> *"So wherever I go, if I go away for the weekend or anything like that, I always take some with me just in case. So it's something extra to have to think about as an, you know, most of the time." (P26)*

Restricting activities

The effects of living in this way were that some women felt that having fibroids had had a great negative impact upon their lives. These women had clear ideas about how they wanted to live and women said things such as *'I'm not leading the life I aim to lead' (P11)* and *'it's not how I want to live really' (P24).* They felt that fibroids were preventing them from doing so. Although they generally tried to carry on with their normal lives, they felt that their difficulties came to dominate their lives and placed unwelcome restrictions upon what they did. This can be seen from the following quotes:

> *"I know that my condition isn't life-threatening, but it's, it's driving me crazy. It's ruining my life, you know. Everything I do is in spite of that." (P11)*

Many women talked about their feelings of frustration and distress when they were unable to do things they wanted to.

> *"I mean my periods were lasting like two weeks as well, so for two weeks out of every month, it was, quite distressing, you know, knowing that I couldn't do the things that I wanted to do." (P21)*

One woman described it in this way:

> *"It boils down to anger, frustration. Not being able to do things, like I say earlier on. You know when you see a tree there, you see something you want to hold. It's so near, but it's so far away. You can't reach it. That sort of frustration. I know I could do this, but because of this I can't do it. You know, so I get upset." (P10)*

Thus these women were conscious of how they struggled to achieve the things they wanted to achieve. They were also very aware of the activities in which they had difficulty fully participating. They felt they had to prioritise the activities that they really wanted to do, since they did not have the energy to achieve everything.

> *"I'm just too tired, too exhausted. Um... I, there are just things I don't take care of anymore, because I'm just not up to it." (P11)*

For some women even doing their favourite activities became difficult at the times when they were experiencing heavy bleeding. One woman who described herself as a *'very keen and conscientious swimmer'* said:

> *"I cannot get myself into that pool. You know, even though I'm wearing a tampon, I'm not, not bothered about swimming when I'm on my period, but I can't, I can't physically do it. I'm too, I'm weak. And I don't feel it's just the bleeding, it's the whole, the whole thing. How I, how it makes me feel." (P15)*

As this quote illustrates, these effects are not seen as being purely physical. They are finding it difficult to lead the life that they want to live. Furthermore, they view the restrictions on their lives as having psychological effects too. Several women recognised that it adversely affected how they think about themselves and their bodies.

Theme three: Effects on the self and others

Some women felt that their feelings about themselves had changed. This was particularly in relation to their physical appearance and body image. They also felt that their relationships, particularly sexual relationships, had been affected. Some women attributed this directly to the symptoms, for example describing how the heavy bleeding prevented them from having sex due to the uncontrollability of the bleeding and the effects this had upon themselves and their partner. Other women felt that this was just one factor among several that affected how their partners viewed them sexually and how they thought about themselves as women.

Body Image

Several women spoke of changes in their body. They described how this had negatively affected their body image and the way in which they thought about themselves. One woman reflected on how this had changed over the past few years since having fibroids:

> *"But certainly I've had a very positive body image before. But I feel like I'm fighting to keep it now." (P24)*

Many women spoke of *'feeling like I've put on a lot of weight' (P18)* which combined with the physical appearance and some similar sensations of early pregnancy made them feel conscious of how they look and what they did:

> *"So your tummy's sticking out and it affects you, the way you look and the way you feel and it ends up making you feel a bit depressed, because you just feel um, a bit unattractive, you know. And I don't like to go swimming because of it. So it has quite a big effect." (P23)*

Although another woman described her feelings as *'superficial vanity'*, she still disliked *'being a dress size larger' (P22).* A few also felt resentful that these changes were not attributable to their own behaviour and therefore out of their control. As one woman said:

> *"I mean the weight issue is an on-going thing. You know that's probably the thing that's foremost in my mind, you, you know, nearly all the time. Um, you know, as a, as an active person who eats sensibly, I'm really very aggrieved about it." (P15)*

Attempts to control their weight were difficult to maintain or ineffective *'unless you starve yourself'* (P17). There was a sense that *'you can help the situation, but you haven't got much control over it' (P17).* One participant described the results of her dieting as:

> *"it didn't make any difference because it's still there and, and it's like being four months pregnant all the time." (P23)*

For one woman, the weight gain was distressing not only because it affected her body image, but also because it was a physical sign of the unwanted fibroid growing inside her. She said:

> *"Because no. I mean it's not nice. When you're, when you've been used to having quite a, a decent figure and suddenly not only are you worrying about what's growing inside you, you've got the, you can actually see it from the outside to a certain degree as well. That your body's changed because of these." (P17)*

Effects on relationships

In addition to their feelings about themselves, a minority of women were also conscious that their negative self-image had affected their relationships with partners. They felt so distressed about the changes in their body that they began to question their partner's feelings towards them. One woman described it in this way:

> *"I felt wretched. I felt horrible. I felt hideous. I felt bloated, fat, heavy, and you know, even to the point I said to my partner, how could you want to be with someone like me? I'm horrible." (P21)*

Some women felt that having distressing symptoms had affected their relationships with partners and children who *'bore the brunt of it' (P10).* These women described feeling *'certainly more irritable... and flying off the* *handle at something that's a very small issue' (P15). One* woman felt that her partner was spending less time with her because of this. She explained:

> *"I feel half the time I don't see him it's because he's keeping away, because I've probably been quite snappy." (P21)*

Another woman felt that her condition and the symptoms had changed the way in which her husband behaved towards her as he was increasingly irritable with her, which was affecting how they related to one another. She reflected:

> *"Um, we're just, we're irritable with each other, you know, and a bit distant. It's just not been a good time, not that, not as close as we'd like to be." (P24)*

However, not all women felt that the relationships were affected by these incidents. Talking about the differences in her body shape, one woman described how she and her husband *'just have a laugh about it' (P23).* Another woman felt that although she was *'really horrible'* to her husband at times because of how she was feeling, he was *'very supportive and understanding and caring'*, so she felt *'it's not a problem' (P15).*

The women who did think that their relationships were affected, usually focused on how it had affected their sexual relationships with partners. Some women felt that their partner no longer found them sexually attractive, because of the heavy bleeding. The following quotes illustrate their experiences:

> *"Um, and my husband in particular. I think one of the things that concerns him is that he is concerned, it's having an effect on my sexual attractiveness to him or his interest in sex with me at the moment. And he's bothered by that." (P20)*

> *"... You know we are friends, but you know the sexual bit is... not there. He will try, you know, he will try to say he want to do it." (P10)*

Two participants said that their relationships were affected because of their own lack of libido or difficulty in maintaining a relationship. One woman explained *'I don't have the energy for a relationship' (P11).* The other woman was very concerned about the effects of fibroids upon her fertility. She was aware that this had reduced her desire to have sex, as she felt reluctant to have a sexual relationship until she could try to conceive. She recognised that this had caused tension within her relationship:

> *"Um, well, My boyfriend's at the end of his tether at the moment. Um, because obviously I haven't got a sexual relationship, cause I, I don't want one. I mean, I can't." (P12)*

Thus for some women the way in which they thought about the fibroids had consequences for their body image and their sexual relationships. One of the women who had found a way to successfully live with the condition did not feel that the fibroids had affected her body image. She acknowledged that if they had, this would have affected her sexual relationship, which would in turn have made the condition more difficult to live with:

> *"If I'm really honest, if I had any problem with it actually, then I would be a bit more miserable, because I wouldn't want it to inhibit my sex life. So I suppose I would be a bit more, but it doesn't." (P22)*

Thus, it seemed that women were more likely to be distressed if they thought that the fibroid symptoms and/or body changes had affected their previous ability to think positively about themselves. Feeling unable to discuss these feelings or 'laugh about it' with their partner contributed towards their belief that the condition had adversely affected their relationships. In turn this increased their distress. These women were clearly struggling between sometimes feeling defeated by effects of the condition and feeling optimistic that treatment would resolve their problems. Women in this situation were often especially anxious to have treatment.

Theme four: Gaining control

One way in which women leaned to live with having fibroids, was by gaining control in various ways. For example, they described being determined and they found their own ways of managing the condition or alleviating the symptoms. Other ways of gaining control involved adjusting the way in which they lived their lives, so that the impact of the symptoms was reduced. Control was also mentioned in the context of treatment, as the women increased their sense of control through monitoring and trying to participate in the treatment process.

Determination

Some women viewed fibroids *as 'something which a woman in theory can cope with'. (P17).* This feeling was reinforced by the knowledge that it is a common condition. This helped women view fibroids as a condition that they had to learn to live with. They expressed determination to try and live their lives as normal. Several of the women said that they were not going to allow the condition to control their lives or overwhelm them. Even when the symptoms were particularly bad, women were reluctant to stop doing their normal activities:

> *"But I've kind of got through it, you know, but I'm determined, I don't want it to affect me. I want to, I want to live my life, you know. I want to just carry on really." (P24)*
>
> *"I just, I know I've got to get up and do my thing every day, and know I've got to go, keep going to work... It's just trundling on and knowing that you've got to keep some sort of routine going, you know." (P21)*
>
> *"Even if I'm in pain, I do go, you know. That makes me feel as if I have control." (P10)*

On being asked whether it affected her social activities at all, one woman clearly demonstrated the struggle between feeling defeated and feeling optimistic:

> *"Oh no. Oh no, no, no. No, two pills down my throat and out you go. Two Nurofen and out the door. No I couldn't, I couldn't have it do that. It would beat me then and I couldn't have that." (P22)*

However, this was more difficult for some women than others. Despite trying to be determined and do the things they want to do, there were times when things did become too difficult and they were defeated by the condition, as illustrated by the quote below:

> *"I set my mind towards things and I try to do it. That makes me feel I have control. You know, I, I, I try not to let it overshadow me sometimes, but you know.... sometimes I can't help it, you know, I just can't be bothered, I don't want to do anything or go out." (P10)*

This shows how the attempt to carry on as normal is an ongoing process in which some women sometimes suffered setbacks. This illustrates the struggle they experience between feeling defeated and feeling optimistic. However, they maintained their sense of control by not allowing it to be a permanent setback. Despite sometimes feeling that the condition did defeat her, the woman above felt that generally she had a lot of control over her condition and she was successful in constantly striving to do her normal activities.

Determination in the pursuit of treatment

Women also gained a sense of control by being determined in their pursuit of treatment. They did this by keeping track of their appointments and treatment progress, usually through regular telephone calls. One woman's described her approach as:

> *"I sort of have a deadline in my mind. I said I will ring them at, I'll give them 'til Christmas and if I don't hear, I'll phone. So I kept, I've done that most of the time. There will be deadlines in my mind." (P20)*

Some of the women thought that they had to be extremely active to get the best possible treatment within the health service, as they could not rely upon the system. One woman described it in this way:

> *"But I felt like I need to, I needed to walk through the whole system with a letter from my GP and, and, and actually see it in writing in, in some sort of appointment book." (P30)*

However, women did not generally accept this as a part of their patient 'role' and expressed some resentment at having to do this. One woman said *'so much of my energy has been actually used towards getting medical attention'* (P11). She consequently felt that this had been detrimental to her ability to cope with other aspects of her condition.

This determination with regard to treatment also showed itself in the way in which women pursued alternative treatments in an attempt to find ways of making themselves feel better. A minority of women had been unable to find ways of helping their symptoms and felt they had no control over it. However, most felt that they had identified things that helped them. One woman said *"I've done a certain amount of self-treatment, which I suppose* *makes me feel I'm in control" (P26)*, thus showing how her determination and success in helping herself increased her sense of having some control over the situation. One woman's perspective was that by pursuing alternative treatments she was avoiding *'giving up'*. She explained:

> *"What you choose between is, is that you are either a victim and please, um, cut me open. You can help me. I can't do anything. I don't know why this happened to me... Or if you start believing that ok, why don't I try? Then, then you feel more responsible for, for your life and, and also for, um, that you are not a helpless or hopeless person who cannot do anything, who just gives up herself." (P25)*

Thus women gained control in a number of ways which helped them avoid feeling overwhelmed or defeated by the condition. It also enabled them to feel more optimistic about the amount of control they had over how they lived their lives.

CHAPTER FOUR: DISCUSSION

Overview of the study

This exploratory study aimed to investigate the illness experiences and illness representations of women with the gynaecological condition of fibroids. Eighteen women with the condition were interviewed using a semi-structured format. The content was guided by Leventhal's Self-Regulation model. The research questions addressed in this study aimed to explore how women understood and thought about their condition. A further aim was to highlight how their experiences and understanding appeared to influence their emotional state.

Qualitative interpretative phenomenological analysis of the interview transcripts revealed eight themes. These themes were drawn into two higher-order themes: 'managing uncertainty' and 'struggling between defeat and optimism'. These themes attempt to capture the experience and understanding of having fibroids for the eighteen women in this study and provide a framework for understanding their levels of distress.

The four themes within the 'managing uncertainty' higher-order theme addressed the factors contributing towards the experience of uncertainty and the different ways in which the women sought to manage it. These themes illustrate the feelings of uncertainty and lack of knowledge or understanding that characterised how many women thought about and coped with having fibroids.

The four themes within the 'struggling between defeat and optimism' higher-order theme addressed how the women actually lived with having the condition. These themes highlighted the impact that having fibroids had upon them and other people. They show that there was often a struggle between feeling overwhelmed by the condition and feeling optimistic about their ability to limit the effect upon their lives. The women differed in the degree to which it had influenced their lives and the ways in which they thought about having fibroids. These four themes capture how this influenced the degree of control that the women perceived themselves to have over their situation.

Overall, the eight different themes highlight the variety of factors contributing towards women's experiences of having fibroids. The inter-relationships identified between these factors supports the use of a biopsychosocial model, as there are clearly many biomedical, psychological and sociocultural factors contributing towards how these women experience this condition and the degree of distress that it arouses in them.

This chapter will firstly discuss the women's distress scores as measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). It will then review the findings from each of the higher-order themes identified in the analysis. This will be done with the aim of elucidating how the women thought about and responded to having fibroids within the context of the illness representation literature and the previous literature investigating the distress levels among women attending gynaecology clinics. The following section considers the methodological issues arising from the study, including data collection and data analysis procedures. Following this, there are suggestions for future research. The chapter concludes with a discussion of the clinical implications of the findings and the main conclusions drawn from the study.

Distress levels of women in this study

Obviously, the small sample size in this study does not allow statistical analysis of the quantitative HADS results, but they were examined in light of the existing literature on women's distress. Comparing the results of the current study with the existing literature reveals that the proportion of women scoring in the clinical range for anxiety and depression is comparable with previous studies (e.g. Agrawal et al, 1990; Salter, 1985; Byrne, 1984; Worsley et al, 1977 Abiodun et al, 1992). Nine (50%) of the women scored in the clinical range for anxiety and four (22%) scored in the clinical range for depression. Although these figures are slightly lower than the findings among women with fibroids in the previous questionnaire survey at the same hospital (O'Donovan et al, 2001; Glover et al, unpublished), they confirm that a high proportion of these patients are distressed.

It is interesting to note that nine (50%) of the women in this study had sought help in the past from a psychologist, counsellor or community psychiatric nurse for psychological or emotional problems. Furthermore, two women requested a referral to a clinical psychologist following the interview. This figure is higher than O'Donovan et al's (2001) findings from the previous survey at the same hospital, which reported that 36% of women with fibroids had sought previous help. It is also higher than Slade et al's (1988) finding that 23% of their sample of first time gynaecology clinic attenders had sought previous help for psychological problems. However, as the reasons for previous help seeking are not known, it is difficult to draw conclusions. It is also difficult to compare the current findings with studies such as Slade et al's (1988), which investigated a sample of women with a variety of gynaecological conditions. However, it again highlights that these women are acknowledging high levels of distress.

Existing studies of gynaecology patients have also suggested that younger women are more likely to have high distress scores. There did seem to be a trend for the younger women in the study to be more distressed, with four of the five women in their thirties having distress scores in the clinical range. This suggests that the sample was representative of women attending gynaecology clinics in terms of their levels of anxiety and depression.

Higher-order Theme 1: Managing uncertainty

There were many factors contributing towards the women's uncertainty and their attempts at managing it. Much of the initial experience of uncertainty around having fibroids was a result of the difficulty that women had in distinguishing between what was 'normal' and what was abnormal. Their experiences concur with the previous literature on women's gynaecological problems (Marshall, 1998; Marchant-Haycox & Salmon, 1997). As Oates and Gath (1989) highlight, the majority of gynaecological conditions present because of a woman's subjective experience of physiological changes or fertility problems. This highlights that having to make a subjective appraisal of one's own health can be difficult for patients, particularly when it concerns anatomy, which is inaccessible to the patient (Marchant-Haycox & Salmon, 1997). Furthermore, many women with fibroids had alternative normative explanations, such as age-related changes, available to them.

As the women in this study demonstrate, judging normality is especially problematic when the symptoms being evaluated are changes in something regularly experienced, such as menstrual bleeding, rather than something completely new and easily identified as abnormal. Bleeding is also a particularly difficult symptom to evaluate, since in any other context, it is a sign of injury and signals the need for medical attention. Furthermore, this evaluation occurs within the context of societal restrictions on discussing menstrual bleeding (Laws, 1992). This may have contributed towards the women's lack of awareness of what to consider as a normal amount of menstrual bleeding, since they are unlikely to have previously discussed this topic in any detail with other people, including doctors, who also found it difficult to advise women what is 'normal'. Marchant-Haycox and Salmon (1997) noted that none of the nine gynaecologists in their study presented an explanation of the continuum of normal bleeding to their patients. Also, as Lee (2000) highlights, there is very little research investigating the 'normal' menstrual cycle.

Within an illness representation framework, this uncertainty about normality is informative. Prior to diagnosis, most women had little knowledge of fibroids, which meant that they did not have an existing illness schema for this condition within which to make sense of their symptoms. Interestingly, even the two women with prior knowledge that they had fibroids, did not initially attribute their heavy bleeding to this cause, although it is a common symptom of fibroids. However, it is perhaps not surprising that women are more focused upon framing their symptoms in terms of the menopause, since this is a topic which has received a lot of attention both within the medical literature (e.g. Ballinger, 1985) and within popular discourse (Hunter & Walker, 1998). As Hunter and Walker highlight, a wide variety of physical and mood changes are attributed to the menopause with little evidence to support this. Therefore, if women are already anticipating that they will go through the menopause within the next few years, unusual gynaecological symptoms may fit their representation of the menopause experience more easily. As the self-regulation model posits, it is only when other evidence causes them to re-evaluate their model that they become more fearful and possibly distressed. Their uncertainty increases as the symptoms no longer fit their model of menopause and they lack an alternative explanation. This situation has been found to be extremely anxiety provoking for people (Bishop, 1991).

These difficulties in making sense of their symptoms continued even following diagnosis. Despite being informed that it is a common and non life-threatening condition, for some women the consequences of the condition can be overwhelming and distressing. In addition, despite the fact that up to a fifth of all women will have fibroids at some time in their lives (Wilson, 1999), little is known about why women get them, research is minimal and treatment options are limited. This only adds to the women's uncertainty as it appears to send the implicit message that fibroids are not something that the medical profession considers especially important or serious, a sentiment expressed by several women in this study. Yet for many women, most of the treatment options seem drastic for an apparently common condition. Thus forming a model of their illness and treatment can be extremely anxiety provoking for women as they seek to make sense of all the conflicting information and their personal experiences.

Consideration of the illness experiences of this group of women with fibroids suggests that for most women, having fibroids does not clearly fit into any of the three main categories of disease identified by Leventhal et al (1984). For many women the condition is potentially long-lasting, it can be highly disruptive to their lives and usually requires surgical intervention. Thus it cannot easily be viewed as acute. Neither can it be considered cyclical, even though aspects of the condition, such as heavy menstrual bleeding may appear to be. Furthermore, despite difficult symptoms and the effects upon their lives, many women struggle with the question of whether they consider themselves to be ill or not, which suggests they also do not regard it as a chronic illness. As Bishop (1991) highlights, people make sense of their symptoms within a social context. Thus, if that context sends the implicit view that women should be able to cope with menstrual bleeding, this contributes towards uncertainty about whether they are ill, particularly if they have found means of limiting the impact that the condition does have upon their lives. Thus individuals continue to seek out and process illness information as a means of managing this uncertainty (Leventhal et al, 1997).

As predicted by the self-regulation model, many women in this study felt a strong need to seek out information. This desire for knowledge in order to alleviate anxiety and manage feelings of uncertainty has been noted by a number of researchers in the gynaecology field (Marshall; 1998; Kavanagh & Broom,1997; Marteau, Kidd, Cuddeford & Walker, 1996). However, for many of the women in the current study and especially in Kavanagh and Broom's study, there was also a sense that this was done out of necessity. Women often felt compelled to do their own research, because of perceived inadequacies or omissions in the information provided during medical encounters. This obviously impacted upon the illness representations that they were able to construct, since many aspects of people's common-sense illness representations are constructed from how they make sense of the information provided during medical encounters (Leventhal et al, 1997). Although some women were able to accept that the doctors did not understand aspects of the condition, such as the cause, most felt that the doctors should have been able to provide them with more information. Again, lack of understanding and information from the medical profession does not have a 'common-sense' fit with having a common condition.

The similarity between the comments of women in the current study and the comments of women in Kavanagh and Broom's (1997) study is striking. Both groups of women described how their anxiety during the consultation made it difficult to retain and understand information afterwards. Both samples of women also placed self-imposed limitations on what they asked whilst actually consulting with the doctor, which may have been due to expectations that the doctor would lead the session. Kavanagh and Broom attribute these difficulties to the power imbalances inherent within the doctor-patient relationship, where the doctor is the 'expert' and the patient receives their advice and care. Whilst some women in this study welcomed this approach, for others it was viewed as a failure to acknowledge or a denial of their expertise about their own bodies. They are seen to be less knowledgeable about their own body than the doctor, who is often a man and usually a stranger. This viewpoint is strengthened by the women's inability to monitor their own condition, since they are reliant upon the doctors to look inside them. Consequently, within this framework, it can be difficult for women to feel empowered to make decisions about their own treatment. This is then compounded by the difficulty they experience in finding out information about the treatment choices available to them. As highlighted by some women in the current study, this can then lead to a feeling that the doctors are keeping information from them and preventing them from seeing 'the whole picture'. Interestingly, research suggests that doctors who confront this power imbalance by being open about their uncertainty within the consultation are actually regarded as more honest and trustworthy by women attending gynaecology clinics (Kavanagh & Broome, 1997).

Within the health psychology and gynaecology literature, it is recognised that the medical encounter between doctor and patient is of great importance (Leventhal et al, 1997; Marchant-Haycox & Salmon, 1997; Kavanagh & Broom, 1997; Bishop, 1991). It also appeared to be a significant factor in women's experiences of having fibroids, with some women locating their distress in the medical encounter and feelings about treatment. The ambivalent feelings towards treatment seen among some women in this study was also noted by Marshall (1998) among her sample of women with menorrhagia. This ambivalence becomes more understandable when consideration is given to their illness representations. As Bishop (1991) points out, health professionals consider treatment options in terms of a biomedical understanding of the disease, whereas patients' responses to these recommendations are more reliant upon their 'common sense' models. Certainly, within this study it was clear that many women struggled to make sense of how they and their doctors viewed their condition and their treatment.

That the women with fibroids and their doctors may be using different models is not surprising, since research has also identified that health professionals working together, such as doctors and midwives, may differ in how they view the same event, such as menstruation (Dufort, Lemelin & Charron, 1998) and pregnancy (Schuman & Marteau, 1993). Relating these findings to the current study, it is significant that doctors have been found to be more likely to focus upon the risks associated with a condition (Schuman & Marteau, 1993). If, as Schuman and Marteau suggest, doctors are more concerned about reducing the illness risks, then this may explain the differences between doctor and patient in treatment choice for fibroids, since doctors will obviously have more experience and knowledge of the potential complications associated with fibroids. In addition Marchant-Haycox et al (1998) suggest that the extent to which a woman seeks surgical interventions for her problems must reflect her expectations of this and alternative treatments. Therefore, if a woman is not experiencing severe symptoms and is managing to lead the life she aims to lead, this will also dictate her views of treatment. If she has been advised to have major surgery, she may feel that the treatment will actually reduce her quality of life significantly in the short-term by making her feel more ill than she currently does. Other women may have strong feelings about not wanting to lose their uterus. This will also impact upon their feelings about surgery. In addition, women close to the menopause are considering whether to go ahead with the treatment with its associated costs or wait for the menopause to bring them symptom relief. Thus, one explanation is that doctors are operating within a more biomedical model than the women, who appear to be using a more biopsychosocial model, which considers wider aspects of their experience.

Consideration of the 'common-sense' attributes of interventions can also help inform why the women in this study seemed to find hysterectomy unacceptable. Previous research has shown that women seeking a hysterectomy for subjective symptoms can exert power over the doctor by imposing a biomedical model upon the doctor and placing responsibility for their distress onto the doctor, so that hysterectomy becomes the treatment of choice to alleviate their suffering (Marchant-Haycox & Salmon, 1997). Interestingly, the authors go on to say that the consultations with women that did not result in hysterectomy were characterised by the doctors' assertion of their ability to look inside the women and confirm that their organs were 'normal'. This has implications for the women in the current study, since their doctors can clearly identify organic pathology, which within a biomedical framework points to active treatment. In contrast to Marchant-Haycox & Salmon's sample, none of the women with fibroids described a situation in which they wanted a hysterectomy and the doctor disagreed. For them the hysterectomy was usually proposed by the doctor.

If women are led to believe that they have a 'common' condition, which is not serious, then removal of the 'healthy uterus' through major surgery does not have a common-sense 'fit' with their illness representation of a non-life threatening condition. This may also be because hysterectomy is a common gynaecological surgical procedure used for a variety of gynaecological conditions. Unlike myomectomy, it is not specific to having fibroids. Therefore within an illness representation framework, the fit between the treatment and illness can be viewed as poor. In contrast, women having a myomectomy did not express such concerns or distress about their treatment. Any treatment concerns that they did have appeared to be focused around treatment delay and uncertainty around the possibility of the fibroids growing back. For these women, removal of their fibroids appeared to be a logical and acceptable decision and there was no mismatch between symptoms and treatment. Kavanagh and Broom (1997) also noted that several of the women with abnormal smear results felt there was a mismatch between their medical treatment and their expectations. They expressed the desire to have the rationale for their treatment explained to them, suggesting that they could not understand why the doctors were proposing certain procedures.

Kavanagh and Broom (1997) highlight that if the different viewpoints and power imbalances are not recognised, the doctor-patient relationship may become conflictual. This was certainly how some women in the current study regarded it. Marchant-Haycox and Salmon (1997, pp.449) described the hysterectomy consultations as *'an activity between opponents rather than collaborators'*. Certainly women in the current study who expressed dissatisfaction with their treatment did not have a view of the consultation as a collaborative process. These women also tended to be those who had been advised to have a hysterectomy and were seeking more 'acceptable' alternatives. Another source of dissatisfaction with the consultation for some women related to the gender of their doctor. Again this supports previous findings in the literature that women who express a preference for a female doctor are most concerned about being understood and treated sympathetically (Ivins & Kent, 1993). It appeared that women who felt that the doctors did not understand their experiences were more distressed.

Although numbers were small in the current study, there did appear to be a trend for younger women to be offered myomectomy and for older women to be advised that a hysterectomy was the best option. This viewpoint is also explicitly stated in textbooks on medical guidelines for managing gynaecological conditions, which usually say that hysterectomy is the treatment of choice unless the patient wishes to become pregnant (e.g. McKay-Hart & Norman, 2000). Such a standpoint excludes consideration of how women feel about their bodies and prioritises the reproductive function of their uterus. This mismatch in points of view led some women in this study to reflect upon the way in which women's bodies are viewed. They felt the need to justify why they wanted to keep their uterus if they did not plan to have children and concerns about sexual enjoyment were perceived to be a less valid reason for keeping the cervix than the 'logical' biomedical reasons for removing it. A purely biomedical model also prevents consideration of the range of meanings, both positive and negative, that a woman may attribute to having a hysterectomy (Dell, 2000). If the woman's body is viewed as 'diseased', then the hysterectomy may be almost inevitable as the hysterectomised body is viewed as 'healthy' (Dell, 2000). Some women in this study clearly had difficulty accepting the view that their body was 'diseased'.

This provides some explanation of why women in the study felt they had to be persistent to seek out information about alternative treatments. Women aim to have their 'common' symptoms relieved in a way that makes 'common-sense'. It also helps explain the doctor's viewpoint about hysterectomy. From a purely biomedical perspective, hysterectomy can be understood as a very satisfactory treatment option, since it removes the fibroids permanently and in addition eliminates the possibility of many future gynaecological problems. As Marchant-Haycox and Salmon (1997) highlight, patients and doctors may be using different strategies in the consultation to pursue different goals.

The time-line component of illness representations was important in women's experience of having fibroids and it has been found to be especially important in its implications for treatment co-operation (Bishop, 1991). As in Fry et al's (1991) study of women with chronic pelvic pain, many of the women in this study were concerned about the interminability of their condition. The women who could envisage an endpoint either through the menopause or through planned surgery generally seemed less distressed by the condition. Interestingly, some of them recalled that previously they had been more distressed by the condition, particularly when they were unsure what was happening and were awaiting appointment dates. In the current study, women described different emotions as a result of the enduring nature of their fibroids, including anxiety, depression, frustration and anger. This wide range of emotions was also noted by Glover et al (unpublished) in their sample of 200 women at the same hospital. Some women in the current study were aware that their emotional reactions were influenced by their perceptions of how treatment was progressing and whether any of the delays were avoidable. Although conclusions cannot be drawn from such a small sample, it appeared that women who blamed problems in the health service for the delay, tended to be frustrated and angry, whereas women who delayed treatment due to their feelings of uncertainty, tended to be more anxious and depressed. This again highlights that many factors may contribute towards the distress among women with fibroids attending gynaecology services and that women may attribute their feelings to many different sources.

Higher-order Theme 2: Struggling between defeat and optimism

Central to the issue of struggling between defeat and optimism is the notion of control. Within this higher-order theme the sub-themes relate to the factors determining the amount of control women felt themselves to have and their attempts to gain it. This perception of control over their condition and treatment is influenced by several factors. These include how they think about their fibroids, themselves and the effects that fibroids have upon their lives and their relationships. Where women perceived themselves to have little control, it was particularly difficult to be optimistic and they tended to describe themselves as more distressed about having the condition and its impact upon their lives.

The identity component of the women's illness representations was clearly influenced by how they thought about their fibroids, which in turn impacted upon their perceptions of the likelihood of cure and how much control they felt they had. For several of the women in this study, there were concerns about having something growing inside them. It was noticeable that the women who had spent time thinking about this and who viewed their fibroids as 'alien' to them, were more distressed and anxious than the women who considered the fibroids to be a part of themselves. These feelings about the fibroids may have influenced the control/cure aspect of their illness representation, since viewing the fibroid as 'other' limits the amount of control that the woman is able to exercise by herself. In terms of cure, it also suggests that she must rely upon the doctors to remove the fibroids.

In common with previous studies of gynaecology outpatients, many women had an underlying fear that they actually had cancer (Kavanagh & Broome, 1997; Marteau et al, 1996; Zadinsky & Boyle, 1996; Fry et al, 1991). Although this can also be understood from a knowledge perspective, there are also clear connections with the construct of control. As described, some women spoke of the need to have the doctor actually look inside them in order to reassure them about their health. They felt they had very little control over the condition, to the extent that they felt they had no way of knowing if the fibroids had grown in size or were actually cancerous. Women who did not feel this need, were those who felt they had some control and who tended to describe having fibroids as *'a nuisance'.* Within a 'common-sense' illness representation, a 'nuisance' is unlikely to be cancerous. Again, it is striking that the woman who felt that she was very familiar with her fibroid and believed that she could monitor its growth, was also the only woman who felt that she had complete control over her condition and the effects upon her life. This helps illuminate the importance of the construct of control and how this contributes towards the individual's distress.

For those women who did have fearful images of their fibroids and who were preoccupied with thoughts of them increasing in size, the descriptions provided by medical staff probably only served to increase these feelings of having something beyond their control. Describing fibroids in terms of foetal size and gestation weeks appears to be reinforcing the view of the fibroid as 'alive' and separate from the woman. It also encompasses the idea that it will continue to grow until it reaches the point that it has to come out. Within this model, there is little space to think about the fibroid as a benign idiosyncratic growth that can be left in place. A further point is that fibroids can cause fertility problems in around a quarter of women with the condition (March, 1994) and it seems particularly insensitive to use these descriptions with women who are concerned about their future fertility. Perhaps surprisingly, none of the women raised this aspect of their care, although when I asked one woman about it, she did say it was *'very weird, because I'm not pregnant' (C15).* If doctors are trained to describe fibroids in this manner, it has an obvious impact upon their own illness representations of the condition, which in turn has implications for treatment choice. If the doctors implicitly view fibroids as 'separate' from the woman, they are probably more likely to advocate removing them. This suggests there could be a difference in illness models between the doctors and any women who view the fibroids as part of themselves, which could be another factor that might reduce the potential for a collaborative consultation.

For many of the women in this study, concerns about the effects upon their lives of having fibroids featured strongly. As described by other researchers, unpredictable heavy bleeding was a symptom which women found particularly difficult to cope with (Marshall, 1998; Marchant-Haycox & Salmon, 1997). This contributed greatly towards women's feelings of distress, as they struggled to control it. Also, in common with previous studies, women were concerned about the effects upon their sexual relationships (Nusbaum et al, 2000; Montero et al, 1993; Fry et al, 1991; Worsley et al, 1977). This corresponds to the consequences component of illness representations. It was noticeable that women who felt that the effects upon their lives were minimal or under their control, were less likely to be distressed. Although this study did not include medical information on the individual participants, it did not appear that the severity of the condition was directly related to the women's distress about the effects on their lives. This again suggests that understanding of the women's illness representations may clarify the factors influencing their distress levels. The important factor appeared to be the perceived degree of control, rather than symptom severity.

The women in the study had found a number of ways in which to maximise the amount of control they were able to exercise. As in Zadinsky and Boyle's (1996) study of women with pelvic pain, almost all had used various self-help strategies and expressed determination to prevent the condition from overwhelming them. Some women expressed resentment at having to be prepared for outings and missing out on favourite activities because of their symptoms, whereas other women minimised these consequences and accepted that they simply had to live 'one day at a time'. It appeared that by finding ways of easing their symptoms or minimising the effects on their life, women were able to gain more control over their condition and consequently feel more optimistic about their current and future situation. Within the framework of the self-regulation model, it appears that psychological factors such as perceived control and potential cure can influence the impact that symptoms have upon the individual's life.

Women who expressed distress about the condition were also those for whom the effect on their body image was a source of concern. They spoke of changes both inside and outside their bodies over which they had little control. It was noticeable that all the women attributed these body changes to the fibroids, having often previously attributed their symptoms to age. Grogan (2000) argues that body image is socially constructed and certainly the women in this study who were dissatisfied with their body shape were conscious of how others viewed them. As Grogan highlights, women of all ages in Western societies are subject to societal pressures to be slim and being slim is associated with many desirable attributes including success and attractiveness. Thus women who experience unwelcome body changes, particularly changes they perceive to be unrelated to their behaviour, are likely to experience high levels of body dissatisfaction and lowered self-esteem. This also provides some explanation of the current participants' feelings of distress, and for some, resentment, since most of them felt that without the fibroids, they would be content with their bodies. Thus the distress about body image was attributed to the fibroids and their perceived effects upon their body shape. Women were also distressed about the lack of control they felt they had to change this situation.

These findings have some links with the previous discussion on the power imbalances within the doctor-patient relationship. Several women felt that only removal of the fibroids (but not their uterus) could help them return to their preferred body shape, since their usual options of dieting and exercise were of limited use. Again, if only the fibroids are viewed as the problem, removal of the uterus does not 'fit' and can be seen as too 'drastic'. This may leave some women feeling that they have to accept their body changes or have an operation that they find unacceptable. Thus again, women are viewed as more powerless and reliant on the doctors to restore not only their health, but also their body image and self-esteem. These high expectations of doctors were reported by Marchant-Haycox et al (1998), who assessed patients' expectations of the outcome of hysterectomy and alternative treatments for menstrual problems. They found that all patients came to the clinic with expectations that extended far beyond the immediate concerns of medical/surgical care, with all patients expecting improvements in their psychological well-being and social functioning. This again shows how women do not view their gynaecological problems within an exclusively biomedical model. Neither can their illness experiences be adequately accounted for in this way.

Further Considerations

Prior to conducting the research, I had anticipated that more women would be concerned about the fertility aspects of having fibroids. Although a few women did discuss their thoughts about the impact upon their fertility, it was only a major concern for one woman. Thus, it was not appropriate to include this as a theme in its own right. As some of the gynaecology literature does suggest that fertility is a dominant theme for women with gynaecological problems (Slade et al, 1988), it is worthwhile considering some of the possible reasons why this seemed to be lacking from these women's descriptions of having fibroids. Firstly, fibroids are typically diagnosed when a woman is in her thirties or forties, by which time many women have already had children. Most of the women with children in this study had had their children prior to finding out they had fibroids. There were also a few women in the study who had chosen not to have children. The mean age of the women in this study was 42 years and as a group they were generally focusing upon the menopause, rather than possible pregnancy. As previously discussed, this may also explain why many of the women in this study were presented with hysterectomy as the treatment of choice, rather than myomectomy. Women having a myomectomy did not express concerns about having chosen the right treatment. In the current sample, all the women in their thirties were having a myomectomy, whilst most of the older women had discussed having a hysterectomy in their consultations. In contrast to all the other women, the woman with great concerns about her fertility was also the youngest participant and was the only woman to have received the fibroids diagnosis following investigations for repeated miscarriages. Thus, it is possible that had the sample contained more younger women with fibroids, the consequences component of their illness representations may have been more concerned with their fertility. Further considerations about the sample are discussed in the methodological issues section.

Methodological Issues

A number of methodological issues were raised by this study. There were some recruitment difficulties, so the recruitment procedure and characteristics of the sample will be discussed. This study was conducted on a topic in which there was a lack of previous research, which was one of the reasons that qualitative methodology was used. Therefore the use of Interpretative Phenomenological Analysis (IPA) and validity of the findings will also be considered.

The Sample

The letter recruitment procedure yielded a 22% response rate and the clinic recruitment procedure had a 35% response rate. Thus there was a difference between the two approaches and the possible reasons for this are discussed below. Although the reasons for non-participation were not known for the majority of women, it is possible to speculate from those cases where reasons were given.

Women who decided not to participate may have been concerned about the content of the interview and the possible consequences of taking part. Although the invitation letter and information sheet explained that participation was confidential and I again discussed this prior to interview, some women required additional reassurance about this aspect of taking part. Furthermore, following the interview two women admitted that they had considered not attending as they had been concerned about whether they would be able to discuss their feelings and experiences with a stranger. The higher recruitment rate from the clinic may have been because the women had a chance to meet with the researcher prior to the interview, which may have reassured them about discussing their problems. Although both confidentiality and the emotional impact of discussing illness were considered whilst designing the study, this was perhaps something which needed to be addressed more explicitly in the information given to participants. Furthermore, this study highlights that although it is time consuming, meeting with participants in person prior to the interview can yield a higher recruitment rate.

Another possible reason for non-participation concerned the women who were recruited via the surgery waiting lists. All patients on the lists received a letter, regardless of the proximity of the date for which their treatment was scheduled. Discussion with medical staff highlighted that these lists were subject to change. Patients and doctors sometimes cancelled operations for various reasons and some patients requested cancellation slots in order to receive treatment sooner. Thus, some patients may have received the letter very shortly prior to their treatment, which may have influenced their decision to take part. Alternatively, their desire to postpone treatment may have also made them reluctant to take part in a research project asking about their experiences.

The target sample of women with fibroids may also have had an impact upon the recruitment rate. Generally most women with fibroids are between 30 and 50 years of age. Obviously this is a group of women who are likely to have concurrent childcare and work commitments. The two women who rearranged their appointments and then withdrew from the study cited reasons about the difficulty of finding the time to take part, due to their family and work commitments. It was also noted that the women who said they did not have time to hear about the study during the clinic recruitment process, usually said that they had childcare commitments. Furthermore, most of the women who requested a home interview also had children. However, the percentage of women with children in the current study (55%) was very similar to the percentage of women (57%) who responded to the previous questionnaire study at the same clinic (Glover et al, unpublished). Therefore, the sample appears to be representative in this respect.

The main concern regarding the women who took part in this study is whether they are typical of women with fibroids, or whether there was a self-selection bias in the women who agreed to participate. The ages of women in this study appeared to represent the age range of women with fibroids and in terms of marital status, the sample was very similar to Glover et al's original study. The most evident sample bias is that the women as a group had a high level of education and all, but one woman was in employment. Nearly three quarters of the women had qualifications at A' Level or above, which is even higher than the 53% in Glover et al's questionnaire study (Glover et al, unpublished). Others possible limiting factors concern the ethnic background of the participants, since nearly three quarters of the sample were white. This is relevant since fibroids are more common in Afro-Caribbean and African women. The hospital at which the research was conducted is a central London hospital serving a diverse ethnic community, including many women who do not speak English. Thus this study cannot be said to represent the views of this section of the hospital's patients. However, women's accounts of their experiences of fibroids seemed to be consistent across ethnic groups within this study and where differences were found, these were noted. Cultural factors were identified by two women and these will be discussed in more detail later in this chapter.

Thus, there are a number of factors that may limit the generalisability of the sample. These include the low numbers of afro-Caribbean and African women in the sample and the lack of data from women with less formal education and women who do not work. Furthermore, non-English speakers are not represented at all. However, in terms of marital status, age range and children, the sample appears representative of women attending the hospital.

Qualitative Methodology and IPA Data Analysis

As previously outlined, the aim of qualitative methodology is to increase understanding of the individual's perspective of the topic under investigation (Elliott et al, 1999). In common with all research methods it is important to ensure the credibility and validity of the findings (Elliott et al, 1999; Barker, Pistrang & Elliot, 1994). To this end, this study incorporated a number of credibility checks. One such check was that four other researchers experienced in qualitative research checked the findings at all stages of the analysis to check the credibility of the themes and their grounding in the data (Elliott et al, 1999). This highlighted a few discrepancies and areas that needed further clarification. However, it also provided confirmation that the examples of the data illustrated the themes and how they had been developed (Elliott et al, 1999). The presentation of the data in terms of the two higher-order themes with their sub-themes was an attempt to provide a coherent account of the results (Elliott et al, 1999). Although time constraints prevented respondent validation, presentation of the emergent themes to the original participants or other women with fibroids would provide further support for the credibility of the themes (Barker et al, 1994). It would be interesting to see whether women agreed that the findings capture the complexities of their experience of having fibroids.

Qualitative methodology was considered appropriate for this study because there was a lack of previous research and the aim of the study was to explore the women's experiences of having fibroids. The use of qualitative methodology was also beneficial in this study as it served to highlight issues relevant for the women, rather than having them imposed by the researcher (Smith et al, 1997). For example, women's strong feelings of uncertainty about the condition and doubts about whether or not they were ill were not anticipated prior to beginning the research. Thus the current study has increased knowledge about the concerns of women with fibroids and has highlighted a number of areas for future research, which could be investigated using both qualitative and quantitative methodology.

Study Limitations and Suggestions for Future Research

One obvious limitation of this study is that participation was limited to women conversant in English. This was due to time and cost constraints. Furthermore, although a biopsychosocial model recognises the contribution of cultural and ethnic factors, this study did not explicitly explore these aspects of the women's experiences. Cultural factors were implicit in some women's descriptions, but only two women spoke explicitly of cultural factors affecting their experiences. One woman was Afro-Caribbean and the other was African and both felt there was shame within their community about discussing illness. As previously outlined, this theme was dropped as it was not specific to the experience of having fibroids. However, it does show the importance of cultural factors on how people think about and cope with illness. It may also explain why fewer women from non-white ethnic backgrounds participated in the study. The identified reluctance for all women to discuss menstrual problems may have been compounded by the additional cultural restrictions. Future research would benefit from investigating the illness experiences of non-English speaking women living in this country. This is especially relevant in light of the current study's findings on the importance of doctor-patient communication and the impact of different models of the condition. If women sharing a language with the doctors are having difficulty making sense of or controlling their illness experiences, it is likely that this is much more difficult for women who speak poor English or who have to use the services of an interpreter.

A further limitation of this study is the fact that it involved a single assessment of the woman's perspective of having fibroids. Furthermore, the women were at different stages of their illness experiences. Although this was suggestive of how age and experiences can affect how they view their condition, it was not possible to study influences over time and see whether women's illness perceptions changed. It would be informative to follow women prospectively over the course of their illness to see how their understanding of their condition and their views of their experiences changes from initial diagnosis to post-surgery or menopause.

The results from this study suggest that the treatment options given to women can influence their feelings of distress in a number of ways. Thus, it would be interesting to conduct research on more homogenous groups of women with fibroids, such as women having different types of treatment, including those for whom the doctors have advised conservative management. It would also be interesting to investigate women who have specifically chosen not to have treatment, against the advice of their doctors. Age appears to have been a factor in the interventions offered to women in this study. Obviously with such a small sample size no conclusions can be drawn, but this is also a possible avenue for future research. Future studies could compare the experiences and illness representations of younger and older women with fibroids.

It had originally been hoped to interview women with fibroids and women with menorrhagia in order to compare the experiences of these two groups of women who often have similar symptoms, yet different organic pathology. Three women with menorrhagia were interviewed, but they had very idiosyncratic presentations, making comparison difficult. Furthermore, some women who were listed on the hospital database as having menorrhagia subsequently turned out at interview to have a diagnosis of fibroids. Thus in the interests of having a more homogenous group, a decision was made to concentrate upon interviewing women with fibroids. However, since the experience of heavy bleeding was a significant factor in the experiences of many women with fibroids, it would be interesting for future research to compare the illness representations of these two groups.

The importance of the doctor-patient relationship also suggests that further understanding of the illness experiences of women would benefit from work investigating the illness models of medical professionals, including the GPs to whom the women often first present. This would highlight whether the hypothesised discrepancies between women's and doctors' viewpoints exist and the extent to which doctors are aware of this. It would also be important to explore the doctors' representations of women with the condition, their understanding of women's distress about the condition and how this impacts upon treatment decisions or recommendations.

Clinical Implications

Medical Care

The results of this study suggest a number of ways in which medical treatment of women with fibroids could be improved. Firstly, there is clearly a need for women to be provided with more information about their condition. It also seems advisable to provide this information in the form of written material or possibly a tape of the consultation. Although women appreciated doctors taking the time to explain things to them during the consultation, the current study confirmed previous findings that retaining the information is difficult, particularly when women are anxious and consultations are necessarily time-limited. Kavanagh and Broom (1997) reported that material which allayed women's fears about cancer was particularly helpful in their sample of women with abnormal smear results. Although fibroids are obviously not directly linked with cancer in the same way as smear tests, virtually all the women in this study had also harboured fears that they too had cancer. Thus, literature addressing this topic may be useful, although obviously this would need to be evaluated.

The actual consultation process was also an issue that concerned women. This study suggests that open discussion of the different treatment options and the rationale for treatment would be beneficial. It would also probably help the women if they had a sense that the doctors understood their concerns about preferences for treatment, especially when they believe they can cope with their symptoms and would prefer not to have treatment. Furthermore, for some women the gender of their doctor was an important consideration in their treatment. Whilst none of the women in this study felt able to request to see a female doctor, several expressed a preference to see a woman. For some women this may have been due to a lack of awareness that it was a possibility. It would probably increase their satisfaction with treatment and their feelings of control over the treatment process, if women knew that they could make this request.

Psychological Care

This study has highlighted a number of issues that may be relevant to the provision of clinical psychology services in women's health settings. It appears that many women with fibroids have fairly high rates of clinically significant distress, in particular anxiety. This suggests that they are a group who could benefit from targeted individual and group psychological interventions. Clearly women with fibroids differ in their concerns and levels of distress, so careful assessment is advised to identify the individual reasons for their difficulties. For many women in this study, the distress was associated with their condition or aspects of their illness experiences. It appears that exploration of women's illness representations may provide clinically relevant material and help highlight the areas of particular concern. The results of this study have shown that there are many aspects of having fibroids that arouse high levels of uncertainty in women, which may be difficult to tolerate. For some women their distress is focused around making treatment decisions, whereas for others their distress is more focused upon the effects that having fibroids is having upon their lives. Some women may benefit from contact with other women with fibroids in order to hear about their experiences and the ways in which they have resolved their uncertainty about having fibroids. As previous research and the current findings highlight, when working psychologically with these women it is important to recognise the wider social context within which both the women and their doctors are working which may be contributing to their feelings of distress.

Whilst individual psychology sessions could help women find ways of coping with the cause of their distress, cost and time constraints limit the number of women who could be seen. The results of this study strongly suggest that psychologists could usefully be involved in training and supporting staff working in these settings. Psychologists could assist in training on doctor-patient communication, which could potentially improve satisfaction with the consultation process for both parties. Training could also focus on the benefits of using a biopsychosocial model in order to understand and highlight differences in illness models, which have been shown to impact upon all aspects of treatment. Furthermore, the regular presence of psychologists within the gynaecology setting would hopefully increase awareness of and consideration of the psychological aspects of gynaecology care.

Conclusions

As in previous research on gynaecology outpatients, a high proportion of women with fibroids attending a central London hospital were found to have clinically significant levels of distress, particularly anxiety. There are a number of similarities between the concerns expressed by the women in the current study and the concerns identified in previous qualitative and illness model studies of women with gynaecological conditions. This suggests that some of the difficulties faced by women with fibroids are common to other women attending gynaecology clinics. Differences between the studies served to highlight the unique problems associated with having fibroids. Their experience of fibroids focused upon the uncertainty aroused by the condition and the difficulty of understanding it in common with the effects and the resultant struggle to remain optimistic over time.

These findings have a number of implications for improving service provision to women with fibroids. It appears that consideration of the illness representations of women with gynaecological condition can increase understanding of the various biomedical and psychosocial factors that influence their levels of distress. Furthermore, these factors have been found to influence how women feel about the condition and their treatment. As this study has shown, the medical consultation and the ways in which doctors and women communicate had a great impact upon women's understanding and views of their experiences. Increasing understanding of their concerns can direct appropriate interventions aimed at reducing the potential for uncertainty and distress.

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APPENDIX A

Letter granting ethical approval

APPENDIX B

(i) **Letter sent to potential participants**

(ii) **Information Sheet**

(iii) **Consent form**

The University College London Hospitals

THE UNITED ELIZABETH GARRETT ANDERSON HOSPITAL
AND HOSPITAL FOR WOMEN, SOHO
144 Euston Road, London NW1 2AP
Tel.020 7387 2501 Fax: 020 7383 3415

Research on the experiences of women attending gynaecology outpatients services

Researchers at the Sub-department of Clinical Health Psychology, University College London are carrying out a study looking at the experiences of women attending gynaecology outpatient services at The United Elizabeth Garrett Anderson Hospital.

The aim of this research is to find out about your experiences of attending gynaecology outpatient services. We are also interested in your understanding of your gynaecological condition. It is hoped that this will provide information to help improve services for women attending the hospital.

If you decide to take part, you will be asked to complete a brief questionnaire and take part in an interview with the researcher. Interviews will take place at The United Elizabeth Garrett Anderson Hospital or if you prefer at another location. You will be reimbursed for your travel expenses.

All the information you provide will be treated in the strictest confidence and only the researcher will know the identity of women taking part in the study. Your decision to take part or not will not affect your care and management in any way. If you decide to take part you may withdraw at any time without having to give a reason.

If you would be willing to take part or would like further information, please complete and return the slip below in the pre-paid envelope. You will then be contacted shortly.

Thank you for your help.

Charlotte Nicholls
Clinical Psychologist in Training

I am interested in taking part in this research and would like more information:-

Name:____

Address:______________________________________
____
____

Contact telephone number:____________________

The University College London Hospitals

THE UNITED ELIZABETH GARRETT ANDERSON HOSPITAL AND HOSPITAL FOR WOMEN, SOHO

144 Euston Road, London NW1 2AP
Tel.020 7387 2501 Fax: 020 7383 3415

CONFIDENTIAL

INFORMATION SHEET

The experiences of women attending gynaecology outpatient services

A high proportion of women attending gynaecology outpatient services have been found to have high levels of distress. As many different factors may contribute towards this, more research from the patient's viewpoint is needed.

The Friends of the United Elizabeth Garrett Anderson Hospital are interested in asking women receiving treatment at the hospital about their experiences and needs. We are also interested in finding out more about how women think about and understand their gynaecological symptoms. This will help us to understand more about the concerns that women have. Important information may also come out which helps to improve services for women attending the hospital.

If you agree to take part in this research, it will take about an hour of your time. You will be asked to complete a brief questionnaire about how you are feeling and then take part in an interview. All interviews will be audiotaped and treated in the strictest confidence. The researcher will be the only person who will know the identity of the individuals involved. You will also be asked to sign a consent form before beginning the interview, to show that you have read this information sheet and agree to take part in this study.

Interviews will take place at the United Elizabeth Garrett Anderson hospital or if you prefer at another location. Travel expenses will be reimbursed. If following the interview, you feel that you would like to talk to somebody about the issues raised, this can also be arranged for you.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. Your decision whether to take part or not will not affect your care or management in any way. All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by UCLH Ethics Committee.

Please do not hesitate to ask if you have any questions or would like further information.

Thank you for your help.

Charlotte Nicholls, Clinical Psychologist in Training (October 2000)

The University College London Hospitals

THE UNITED ELIZABETH GARRETT ANDERSON HOSPITAL
AND HOSPITAL FOR WOMEN, SOHO
144 Euston Road, London NW1 2AP
Tel.020 7387 2501 Fax: 020 7383 3415

CONFIDENTIAL

CONSENT FORM

Study: A study of women's experiences of attending gynaecology outpatient services

Investigator: Charlotte Nicholls, clinical psychologist in training

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To be completed by the patient:

1. I have read the information sheet about this study YES / NO

2. I have had an opportunity to ask questions and discuss this study YES / NO

3. I have received satisfactory answers to all my questions YES / NO

4. I have received sufficient information about this study YES / NO

5. Which health professional have you spoken to about this study?

....

6. I understand that I am free to withdraw from this study:

- at any time
- without giving a reason for withdrawing
- without affecting my future medical care

YES / NO

7. Do you agree to take part in this study? YES / NO

Signed..Date......................................

Name in block letters..

Signature of Investigator..

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabeth Garrett Anderson Hospital and Hospital for Women, Soho, and University College Hospital.

APPENDIX C

(i) Hospital Anxiety and Depression Scale (HADS)

(ii) Participant Interview Schedule

(iii) Demographics questionnaire

Please read each item and place a tick on the line alongside the reply that comes closest to how y have been feeling in the past week. Don't take too long over your replies, your immediate reacti to each item will probably be more accurate than a long, thought-out response.

I feel tense or "wound up"

Most of the time _____
A lot of the time _____
Occasionally _____
Not at all _____

I still enjoy the things I used to enjoy

Definitely as much _____
Not quite as much _____
Only a little _____
Hardly at all _____

I get a sort of frightened feeling as if something bad is about to happen

Very definitely and quite badly _____
Yes, but not too badly _____
A little, but it doesn't worry me _____
Not at all _____

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 _____

Worrying thoughts go through my mind

A great deal of the time _____
A lot of the time _____
From time to time but not too often _____
Only occasionally _____

I feel cheerful

Not at all _____
Not often _____
Sometimes _____
Most of the time _____

I can sit at ease and feel relaxed

Definitely _____
Usually _____
Not often _____
Not at all _____

I feel as if I am slowed down

Nearly all of the time _____
Very often _____
Sometimes _____
Not at all _____

I get a frightened feeling like butterflies in my stomach

Not at all _____
Occasionally _____
Quite often _____
Very often _____

I have lost interest in my appearance

Definitely ___
I don't take as much care as I should___
I may not take quite as much care ___
I take just as much care as ever ___

I feel restless as if I have to be on the move

Very much indeed _____
Quite a lot _____
Not very much _____
Not at all _____

I look forward with enjoyment to things

As much as I ever did _____
Rather less than I used to _____
Definitely less than I used to_____
Hardly at all _____

I get sudden feelings of panic

Very often indeed _____
Quite often _____
Not very often _____
Not at all _____

I can enjoy a good book or radio or T programme

Often _____
Sometimes _____
Not often _____
Very seldom _____

Thank you very much for your help

Interview Schedule:

The Experiences of Women attending Gynaecology Outpatient Services

Disease Identity

Can you tell me a brief history of why you are attending the clinic?
When did you first become aware of this?

Timeline

How long do you expect your condition to last?

Consequences

How has having [condition] affected you?

What are the effects on your everyday life?
(Prompts: work, socialising, everyday activities, relationships, family, friends)

What is the most difficult aspect for you?

Control

How much control do you feel you have over your condition?

What would make the situations better for you?

What would you like to change?

Cause

What do you understand about the cause of your condition?

Feelings about diagnosis and distress

What are you thoughts about having [condition]?

To what extent do you feel that your condition influences how you generally feel?

Care received

What do you feel about the care you've received?

Study of women's experiences of gynaecological problems

1. What is your age?________________________________

2. What is your marital status? (Please circle)

married
single
divorced
in a relationship - not living together
living with partner
other (please state)____________________________________

3. How would you describe your ethnic background?

____

4. What is your occupation?

____

5. What is your highest qualification (e.g. O' levels)?

____

6. Do you have any children? (Please circle)

NO

YES -→ How many pregnancies have you had?__________
How many children do you have?______________
What are your children's ages?________________
How many of your children live with you?________

7. Have you ever seen a psychologist / psychiatrist / counsellor?

____

8. Have you ever been referred to a gynaecologist before this referral? If so, how many times?

____

APPENDIX D

Example of one interview transcript (P17)

Interview Transcript (P17)

Notes

- The interviewer's comments are in italics.
- ... indicates a pause
- A few sections of the transcript containing identifying information have been removed. This is indicated in the text.

START OF INTERVIEW

Maybe if we could just start by, if you could give me a brief history of how you came to be attending the clinic

Well I came off the pill after years, after obviously using the pill as a contraceptive. And then I started getting very, very heavy periods which didn't last the normal five, seven days. Went on and I had a few days off and then started up again and it got quite horrendous. Obviously with my job, I'm out and I go away quite a bit. It was just affecting, you know, really affecting my job and everything. So I went, obviously went to the doctor's and said - you know I don't think things are quite right. And um... I went obviously to my local hospital and they did a scan and.... they found that I had some fibroids, which they didn't think were too, you know, because they weren't very large at that time, they didn't think that was really the problem. I went back to the doctor's again and they gave me different types of pills to try and control the bleeding. It still didn't work. In fact it got worse and worse and it got to the stage where I just thought I can't... cope with this much longer, I'll go back on the pill. But because of my age and because I smoke, they were very anti that. They didn't want to put me back on the pill. So I had a very sympathetic doctor who at long last was listening to me. Before that they were just saying, you know, it's your time, it's your age, you know, it's something you've gotta, you know, cope with. And she said, no this, there's more to this. And I went back to my local hospital and they referred me up to here. And I came up to here and this is, you know, when it all started and they decided to put me, er, to give me this special coil, which to control the bleeding and really in theory it should stop. But, you know, it hasn't a hundred percent. But it's obviously a hundred percent better than what it was. And that's why I'm here and I attend the hospital here now.

Can you tell me a bit about the bleeding when it first started, How did it, how did it affect your work?

Well it affected me, because obviously I was bleeding very heavily, so every sort of fifteen minutes, half an hour, I was having to get up and go to the loo and check myself out and obviously I have clients I see. I was out with a particular client and I had a very heavy bleed and I just, it was embarrassing. Um… it did, it affected you not just physically, mentally as well. Because you are, I was becoming like, I've spoken to other women that have had the problem, you become so obsessed by the fact you're always bleeding and you get this sort of thing, you're going to bleed to death. Because it's quite frightening when you've not had, when you've had a sort of normal period and then suddenly you have this horrendous bleed, it is very frightening. And you start thinking the most awful things and you know, ok, if it goes on for a day or so, that's fine, but you know, to go for… you know, non stop and have a couple of days off and you think that's it and then you start up again, it's frightening.

Can you tell me about some of those thoughts that you're having?

Well of course, you know, at night-time I used to think oh, I'd be panicking that when I'd go to bed at night, I'd think, god I could bleed to death. And I'd sort of wake up and the first thing you'd do is look at, a really daft thing, but you start looking at the bedding. See if you've sort of, you know, blood everywhere. It's, it's just things like that and obviously you, you do start thinking oh have you got cancer, have you got this, have you got that, have you got a tumour. And of course when they say you've got fibroids, it's very, they're very blasé about it, because no one seems to understand. They don't know why women get them, which I find very bizarre, you know, cause it's quite common in women to have these. And of course, because it's not explained to you, because no one really understands the reason why some women get them, you start thinking you've got these huge things growing inside you. And obviously you've seen these films on TV where things start, It does, it makes you think and you think you've got these things inside you and they're gonna get bigger and bigger and bigger and it is frightening.

So you start imagining all these things about them?

Yes you do. Yeah. And obviously you do the big 'C' word is there obviously.

And has anything helped alleviate those fears?

Well I, I mean they're very sympathetic here. Um, they do try to explain, but I still haven't, I still can't get why you, why there are fibroids growing inside you, because no one seems to know, which… fascinates me. They seem to know about other things. Yeah, they are very, they are helpful. Um, they do try and sort of, I mean, I wasn't hysterical about it, but you know, if it had carried on much longer before I had some help, yes I think I would have got very hysterical, because it was really affecting me, my life. I just couldn't do anything. I went to work and came home, cause when I was bleeding so badly, I just daren't go anywhere. I'm too scared too, in case I had an accident, which is not, it's not, it's embarrassing, as well as upsetting. So they were very, um they sort of explained what they were doing and things like that. But I think one thing I, I would criticise them for, if they're, you know, when you have a problem, you obviously come to, to the hospital, because you have some sort of problem. They're talking to you at the time, but sometimes you're not actually taking it in, because when they, when I actually had the um, sort of mini op, um to insert this special coil and obviously they have a look to see if there's any other problems. They obviously come round afterwards when you've woken up and say yeah, everything's fine, blah, blah, blah. And of course, you should think oh my god, thank goodness for that and you're not actually taking in what they're saying to you. And I would've like, I know they're very busy, but it would have been nice to have a letter saying everything's fine, this is what we found, this is what we haven't found. And they, and obviously you don't get that. So you go home and you think oh yeah, it's great and then you can, you know, not necessarily straight away, because you're so relieved that they didn't find anything like, you know, cancer, which... That um, then you start thinking about things at a later stage, which... I mean I did speak to um someone, not this time, but the last time, because I was slightly concerned about something. And they actually went back through my notes and said yes everything was fine. Um, they also looked for something else, which sort of made me feel a lot better. *[section containing identifying information removed]* So I did go when I went back. I did ask and I had a very nice doctor who went through it and explained it all again. So that's the thing that I would say, that it would be nice to have a, have a follow-up letter to say everything's fine. We did this, we did that. Because at the time and even before when you're sitting in the ward waiting to go, you're slightly anxious, that they're telling you what they're going to do, but you're obviously not taking it in. You're, you're anxious. I mean I don't particularly like hospitals like you know, most of the time. So you're anxious, so you're not really taking any of it in. And then afterwards when they say everything was fine, you think great and you just can't wait to get out. So, um...

So what sort of things are you concentrating on at the time, when, before the operation?

Well, I was just, I was thinking um, you know, everything's going to be fine. They're not gonna find anything. I was thinking no, no, no. You know, and I also was thinking, well if something isn't right, I'm not gonna tell my mother. I'm gonna lie. Because she's getting to a stage, a certain age and I wouldn't want her to know. Um... I, you know, I was just thinking everything going to be fine, but if it isn't, I'll just tell a few people. And I had sort of worked out in my head who I was gonna tell. And um, and then obviously, then you know, afterwards I just thought right go. I want to get home now. It's done. It's over. And I can hopefully start being, going back to how I was, having the normal sort of period or hopefully no period at all. You know, going back to, you know...

And you feel you haven't gone back to how you were yet?

No, I won't do now, no. I'm obviously a lot better than what, what I was before. I um, I had this coil fitted, but no, it should work within six months and it hasn't, so I still bleed, but obviously nowhere near. So it, you know, it's not horrendous. At least it's controllable now, whereas it was, wasn't before. I had no control over it.

That must have been really difficult.

Oh yes, it was. Oh yeah. You know, going out in the evenings and sitting there and suddenly you get up and you think oh my god. It's frightening, very, very frightening. And you do think the worst and it doesn't matter how, what anyone says to you. Especially if you go to see, especially a lot of men doctors, they're not sympathetic, because they don't have, they've not experienced it. And it doesn't, I don't care what they've said, they don't experience what a woman goes through every month, so they can't be that sympathetic. Um...so, and luckily enough I had, I met a very nice doctor.

And was that a female doctor?

Yeah.

So do you feel that makes a difference?

Yes, yes I do. Also, when it's a man doctor, I mean I'm not being funny, you don't, you tend to think, oh I want to get out of here. And it's nothing to do with them, because they're charming, they're lovely. But you just say what you have to say and get out.

So you feel that you would say more

Yes, yes. It's a psychological thing. It's a barrier you put up because he's a man, because you feel you can't say, it's sort of personal. You're saying personal things about yourself and you don't want to say it to he, they're a stranger anyway, but especially being a man. A woman it's very different, but not, you know. So, yeah...

Have you been able to request to see a woman, female doctor?

No, because I think and because they're so busy anyway. Um, I think, you know. I, I do sit there and think I hope I don't see a man doctor. And you do, of course you do, but obviously if you get one, you, I go along with it, because you know, they're very busy and if you say no, no, no, then obviously you're putting everyone out by um. And I mean they do have lots of problems up there, because you know, every time I go up there, there's always sort of um, young sort of Indian women or whatever up there and they're with their husbands and they have um, a lot of them they don't obviously speak English, so they have their chaperones and all the rest of it and obviously when they go in, it's very time-consuming for the doctor, because it takes much longer. And I mean, that throws everyone out and of course you can see when the doctor comes out, their hair is standing up on end slightly, because obviously their religions, their husbands have to be in, they come out and they go back in and all sorts of things. So that, you know, for you to say oh I'm a bit, to be a bit silly, saying oh I don't, don't want a woman doctor, you know, isn't on. It isn't fair. They have enough.

But if you could, that's what you'd like?

Oh yes, I think so. Yes. And I think it would be, it's quite a good thing to have a doctor of a certain age, because they've probably experienced some problems as well, probably themselves.

Right. So that's important.

Well yes, because you know, when you're talking to people, you know, some people would think god she's exaggerating or whatever. But when it actually happens to you, it's not funny. And you know, er, if you speak to people that have had, have been in the same sort of position, that's had problems, you know, you feel they understand what you're saying. Whereas you know, other people think, oh god, she's just, wants a few days off work or whatever and get on with it. It's something you're gonna have every month and everyone experiences that, but it isn't, isn't the norm.

Have you found it easy talking to other people about it?

Yeah, I've talked to a few people that have had, experienced the same sort of problems or you know, fairly similar problems. Yeah, because it does make you feel a bit more at ease. Um, and as it is, a friend of mine, has just experienced problems that I've had and I've said to her that, you know, if she, it's only just started, not to, you know, like I did, for quite a while, do nothing about it. And then, just going, kept on going to my local doctors and they were giving me a pill to stop this and a pill to, you know. And in the end I thought I can't cope with this, it's not working and I don't particularly like taking tablets anyway. I don't think it's um... So I've sort of said to her, don't leave it. Get it sorted for your own sanity if nothing else. Because it is, you do worry. You do worry about it. It's, and you know, the more it happens, the more the months go on, the more it becomes a slight obsession, that you know and you just, nothing else matters. It becomes, you know. And it's not because you're getting on, um... It's because it's frightening and you don't feel anyone's helping you. And if you've, for years had normal periods and then suddenly this. You know, it does become. Well it was my life, you know. I couldn't think of anything else. I used to dread it, thinking god, here we go again. and you know, with work and everything. [*section containing identifying information removed*] It was just an absolute nightmare.

And did it affect your relationships?

No. No, because you know, um it didn't affect my relationships, but it used to, well, I suppose it, well not really, no it didn't really. But going socially, being sociable yeah, it used to be quite difficult, because you used to go out in the evening and if I was having a really bad time, where I was, if it was pouring out of me, which it used to do. Wherever you went, you used to have to think god is there a loo nearby and I don't want people to know what I'm up to, that

I'm going in and out of the loo every five seconds. You know, because obviously with your close friends it's slightly different, but you don't want the world to know that you're having these problems. You know, no one likes to say, to actually tell people that they're having a period at this moment in time. I know it's a natural thing, it happens, but you don't, for some reason you don't want to say to people that I'm having my period at the moment and I've got problems, so if I disappear. So you try to do it discretely, it's quite difficult.

And that's particularly difficult with your job when you're constantly meeting people?

Hmm, hmm, oh yeah.

So was there any aspect of your life that it didn't interfere with?

No, because it's, you know, when you're bleeding, it doesn't stop, when you want it to stop. Unfortunately, it doesn't. You can't say right, I'm not, I'm not to bleed today, because I'm doing this. And it was, because of the way I was, you never knew when you were gonna really be, you know. You had no warnings. And that, that was hard.

So it was totally unpredictable?

Yeah.

And did it ever stop you doing anything?

Oh yeah. Oh yeah. Of course it did. It did, because um, there was once or twice, when I completely flooded and lucky enough, I was with some very good friends and obviously that was fine. But you just thought, no I'm not, you know, when I knew I was very, very heavy. I had very heavy bleeds and clotting and all sort of things, you just thought well I'm not going, because I can't dress up. I can't wear nice clothes. Because you've got, you obviously don't wear, you can't wear tampax or anything like that, because they're not sufficient. You're having to wear towels and you feel everyone can see what, that you're wearing them. Which isn't the case, but when you, because my bleeds were very, very heavy, I couldn't just wear one towel anyway. It wouldn't last more than ten minutes, fifteen. I'd have to go to the loo. So it did stop you doing lots of things. Um... and you know, for instance, I come up on the train in the morning. I used to sort of have to think now can I last, will I, will these towels last me 'til I get to work. Things like that. And you know, the train was delayed and you'd be sitting there, oh my god, oh my god. You know, it's very stressful.

So you're constantly having to plan and think ahead?

Yes. Yeah. Yeah. Oh yeah.

And what would you say was the most difficult aspect of the whole experience for you?

It's just not... it's just, you know, I still don't know why after coming off the pill, I suddenly started to bleed in this manner, whereas when I was on the pill, it was normal bleed. And, you know, if I had known that the pill could've, would've caused this to happen. Because I'm not sure if the fibroids are the cause, because no one's really, I don't think the fibroids are a hundred percent the cause. If I had known years ago that by being on the pill for such a length of time and then when you actually come off, that you could start having these problems, I would never have gone on the pill in the first place.

So... you have thought a lot about the cause of why this has happened?

Yeah, because I think, I think when you're younger, I think they just put you on the different types of pills. And, um, it's like giving out smarties really. And there's no real check-ups. You go down, you go every so often, you get um, they might do your blood pressure and that's it and they dish you out some more pills. And... I think that's slightly worrying. Um, and obviously, because we need to have some form of contraceptive, you go along with it, don't you, and it's quite an easy thing to take every day. So, but if you really, you know, and I don't think we think about what we're doing at the time and it's only 'til when you get to a certain, you know. And obviously when you get to a certain age, they don't want you to go on, on the pill and that's um...I think it's slightly worrying, I think one should be more aware of what you're doing at an earlier stage. And what it could be doing to your body for later on. 'Cause it's not a natural thing. You know, you're on the pill and it obviously, it does sort of, your period, your bleed is, is very different by being on the pill. You don't have such a, a, you don't have probably a normal bleed and if you're on the pill for years and years...It's, it's, it's doing something to your body. But at the time, you just think, oh you know, it's convenient, so, you know. Um, and it's a woman that has to, most of the time has to think on that. It's not the man. The man just sort of takes a back seat. So I think you should be given more information.

Do you feel that you've had enough information now about your condition?

Well, I still ask every time I go, I ask something more. But I don't, no one's given, been able to give me an answer about why women get fibroids, 'cause no one seems to know, which I find fascinating. And that, you know, the only thing I know, it's very common in, um, in Africa. It's much more common in black women for some reason, than white women. And a lot of women, you get, you tend to get fibroids at a certain age and most women can go through life and it doesn't, they won't know that they had them. But no one knows why we get them. And because it's such a common thing within women and women do suffer because of them, you wonder why they haven't done some research to find, find out why and maybe be able to prevent it. Because I'm sure they wouldn't have so many women in, in the surgeries and in these hospitals if they could, they could find a cure. Because I'm sure it's something we must be doing to get them. We must be doing something to our bodies to get these fibroids, whether we're not eating properly or whatever.

It sounds as though you've got your own thoughts about what you've been doing?

P Well no, because I, I do think, I think yes now what could I have done to cause, but I can't think. I eat quite healthy and whatever. Yes, I smoke, but um, I think that wouldn't be the cause. It does fascinate me. I'd love to know why... And every time I go, I do sort of bring this up, because I think some one, one of them, because I see, obviously I see a different doctor every time and I think well some one might know (laughs) They don't.

But you're testing them all out?

Yes. (laughs)

What are your thoughts about having fibroids?

Well I don't like it. I don't like them. I don't, and sometimes when you've, you know, when you're feeling slightly down and you get, you know, obviously you get slightly depressed um, either when you're having a bleed, when you've got your period or just before. And I sometimes think and then I start thinking yes, I've got these creepy crawlies inside of me. These little um, um. And obviously they do get bigger. They are growing inside me. And I don't like it, because having fibroids causes your stomach to swell and some women suffer quite badly. They actually look pregnant. Um, cause your stomach just blows out. And no, I don't like it and I would like them to be removed. 'Cause I think ok, if you could get, if you could remove them um, I think it would help you. The fact that I know they are inside me and they don't get bigger, or they get bigger. They stop, they'll stop growing and probably disappear when you have your menopause, but before then they can grow and they can grow and grow. And you do see women, you know, I've actually said it to someone, when's the baby due?

And they had fibroids?

Hmm. Hmm.

So, has it changed how you think about yourself?

Well I mean, I, I, because I do have a sort of swollen stomach. Not, I now don't eat wheat products, cause that's helped. Primrose oil tablets I take, because apparently that helps, that helps the swelling. I stay off anything wheat, anything like that. Because no, I mean it's not nice. When you're, when you've been used to having quite a, a decent figure and suddenly, not only are you worrying about what's growing inside you, you've got the, you can actually see it from the outside to a certain degree as well, that you're body has changed, because of these. No, it's not, it's not nice. And I mean, everyone tries to, most women try to make the most of themselves and then you know, and obviously people, an outsider will think, god she's putting on weight. Well, it's not that you're putting on weight, you have a problem. And it's hard...

And it's not a problem that you can explain to people?

Yeah, and you know, unless you starve yourself and not eat, you'll not... You can help the situation, but you can't, you haven't got much control over it.

So do you feel you have any control over it?

No, I have, because I am being, um I am doing, I'm eating very healthy. I've stopped all the Danish pastries first thing in the morning or the wheat and all the rest of it and it has helped. I miss it all, but it's helping.

You were talking just then about sometimes when you are feeling low. How much do you think having fibroids influences your mood?

Oh no, I don't think it does, but then of course when you're low, you start, 'course you're feeling, you tend to feel sorry for yourself don't you, you know. So you start thinking, you know, and I think yes, why have I got fibroids? Why hasn't my sister? But it's only when I'm quite low and then um... occasionally when you might see, listen to a medical program on TV or something and you'll hear something and you think ooh. Um...but I've accepted it now. I didn't at first. I didn't like the idea at all and I didn't like the thought that something was growing inside me and I had no control of it. Um... I could have them removed, but it's not a very good thing to do, because it's quite dangerous as well and you can bleed very badly throughout, when you're operated on and if that's the case they will do a full hysterectomy, which is, I'm adamant I don't want. So I wouldn't have it done and there's no, they could grow back anyway. There's no... they can't say that they wouldn't grow back. So, what's the point in going through it all?

So even though you want to get rid of them, you've got to keep them?

Yes, I mean, the doctor I saw last time was saying that um, I'm obviously at that age, where you know, I'm coming up to what forty seven. It's not gonna be long. Um, so I've only got a few more years and hopefully they'll disappear. So that sort of cheered my up a bit.

And how do you think those few years are going to be?

Well, compared to what they were, you know, before, it's a hundred percent better. But now and again, yes I do, do, sort of worry about things and think ooh, you know, is everything ok? Um, um, which you do, because you do, you listen to the news and hear frightening, you listen to the news and frightening stories about how someone um, complained and went on about not just, you know, this problem, but another problem and then it's all too late. And it does, it does worry you a bit.

And... what would situation better for you?

What would?... Well when you go, when you go to, when you go to see them every six months or whatever, I tend to just sit and have a chat with them.

Um, they never take your blood pressure, well they've never taken mine, You know, and they sort of ask you are you ok? And sometimes you say oh, I'm a bit tired, I'm very tired, I'm getting this, I'm getting that. Um and they always say well that's part of it or, but they don't actually, they just talk to you. And they're quite reassuring that, in the sense that they say to you, well you know, that's part of, you know, the fibroids can cause this, that and all the rest of it. But they don't actually do any tests, you know, actual tests on you like um, well they never take my blood pressure or things like that and sometimes, just silly little things like that could make you feel a bit, slightly happier that you know, you haven't got high blood pressure or you know all the rest of it. And um, they never do an internal or anything like that and you, because you know you've got these fibroids inside you, I just would like to know if they've stopped growing or they've got bigger and bigger, which is just for my benefit and you don't get that.

So you've got, like you were saying, all these ideas about what is going on and you'd like some reassurance about it all?

Yes, yeah. Not just a little chat when you go in and say, they obviously ask how your bleeding is and is it on a regular thing and you say yes, yeah, yeah and then you talk about a few things and that's the end of it. Er, if they could only sort of look, actually look inside of you and each time you go in and say everything's fine, you can go home and be quite happy

Right. How do you feel after you've been to those appointments?

Well, a couple of times I've felt oh, why did I bother coming? And then a couple of times I've been and we've talked about things and last time I spoke to, it was nice, a nice man, the doctor. And we spoke about fibroids and he sort of spoke about that you could have these, because I was taking um... they gave me a pill to take to try and control the bleeding a bit more, because I was bleeding a bit heavier. And he said I don't know why you're taking them, you shouldn't be, it's obvious that you will always bleed. Because this coil in theory, you stop bleeding after a couple of months. You don't even bleed at all. Well it hasn't worked like that for me. And he said you shouldn't be taking it, these tablets, because they were having side effects I didn't like, terrible sickness and diarrhoea. And he said no you shouldn't. And then we were just talking about the fibroids, could they be operated on and he was explaining all that. So I felt a lot better when I came out. He was saying that you shouldn't, he wouldn't advise it and he was, you know, talking about that side of it.

I just wanted to ask you about something that you were talking about before, when you were sort of saying that you do wonder why you and not your sister. Do you compare yourself to other women when you think about it?

Well, um no, but because, no. It's really my family, because you think something like that is gonna be passed on, because, apparently because it's so, so common. [*section containing identifying information removed*] And none of my family and in fact none of my sort of relations, any of them have had any problems. It's me. And I think how comes it's happened? Because normally, with certain things, you find that it goes, it's in the family or something, whereas nothing. And having a sister, yeah...It does, it's just, you do. I'm not jealous, I'm not, you know, angry about it or anything or bitter and saying why hasn't she got it and not me. Why is she, she's not had a problem. *[section containing identifying information removed]*

And you're saying that you have friends who have similar problems, who have fibroids?

Yeah, a few, a couple of them, yeah.

And how do you feel that your experience of having fibroids has differed to theirs?

Well one of them that had, well they've, they've all, the ones that have had, it's only been a couple that have sort of, suffered as badly as me and they actually had the coil, this coil fitted and it worked for them. No more bleeding.

Is that disappointing for you then?

Well it is and it isn't. I mean it was, I think, I would be slightly concerned, I know it's silly, but it's a natural thing that a woman should bleed every month and the fact that you, if it, if it completely stopped, I think well it must be doing something else within your body, cause it's not natural. So, I think in some ways, I'm happy that I'm still having a bleed. But it, it's obviously building up. As the time goes on, I would just hate to think it's gonna start up again. Um... but yeah, there are times when I think yes, it would be lovely not to have to worry about it at all, but then I think well, it's not a natural thing to be happening to you, within your body.

We've nearly finished. I'm just was interested to ask you how have you coped all the time with these things, with the effect it's had on your life?

I've had to. I've just had to. I'm quite a determined person. I've just thought it's not gonna get to me and... I mean there was times when I, you know, I used to come home from work and sit there and cry and think I can't cope with this. And I used to talk to my friends and I had some very, very good friends, even though they've not had any problems. They said I'd hate to think that we're gonna experience what your going through. They've actually seen it, been with me when I've sort of been in a, in a state and had to run off on them. They've were very sympathetic and whatever and I've got a very good, I've got a great Mum and family, so they've been quite supportive. And I'm quite determined and I just think no, I'm not gonna let this get to me. 'Cause I mean, you could. I know lots of women when they have a bad period they stay off work for a week. Well, I, I don't. I was determined it wasn't going to do that to me. I mean, I can't have time off anyway. I have to be there. Um, I never had one day off, because of it. Because I'm, I thought I can't allow, this is gonna keep, this isn't just gonna last for a month or so, this could be going on for a long time, so I've got to not let it take my life over and control me. I've got to get, you know, I've gotta be able to cope with this. It wasn't, it wasn't easy and there were times I was terribly miserable about it, thinking oh god, you know. But you can't allow it to control your life, because you just wouldn't do anything, you wouldn't go out. You could become very depressed. And I can understand women getting very depressed.

But do you feel that you've been depressed about it?

I did get depressed, but not, you know, if I, I, the way I think, if I get depressed about anything, I always think of people worse off than me [*section containing identifying information removed*] I think there's people that are suffering and having, have got real problems. Yours is just something you're gonna have to put up with. You can try and do something to help it, but you know, don't allow it to take your life over.

But it sounds as thought that's been hard?

It has been hard, yeah. And there are times, you know, a couple, I used to go to the doctors and I'd sort of, one of the doctors I went to see, she wasn't particularly sympathetic. She spent the whole time in the surgery looking for her stuff as she was talking to you, so she wasn't actually listening to what you were saying. And you'd come out and think I could have bashed my head against the wall and she wouldn't even notice. So yes, until I actually met the doctor that was very, a young doctor, she, who was very sympathetic. If I hadn't have met her, I could still, I don't think I would've, 'cause I would've had to, I would've gone private. It was getting to that stage where I would've just gone to see someone privately.

Was that almost at that stage where you felt you had to do anything?

Yeah, oh yeah. Because | just thought, you know, I can't. Because you do, you start, it's a fear of, you know, you go to bed at night and you think god, will I, will I bleed to death? I mean I know it sounds crazy, but if it's not happening to you, it's quite frightening when you have huge clots and you just cannot control it. And you just think, you know, and you think god, I'm losing all this blood. What's it doing to my body and you know, I'm gonna get anaemic and I'm gonna get this and that. And of course you've got more blood inside of you than you actually realise. You know and it's not, you're not losing pints and pints of it, but at the time you think you are. You think, god I can't, this, this isn't natural, I can't be losing this amount, you know. I'm gonna, something gonna happen, dreadful, it's gonna happen to me and of course you think you're gonna bleed to death in the night.

And at the time, you really believe that?

Yes, you start, because it's frightening. And of course, so you put your alarm off, er alarm on, so you get yourself up in the, you know, to check things out. And you don't sleep well anyway, because you're worrying about it. So you're exhausted because you haven't had a good night's sleep and you're exhausted because you're probably, probably you're slightly anaemic at the time anyway. Um, so it's quite a vicious circle.

And then you're carrying on with your work?

Yes, and pretending everything's alright, when you're freaking out.

In private?

Hmm. Hmm. And you don't want everyone to know that it's, um, you're bleeding at the time. So apart from a couple of colleagues, you just keep it quiet. So you have to, sort of, you know, oh it's really difficult.

Well you've told me a lot of things, um. I think we've covered pretty much everything that I wanted to talk to you about. Is there anything that we haven't talked about that you think is important or that you'd like to say more about?

No, just what as I said, you know, and after seeing the doctors and especially after having, you know, something, a coil fitted, or whatever, or you've had some form of operation and they've looked inside you, it would be nice, even though they're telling you and they're very reassuring at the time and very sympathetic. They've all been, they've all been very nice. It would be nice to get that letter to say everything's fine and we did this, that and that. 'Cause at the time, all, as, as long as they say everything's fine, you just think great and you're not listening. You're seriously not listening, 'cause you've worked yourself up probably before you went in.

And it would be nice to actually have something to look at?

Yes. Yeah, yeah. And they say they've done this, this, that and the other and you know, obviously that they didn't see any cancerous cells, or whatever they can see. I mean, I'm not a doctor, so I don't know, but it'd be nice to have that, because that, tumours and all the rest of it, 'cause women do worry about it. And you don't necessarily, unfortunately the signs are not always there for you, obvious sighs for you to take action until it's too late... So that's the only thing I'd say.

So are you still worrying about it being cancer?

No, because no, because I, I spoke to some one [*section containing identifying information removed*] Yeah, I did ask and that was fine, 'cause I actually said, look, you know, I, I, you know, you'll probably think I'm being very silly and selfish, but I've gotta say it. And they said, no, that's fine. So, and they said, everything, you know, you probably didn't take it in at the time and I said no. I just wanted to get out, get home. Not that, you know, there's anything wrong with hospitals, but to me, I hate even, I loathe going to a hospital to visit some one that's just had a baby. I find it very difficult.

So going in for your own operation?

Hmm, Yeah, I don't. I just do not like hospitals. I don't know why. Um, so I just want to get in and out as quickly as possible. And even though you're talking to all the women that are waiting to go in on the wards, you've all got very different symptoms. You're all going in for very different reasons, but by the time you've finished talking to everyone, you've all got everyone else's symptoms. D'you know what I mean? You just start thinking oh yes, I don't know, I think I might have that as well. (laughs) And it's because, because and you're talking, you're all talking a load of rubbish, because you, even though, the doctor's explained what the problem is with you, you're not actually, because you're not a doctor, you're not, you're not high up in medical terms and everything, you get it slightly wrong anyway. So by the time you've finished, you've got all theirs as well. (laughs) So, so when the doctor comes up and says everything was fine, you think great, I'm going, if that's fine. And I remember saying thank you very much. And I was literally getting dressed, even though. I actually took myself home, because you're meant to have some one come up to take you and I just thought no. I said no, I'm fine, I'll be fine. I just want to go home. I'm, you know, I haven't got far to go. Um, 'cause I just wanted to get out of there.

So you got yourself out of there?

Yes. [*section containing identifying information removed*] Mine isn't life-threatening. It's just it's not a pleasant experience to have to cope with every month, but it's a lot, a hundred percent better to what it was. So that, I'm grateful, I'm really grateful for that. If it had carried on, no I wouldn't, I don't know what I would've done. Um, because I'm adamant I don't want a hysterectomy. Um, I think there should be something else that one can do to women, as it seems quite a common thing with women. They always, and obviously a lot of women when they get to a certain age, oh yes, I'll have a hysterectomy, because that's great, I don't have to have another period. So, it's an easy option. And that's, I think is wrong. And so many women, oh that's fine, I'll have one. And I don't and I don't want that. 'Cause part of you, you, part of you's gone and there's lots of side effects anyway from that. Um it's, and it's something, if there's some other way they can help you, I'll go along with that. [*section containing identifying information removed*]. ...and then you sort of, you get this guilt, cause you think I've been whinging on about my little problem.

But to you, it isn't.

It isn't, yeah, because it's very different. Everyone else has different symptoms, different illnesses and whatever and ok, it might not be life-threatening, but at, you know, at the same time. But yes, you do feel guilty and I did for a while. I thought, god, stop feeling sorry for yourself. I felt guilty about asking, you know, knowing that, you know, mine wasn't life-threatening. Well, well, at the time, I wasn't sure whether it was or not. Did they, you know, look?

So it's not life-threatening

[*section containing identifying information removed*] Which, and that in itself, is you know, you just think well, if you're not gonna get a nice doctor, who's not gonna note of what you're saying and you're just becoming a hypochondriac and you're becoming a silly woman, um, go away you, you know, it's what do you expect, you have it every month. You could, you could end up with something life-threatening um, and it's too late. And I think that's what women worry about.

That's your view of what makes women distressed?

Hmm. Hmm. Because you do hear of breast cancer and whatever and you do hear of women going to the doctors. They don't, you know, there's nothing wrong with you, that's not a lump, that's this or you being a hypochondriac, go away. And then it's too late. And it's common, it's very common.

What would, how would you describe it? You say it's not life-threatening, but what term would you use to describe having fibroids?

Well no, mine aren't life-threatening. It's just an inconvenience and you know that um, I just know that they're growing inside me all the time and it would be great if someone said I'd remove them and I'd love to think that there's such a thing as laser treatment that they could remove them and I'd be much happier. And I do. I don't like it, I don't like the idea of something inside me. And the fact that no one can tell me why women get them. I find that very hard to take on board. Surely some one, or it's not, or to the doctors it's not, because it's not life-threatening and they've got, which is understandable, they've got much more important um, subjects to research on, than something that isn't life-threatening. And a woman in theory can cope with it.

Right.

But it isn't life-threatening, whereas lots of other things are and they've got to find cures for them, much quicker.

Right. Is there anything else that you'd like to say?

No, no.

Ok, well thank you very much.

END OF INTERVIEW