

“LET IT BE FINAL HOW I WANT IT TO BE FINAL”:
AN EXPLORATION OF WOMEN’S ATTITUDES TO, AND EXPERIENCES OF,
HYSTERECTOMY AND MYOMECTOMY

by

JULIE ASKEW

(Under the Direction of David Wright)

ABSTRACT

This study aims to explore the experiences and attitudes of women who have received surgical treatment for uterine fibroids. The women have either had surgery to remove their uterus (hysterectomy) or surgery to remove the fibroids while retaining the uterus (myomectomy). It is estimated that symptomatic uterine fibroids affect about thirty percent of all women, and in the United States they account for around 70% of the estimated 600,000 hysterectomies carried out each year. Using a qualitative long-interview approach this study attempts to understand women’s role in the decision and treatment process, and how values and experiences differ by treatment type. Eighteen women participated in the study and an analysis of patterns in the themes resulting from the data suggests there were differences between the two groups of women that require further investigation. These include the type and severity of symptoms from the fibroids, a woman’s financial situation and level of health insurance, the level of empowerment she feels when facing authority figures, the attitudes she and those around her have toward the female body, and her level of information about topics such as fibroids, treatment options, and female anatomy. The opinions of doctors may well be an important factor in treatment decisions,

but it is concluded that much greater attention needs to be paid to the women patients and their influence on outcomes.

INDEX WORDS: Women, Health care, Fibroids, Hysterectomy, Myomectomy, Feminist, Uterus, Sexual function, Women's health

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DEDICATION

This dissertation is dedicated to Dr Edouard Servy for removing my fibroids, and restoring me to health with wisdom, skill and humanity; it is because of doctors like him that women's health care is made richer.

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First and foremost I want to thank the women who took part in this study. They were generous and trusting, and I hope the investment of women like these will help to improve women's lives in the long-term. Becky from HysterHome was extremely supportive of this project and her enthusiasm helped to get recruitment rolling. I would also like to thank David Wright for putting up with me for the last five years! He patiently read and re-read multiple drafts of this dissertation, in addition to many other publications and presentations of mine. He manages to help me improve my work without ever criticizing or trying to change my approach, and I really appreciate this. Jerry Gale was another important source of help and encouragement as he worked with me on coding and thinking the concepts through. I chose my committee well, they are all supportive and generous with their time, and each person has played a role in my getting to this point. Last but certainly not least, the Graduate School at UGA has been a key player in my financial survival – thanks to its generosity this study was not only funded, but I was provided with an income that enabled me to focus my energy where it was needed.

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CHAPTER 1

INTRODUCTION

This study seeks to explore the experiences and attitudes of women who have received surgical treatment for uterine fibroids. The women have either had surgery to remove their uterus (hysterectomy) or surgery to remove the fibroids while retaining the uterus (myomectomy). Using a qualitative interview approach the study aims to understand women's role in the decision and treatment process, and how values and experiences differ by treatment type and race. The study is set within the context of the history and culture of the U.S. medical system, and is guided by a feminist epistemology that gives voice to its participants and values their role in the creation of knowledge.

The literature contains claims that historical biases in health care against women have left significant gaps in our knowledge and understanding of women's diseases. Further, it is suggested that women patients may not feel empowered in their health care choices. These problems are illustrated by the common condition of uterine fibroids, the leading cause of hysterectomy in the U.S. today. There is as yet no cure for this problem, and despite the existence of surgical and medical treatments that remove or reduce the fibroids while sparing the uterus, hysterectomy is still the usual treatment of choice. While this surgery offers a definitive approach to fibroids, there remains much controversy about its frequency of use. The literature offers us many examples of why doctors elect hysterectomy as a preferred treatment, but what is not so clear is the role of women patients in the decision making process.

If it is possible to reduce the number of unnecessary hysterectomies, then it may be that pressure for change will have to come from women patients. This study compares women who have had hysterectomy with those who chose myomectomy so that we may expand our understanding of the woman patient's perspective. It is hoped that the results of this study will

contribute to the design of interventions that empower women in their treatment choices, and that this may in turn lead to a reduction in unnecessary surgeries.

CHAPTER 2

LITERATURE REVIEW

“The medical system is strategic for women’s liberation. It is the guardian of reproductive technology– birth control, abortion, and the means of safe childbirth. It holds the promise of freedom from hundreds of unspoken fears and complaints that have handicapped women throughout history. When we demand control over our own bodies, we are making that demand above all to the medical system.

It is the keeper of the keys”
(Ehrenreich & English, 1973, p. 5)

Women and health care

In 1990, a House panel in Washington, D.C. was informed that more than half of the population (the women) in the United States (U.S.) was at increased risk of health problems due to its systematic exclusion from medical research. In 1986, the National Institutes of Health (NIH) had issued a policy statement to encourage more clinical trials to include women, but by 1990 there had been limited progress (Johnson & Fee, 1997). Apparently the discrimination was also extended to rodents, as only male rats were thought fit for scientific research (Nechas & Foley, 1994).

Some claim the health care system in the U.S. is a reflection of discriminations that take place in wider society (e.g., Bernstein & Lewis, 1996a), and the literature offers many instances of biases against women that exist in the medical culture. For example, despite the fact that women form the larger part of the population, Bernstein and Lewis claim there is “profound scientific ignorance” (1996b, p.10) about the female body and diseases that affect it. One such disease, cardiovascular disease (CVD) is the primary cause of death for women, but gendered differences in risk factors, such as the protective role of estrogen, were overlooked

until relatively recently. Pollard (1999) argues this was due to CVD being labeled a male disease.

Largely due to the efforts of the women's movements, there have certainly been improvements in specialist areas of women's health such as breast cancer (Blumenthal & Wood, 1997). For much of history, however, male physiology and anatomy has been the normative standard by which the health and behavior of both sexes have been judged (McBride & McBride, 1994). While men undoubtedly experience problems with health care, Brin Hyatt (1999) argues their status means their medical treatment depends on issues such as lifestyle or type of illness, but never their sex. Conversely, according to this argument women are disadvantaged and medicalized purely as a result of being women.

Further problems with health care for women may stem from the 'gender' of the medical system. As members of a traditionally White, middle-class male profession (Lorber & Moore, 2002) doctors tend to be afforded high status and power in society (Morgan, 1998). Reinforced by a culture of "aggression, competitiveness, rationality, unquestioning self-confidence, [and] emotional coolness" (Young, 1981, p. 152), doctors can control areas that have become key to our survival and quality of life. These include screening and testing, surgery, vaccines, specialized technology and genetic manipulation (Morgan, 1998). Medicine, it could be argued, has evolved to become a male paradigm and as such Ehrenreich and English (1973) have viewed the medical system as "strategic to women's oppression" (p. 5). Johnson and Hoffman (1994) have argued that if women had been the benchmark for human health it is unlikely they would have been so "often misdiagnosed, inadequately researched, or inappropriately treated" (p. 29).

The History of Women's Health Care

In order to understand the culture of health care and its relationship to women, it is helpful to understand its process of evolution. Ehrenreich and English (2005) have given a

detailed account of the history of what they term “the politics of sickness”. This history is often portrayed as “science versus superstition” (p. 37) where the theories of those considered experts were in competition with the folklore and lay healing skills of women who were herbalists, midwives and counselors to their communities. The conflicts appear to have stemmed in part from the fifteenth century, when Pope Sextus IV pronounced that women should not practice medicine unless they were university graduates, despite the fact that the laws in most countries prohibited women from obtaining such an education (Crook, 1995). In the centuries that followed, it is estimated some five million women across Europe were executed, labeled witches primarily for their work as healers and midwives to their communities (Crook, 1995; Ehrenreich & English, 2005). As a result the male physician was established as a professional of high social standing, and it was this European model of healing as a “male enterprise” (Ehrenreich & English, 2005, p. 46) that was transported to colonial America.

History has not tended to record women in a positive light, as typically they have been viewed as weak and unstable. Judeo-Christian traditions, for example, are based on the belief that woman was created from an inconsequential part of man, and was predisposed to moral weakness (Ehrenreich & English, 1973). Later theories, such as those of Freud, portrayed women as sexually passive, defective versions of men (Bernstein & Lewis, 1996c). As Ehrenreich and English note, however, these frailties were often differentiated according to social class, as they did not appear to prohibit women of the working classes from heavy manual labor or the primary responsibility for childrearing.

Typically historical views of women as the weaker sex have identified their frailties as stemming from the female reproductive organs. Since the time of the ancient Greeks, the uterus has been blamed for all manner of women’s problems from constipation to tuberculosis (Ehrenreich & English, 1973). For many years it was believed that intellectual pursuits such as

reading could cause the uterus to atrophy (West, 2000), while diseases of the ovaries were thought to be the cause of psychological illness (Ehrenreich & English, 1973).

Such beliefs resulted in the female reproductive organs becoming the focus of medical treatments for a variety of complaints. Some of the more bizarre and unscientific treatments that women were subjected to included leeches on the genitals and cervix (apparently doctors were advised to count the leeches, as it was not unknown for them to enter the uterus), surgical amputation of the clitoris, and removal of the ovaries, a surgery known at the time as ovariectomy. According to Ehrenreich and English (1973), some individual doctors in the 1800s removed thousands of ovaries apiece, as it was observed that castrated women were docile and easier to manage. With the arrival of anesthesia during the nineteenth century (and one may assume that surgeries were attempted without it) it was possible to perform hysterectomy to remove all the reproductive organs. At this point, West (2000) alleges, it became possible for a woman to find herself subjected to gynecological surgery for any complaint that her husband, father or doctor might claim existed in her.

While these accounts of medical practice may read like ancient history, there is evidence that harmful practices targeted at the female sexual and reproductive organs persist today. For example, it is well documented that low-income women, and particularly women of color, have been the targets of involuntary sterilization campaigns for many years (Ehrenreich & English, 1973; Hartman, 1995). Morgan (1998) argues that such practices have been highly damaging to women: “it is possible to read the history of Western medical research as reinforcing repeatedly the normativity of white male experience. This practice has proved dangerous and sometimes deadly to women” (p. 103). How far any of these norms are perpetuated within current Western medical practice is highly debatable, but the history of women’s health care nevertheless forms an important backdrop to understanding the current culture of the medical system.

The Culture of Medicine in the United States

Lorber and Moore (2002) claim that illness is a social phenomenon rather than just a physical state. Thus, what is considered as sickness or suitable treatment will vary from one culture to another. Equally, physicians' knowledge and attitudes will be a reflection of the prevailing philosophies of their wider culture (Ramsey, 1994), and their perspectives will often guide their responses to different patient groups (Roter & Hall, 1997). The literature on women's health care will be examined here for evidence of perspectives in the medical culture of the U.S. that could negatively affect the treatment women receive.

Medical sexism. In contrast to periods of history when women were prohibited from further education, the majority of health care workers in Western societies are now women (Lorber & Moore, 2002). However, according to Lorber and Moore, despite these increasing numbers of women "the profession has not 'feminized', but is still somewhat gender-segregated and gender-stratified" (p. 37). So, for example, male physicians are more likely to move up the professional ladder and to specialize in higher paid areas. Gender stratification is also apparent in the larger number of women who enter nursing which, Young (1981) argues, can result in a sense that doctors (male role) think whereas nurses (female role) care.

Societal forces and the culture of the medical system combine to shape doctors as professionals (Kleinman, 1988). Fugh-Berman's (1994) recollection of her training as a medical student provides an illustration of this shaping process. Fugh-Berman describes disrespectful attitudes to female cadavers, the preferential treatment afforded to male students, and a general harassment of female students. Such reinforcement of stereotypes and prejudices, where they exist, may impact practice. "Female medical students go through an ordeal, but at least it ends with graduation. It is the patients who ultimately suffer the effects of sexist medical education" (Fugh-Berman, 1994, p. 53).

Some evidence of these effects is apparent in the literature. For example, McBride and McBride (1994) argue that women tend to receive less attention from doctors and less treatment, as their complaints are not likely to be taken as seriously as men's, nor is their work-up likely to be as thorough. The published responses to a study by Seago and colleagues (1999) make particularly interesting reading when considering the issue of medical sexism. In a discussion of planned cesarean hysterectomies (women who have their uterus removed in the same surgery that delivers their baby), the male physicians discuss related issues such as residents' training and symptomatic fibroids. One elderly male doctor states that he is pleased to see credible evidence in support of this procedure, as he has performed over one hundred such operations for the purposes of sterilization. Interestingly, the lone female discussant is the only physician to point out the high incidence of psychological problems that she has observed in her patients following cesarean hysterectomies.

Despite the sexism that appears to be apparent in some sectors of the medical professions, one might surmise that women doctors would be gentler, less intimidating and better communicators than their male colleagues (Lorber & Moore, 2002). Evidence does indeed suggest that women treated by women doctors are more likely to have regular PAP tests and mammograms and less likely to have a hysterectomy (Domenighetti & Casabianca, 1997; Kramer & Reiter, 1997) than women with male physicians. However, some argue there is a role conflict for women doctors (Roter & Hall, 1997), as the medical culture and lack of female role models leads to a gender bias in *all* practitioners. As one female physician explains: "We have been taught by men. We have modeled ourselves after men in the field. We have learned to think like men, as if this were the greatest compliment they could bestow on us" (Wallis, 1994, p. 16). Consequently, Mendelsohn (1982) argues that women may tend to practice medicine as though they were men. While women patients may express a preference for women physicians, evidence does suggest these patients, particularly those who are women

of color, may complain that doctors in general lack respect for women and their particular health needs (Groff et al., 2000).

Race and SES. According to Bernstein and Lewis (1996b), the most important factor in a woman's health is her position in society. In the U.S. in 1998, for example, a Black woman could expect to live about five years less than a White woman (Lorber & Moore, 2002). It has been documented (e.g., Adler & Coriell, 1997) that race and social class exert a strong influence on risk factors for disease, in addition to determining the quality of health care one can expect to receive (Williams, 2000). Research suggests that compared to Whites, Black people tend to be offered a narrower range of medical procedures, are more often subject to unfair treatment access, and are more likely to have a lower limb amputated (Williams, 2000). A poor woman of color is said to have "triple jeopardy" (Bernstein & Lewis, 1996a) as she suffers the effects of poverty in addition to being subjected to racism and sexism. Such women patients may lack the information to make educated decisions, and when their treatment is inadequate they may feel they have little recourse (Nechas & Foley, 1994). The resulting mistrust of institutionalized medicine is well described by Snow (1993) who claims that poorer people of racial minorities may instead turn to traditional remedies and lay healers to resolve their health problems.

Doctors and communication. As part of their medical enculturation, it has been suggested that many doctors learn to develop defense mechanisms that may result in communication problems, leaving patients feeling they are not properly understood (Young, 1981). In a study of the British health care system (where litigation for medical negligence is not as high as in the U.S., but is steadily rising), for example, patients' decisions to take legal action were strongly influenced by poor communication with, and insensitivity from, medical staff (Vincent & Young, 1994). "Complaints about the lack of clear, sympathetic explanations point to deficiencies in communication, and a failure to appreciate that in some circumstances

the emotional needs of patients may be as important as their physical state” (Vincent & Young, 1994, p. 1611). Where doctors do not take the time to explain the situation and options fully, it could have profound effects on a patient’s life. In the case of hysterectomy, for example, Wallach and Eisenberg (2003) argue that many women are left having to make a potentially life altering decision with woefully inadequate counseling.

A further impediment to good communication from doctors may be the technical language they use. For example, an article written by medical doctors on the decision analysis for hysterectomy (Scott et al., 1997) points out that discussions with women over sexual function could be handled with a few simple questions such as: “How important are uterine contractions and tension on the uterosacral ligaments to your enjoyment of intercourse?” and, “Are vaginal barrel tone and length significant components of your response and enjoyment?” (p. 1192). It would seem unlikely that many women would have considered their sexuality in these terms, and such an approach might therefore fail to be conducive to sensitive doctor - patient discussions of sexual pleasure.

A disease model. With modern Western medicine it is argued that we are living in an age where normal human conditions are increasingly medicalized (Tiefer, 1994; 1996). This is the process where ordinary life occurrences, such as childbirth and menopause (and most recently sexual intimacy), are defined as problematic and become subject to management by the medical system (Brin Hyatt, 1999; Lorber & Moore, 2002). Morgan (1998) argues that the process of transforming ordinary life in to medical dollars can in fact be a dangerous one. It may, for example, lead doctors to view healthy organs, such as ovaries or breasts, as potentially cancerous and therefore subject to removal (Morgan, 1998). Additionally, the medical model tends to assume that ridding a patient of one condition through treatments such as surgery will make them better, when in fact they may be substituting one set of problems for

another (Payer, 1988). This issue is particularly contentious in surgeries such as hysterectomy, a subject that will be explored more fully later in this study.

In summary, the literature suggests the medical system may prove a hazardous and disempowering place for some women. The history of modern health care demonstrates a long exclusion of women, and the resulting paucity of knowledge about their bodies has sometimes led to dangerous and unnecessary treatments. Evidence suggests there is room for further exploration of the experiences of women, to determine the extent to which women are becoming informed consumers of health care, and to assess the level to which they are able to exercise full control over their bodies and medical treatment decisions.

The Significance and Functions of the Female Reproductive System

In a history that documents examples of medical biases against women, no specialty appears to have attracted greater criticism than that of gynecology (Bernstein & Lewis, 1996b). Ehrenreich and English (2005) describe some of these concerns, one of which is directed at the man commonly accepted as the father of gynecology in the U.S., J. Marion Sims. In the 1800s, J. Marion Sims developed his techniques through surgical experimentation on Black female slaves, who are said to have endured multiple surgeries (up to thirty in a two-year period) in the name of progress (Bernstein & Lewis, 1996b). Later in his career, Sims is reported to have moved to New York, where he continued his gynecologic experiments on poor Irish women from the Women's Hospital (Ehrenreich & English, 2005).

The attitudes that doctors and patients have toward the female reproductive organs are important as they indicate rationales for treatment choices. Some of these attitudes that are represented in the extant literature will be explored here.

The Uterus

According to Maclin (1998), for many physicians the uterus is thought to have little value unless it is to be used for gestation; this may be due in part to the fact that the childbirth

function (Sloan, 1978) has always been a significant cultural indicator of a woman's value and identity (Dell & Papagiannidou, 1999). The uterus is the primary organ associated with a woman's capacity to be fertile, and our "everyday language reinforces the conception of the womb as a permanent space, an empty lodging waiting for a tenant" (Greer, 2000, p. 47).

Outside of gestation, many people may be unaware of other roles that the uterus is thought to play. For example, it is an organ that has been found to produce prostacyclin and prostaglandin, chemicals that are significantly implicated in cardiovascular function (Plourde, 1998). According to Plourde, researchers still "really don't know the total functions of any of these chemicals, or how their loss affects a woman throughout her life" (p. 69).

Other literature on the uterus suggests it is perceived as an organ that holds powerful meaning and significance. It has long been thought of as a source of youth and vitality (Thakar & Clarkson, 1997), and it is uniquely female -- tied to the natural forces that regulate a woman's cycle (Sloan, 1978). It may, therefore, play a powerful role in a woman's sense of her identity. In some feminist literature it is suggested such images may be threatening to the male psyche. Irigaray (as cited in Whitford, 1991), for example, claims the uterus is "fantasized by many men to be a devouring mouth, a cloaca or anal and urethral outfall, a phallic threat" (p. 41). This power, it is argued, leaves men deeply envious and the surgical removal of the uterus therefore signifies men's attempt to deal with this envy (Corea, 1985).

The Ovaries and Cervix

Other parts of the female reproductive system are also considered to have important functions outside of fertility. The ovaries, for example, do not shut down at menopause, but continue to play an important role in a woman's health by producing vital hormones. Plourde (1998) argues that research has yet to provide a definitive picture of this process. The cervix additionally plays significant roles, which include housing nerve branches implicated in sexual function, helping to keep the floor of the pelvis intact to support the vagina and bladder, and

the production of chemicals to guard against genital tract infections (Goodwin, Broder & Drum, 2003; Plourde, 1998).

Attitudes to the female reproductive system that are based on limited understanding could prove problematic for women's health care. If one believes the uterus is only required for gestation, for example, it ceases to have much value once a woman gives birth to her last child. Additionally, in the area of sexuality confusion about the role of the reproductive organs may leave women making treatment decisions that could have lasting implications.

Rethinking the Sexual Organs

In 1872, about 100 years before Masters and Johnson documented it, a team of researchers in St Louis described the movements and “gyrations” of the uterus and cervix during sexual excitement (Sloan, 1978). With the benefit of modern technology and laboratory techniques, Masters and Johnson were later able to obtain more detailed data. They subsequently devoted an entire chapter to the uterus in their book ‘The Human Sexual Response’ (1966), which offers detailed descriptions of the role this organ plays in sexual pleasure.

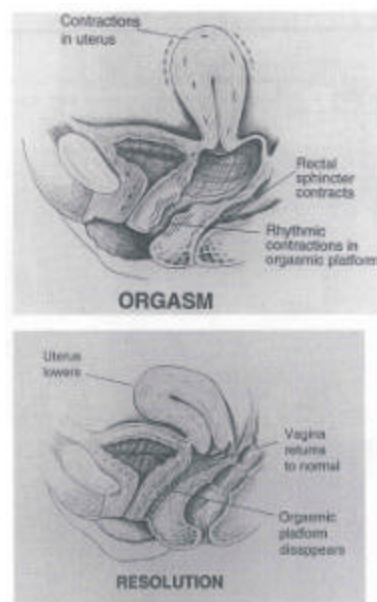


Figure 1.1: Movements of the uterus during sexual excitement.

The uterus elevates during arousal, which leads to ‘tenting’ in the vagina; it has been observed that the uterus may increase in size as much as 100% during this period. Then, within seconds of orgasm, the uterine muscles undergo rhythmic contractions (see figures 1.1 and 1.2), the cervical os dilates, and the cervix is observed to ‘dip’ repeatedly. Throughout the arousal process there are levels of pelvic venous congestion that may leave a feeling of pressure or pain, which can normally be alleviated by orgasm.

Current human sexuality experts (e.g., Bancroft, 1995) have corroborated these changes in the uterine architecture. With such well-documented knowledge of the uterus as a sexual organ that is deeply implicated in a woman’s sexual sensations, research indicating that removal of the uterus (with or without the cervix and ovaries) has no significant effect on female sexual pleasure remains perplexing. The conflicting opinions about this issue will be explored further in the section on hysterectomy.

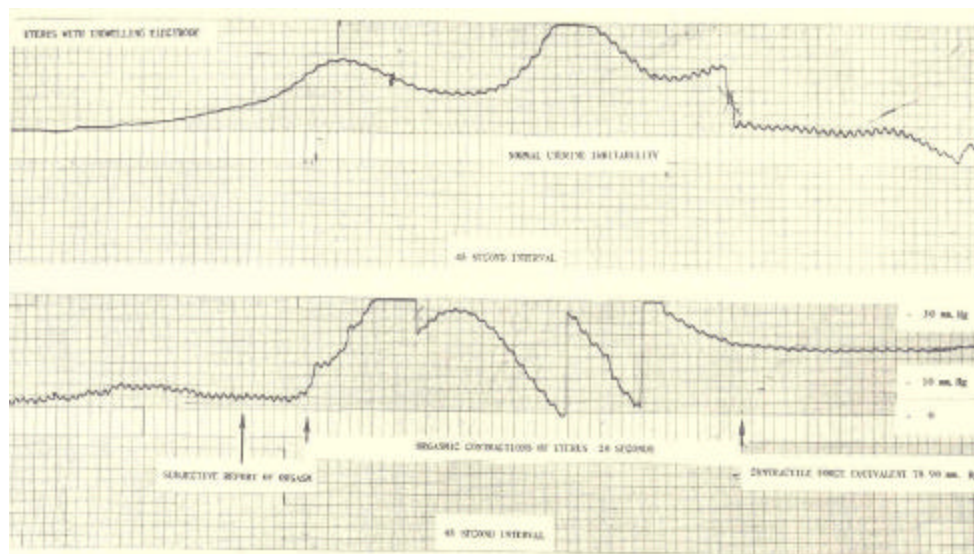


Figure 1.2: Uterine contraction in orgasm indicated by intrauterine electrode (taken from Masters and Johnson, 1966, p. 117)

“Useless Uterus Syndrome”

In a review of gynecology textbooks, Scully and Bart (1973) noted that a woman’s anatomy is often depicted as necessary only to produce babies, or to satisfy a man’s sexual

needs. More current publications suggest this trend is continuing. In a pamphlet produced by the American College of Obstetricians and Gynecologists (1999) for example, the uterus is described merely as “a muscular organ located in the female pelvis that contains and nourishes the developing fetus during pregnancy.”

Sloan (1978) has observed that after the age of 35, many gynecologists will consider the primary function of the female reproductive system to be almost over, resulting in a form of thinking he terms “useless uterus syndrome” (p. 604). Tavis argues these views are persistent and may result in hysterectomy, a surgery she claims is considered of no greater consequence to some than a “female form of appendectomy” (Tavis, 1992, p. 163). Ironically, where these female organs were once removed to sedate women, or because they were thought to exert a powerful influence on many aspects of health, today they have become organs that many believe a woman past the age of forty can easily live without (Ehrenreich & English, 2005).

Uterine Fibroids: A Common Women’s Health Problem

A common condition that illustrates the issues women face in health care is that of uterine fibroids. These fibroids are solid benign tumors of the uterus with a distinctive whorled appearance (Dionne, 2001). They originate from a single muscle cell and as such are unable to spread like cancer cells, but they do demand their own blood supply and their growth may therefore lead to a corresponding expansion in uterine blood vessels (Goodwin, Broder & Drum, 2003; Thomas, 1992). Figure 1.3 illustrates the different types of fibroids and the ways in which they distort the normal uterine architecture.

In much of the literature on fibroids the reported prevalence rates are misleadingly low, as many women have smaller asymptomatic tumors that are not found, or not in need of treatment (Scialli, 1998). While only about twenty to thirty percent of the U.S. female population will suffer from symptomatic fibroids (Newbold et al., 2000) where clinical

symptoms become obvious, ultrasound evidence (Baird et al., 2003) suggests the rates of fibroids are actually so high that “if you look for uterine fibroids by ultrasonography in women in their late 30s and 40s, you will find them the majority of the time” (French, 2003, p. 2584).

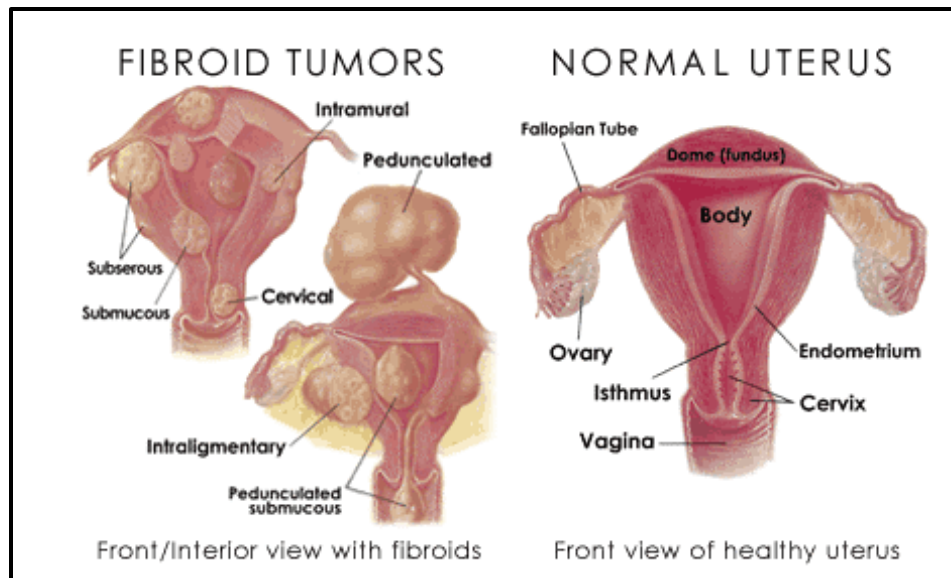


Figure 1.3: Normal uterine architecture contrasted with a uterus with fibroids.

Regardless of how they are diagnosed, the incidence of uterine fibroids is far higher among African American women than any other racial group (Marshall et al., 1997). One study of hospital patients (Kjerulff et al., 1996), for example, found 89% of Black women had fibroids, compared with only 59% of White women. Black women will also tend to have more numerous, larger fibroids and their clinical symptoms will tend to appear at a younger age. Additionally, Black women are the racial group most likely to be treated with abdominal hysterectomy for fibroids (Dicker et al., 1982), although it is unclear from the literature whether this is just a consequence of their more extreme symptoms. It is interesting to note as an aside that only one book in the lay literature (Brown, 2002) appears to focus exclusively on this issue as it affects African American women, and even then, the possibility of discriminatory factors in treatment options is barely hinted at in one brief paragraph.

For any woman with symptomatic fibroids, the problems can be extremely distressing as they may include: heavy menstruation (menorrhagia) with episodes of flooding and the passing of clots that can lead to anemia, pressure on the lower back or nerves that can cause leg pains (Meisler, 1999), infertility, miscarriage or pre-term labor (Kramer & Reiter, 1997), and abdominal distortion and pressure on the vagina, intestines, bladder and bowel that can result in pain and impaired function (Hutchins, 1995). A survey from the Centers for Disease Control (Kjerulff, Erickson, & Langenberg, 1996b) helps to underscore the problems some women face. The authors reported that in the previous 12 months, 34.8% of the women questioned had been confined to bed for an average of 16 days as a result of fibroid symptoms. Additionally, it should be borne in mind that deterioration in symptoms generally occurs over a prolonged period (Carlson, Miller & Fowler, 1994b) and women may therefore be living with chronic problems for many years.

At the current time there is still no certainty about what causes fibroids, and there is no cure for them. Due to the fact that fibroids usually cease growing after menopause, the most popular theories link them to steroid hormones, both within the body and from the environment (Brosens et al., 1999; Meisler, 1999; Newbold et al., 2000). Other possible explanations include genetic factors (Newbold et al., 2000), obesity and radiation exposure (Schindler, 1999).

Given the prevalence and effects of fibroids, it is perhaps surprising that so little is known about their etiology. Uterine fibroids are far from being a modern complaint (Dionne, 2001), as in the 1860s the notorious J. Marion Sims was writing about their occurrence. At that time, however, treatments were particularly brutal and usually resulted in “fearful” bleeding and death (Barlow, 1992). Although women appear to have been suffering with fibroid symptoms for centuries, this woman’s disease is non-lethal, which may be one reason why research interest has been lacking (McBride, 1999). A further explanation may be that the

‘cure’ for symptomatic fibroids has increasingly become a simple one: surgical removal of the uterus (Newbold et al., 2000). However, concerns over rising health care costs (Newbold et al., 2000), and perhaps the controversy over hysterectomy, have meant that alternative treatments are beginning to gain interest. The two primary surgical treatments for fibroids will now be explored.

Hysterectomy

Of all the treatments for uterine fibroids, hysterectomy is by far the most common, as around 68% of hysterectomies can be accounted for by a primary diagnosis of fibroids (CDC, 2002; Greenberg & Kazamel, 1995). As a standard treatment for many years, hysterectomy has become extremely prevalent and is now the second most common surgery in the U.S. (Scialli, 1998). However, while hysterectomy may be common it is also a controversial procedure, and this is reflected in the comparative size of literature devoted to each of the two treatments in this review.

The controversy appears to be caused in part by the high rates of hysterectomy (Mayfield, 1993). Approximately 600,000 hysterectomies are carried out in the U.S. each year at a cost of more than \$5 billion (CDC, 2002). This is by far the highest rate in the world (Wallach & Eisenberg, 2003). Concerns have also been voiced about the fact that hysterectomy is a dangerous procedure used primarily to treat non-dangerous conditions (Groff et al., 2000; Mendelsohn, 1982). For example, the percentage of hysterectomies for a diagnosis of cancer has decreased, while hysterectomies for fibroids have seen a marked increase since the early 1990s (CDC, 2002). It is believed that over 90% of hysterectomies in the U.S. are now performed to treat non-malignant conditions (Carlson, Miller, & Fowler, 1994a). While hysterectomy is a definitive cure for fibroids, some such as Goodwin, Broder and Drum (2003) claim “many hysterectomies are unnecessary, the medical equivalent of killing flies with a sledgehammer” (p. 2).

The history and process of hysterectomy may be further contributory factors to the controversy that surrounds this surgery. The first elective hysterectomies were performed in the early 1800s, and by the early 20th century the classic techniques were essentially defined. With few major advances it is essentially these techniques that have been passed down to gynecologists today (Garry, 1998). Plourde (1998) argues that even the term ‘hysterectomy’ is an ill-conceived nomenclature as it stems from the Greek ‘hyster’, and as such infers the removal of the cause of emotional instability. Ironically, it is precisely this surgery, particularly where concomitant removal of the ovaries results in what West (2000) terms ‘female castration’, that some researchers believe leads to longer-term emotional and psychological issues (Cloutier-Steele, 2002; Payer, 1987).

While hysterectomy is common, it is clearly a surgery that requires a certain level of skill if it is to be performed without morbidity. The complications that may arise from hysterectomy have exacerbated the debates over its efficacy. The uterus is intimately connected to other pelvic organs and structures, which are linked by a system of nerves and blood vessels. Blunt dissection of the surrounding area is necessary to remove the uterus, and this may result in problems for the patient if a mistake is made (Thakar & Clarkson, 1997). Over half of all hysterectomies in the U.S. include bilateral oophorectomy (removal of both ovaries), even though the ovaries are often healthy and their removal results in immediate menopause (CDC, 2002). Removal of the healthy cervix during hysterectomy is also common, and reasons for this are said to include fears of cervical cancer developing at a later date, and unwillingness on the part of the surgeon to appear inexperienced if a ‘stump’ is left behind (Thakar & Clarkson, 1997).

Potential Complications of Hysterectomy

Undoubtedly, many women report feeling better after their hysterectomy, as they are relieved from what may well have been years of extremely debilitating symptoms and poor

quality of life (Cloutier-Steele, 2002). However, the literature suggests that a substantial number of women develop highly distressing symptoms following hysterectomy. Some sources estimate that anywhere from a quarter to a half of women undergoing hysterectomy will suffer with resulting chronic problems (Plourde, 2003; Schofield et al., 1991), although the figures are hard to quantify as much of the outcome literature is produced by the medical teams performing the surgery (Cloutier-Steele, 2002).

There appears to be a dearth of prospective research that enables the accurate prediction of which women will have negative hysterectomy outcomes, and such research could go some way to helping women make informed decisions. Plourde (2003) suggests the distinction often falls between those women who keep their ovaries, and those who do not. In support of this observation, West (2000) argues, “no woman whose ovaries are removed during surgery ... will be the same afterward” (p. 39).

Once a woman’s ovaries are removed she is put into immediate surgical menopause, which can lead to further health problems. According to Plourde (2003), part of the problem is that women rarely have their complex balance of hormone levels accurately measured prior to surgery, which means that hormone replacement therapy following surgery can become a hit and miss affair. Even if a woman’s ovaries are left in place, hysterectomy by necessity reduces their blood supply, and as a result women may experience partial or total ovarian failure any time after surgery.

The problems that may result from hysterectomy can be extensive. As previously explained, the chemicals produced by the organs of the female reproductive system are considered to play a vital role in healthy cardiovascular function (Plourde, 1998; Pollard, 1999). Evidence suggests that a woman may triple her risk of illnesses such as high blood pressure, arterial disease, heart disease and heart attack if she has a hysterectomy (Cloutier-Steele, 2002; Easterday, Grimes & Riggs, 1983; Payer, 1988; Schofield et al., 1991). Other

complications that have been linked to hysterectomy include osteoporosis and weight gain (Plourde, 1998), problems with bowel and bladder function (Garry, 1998; Schofield et al., 1991), relationship problems (Bernhard & Harris, 1997; Plourde, 1998; Richter et al., 2000; Williams & Clark, 2000), and psychological problems (Schofield et al., 1991). In the latter group, evidence suggests that women may suffer a degree of stress response following hysterectomy, such as nightmares and depression (Payer, 1998). This is not a recent revelation as Sloan (1978) reported on a number of studies dating back to the 1950s, where psychological problems resulting from hysterectomy were clearly documented. In considering why a woman might experience such profound effects from hysterectomy, Plourde (2003) draws a parallel with men who have both testicles removed, and the well-documented evidence that as eunuchs they will cease to function in the same way following their castration.

A contentious area in the literature considering the effects of hysterectomy is how and whether the surgery impacts a woman sexually. Results from studies fail to give a definitive answer, but in general the current trend appears to lean toward reassuring women that their sexuality will either be unchanged (Thakar & Clarkson, 1997), or that they will experience improvements in their sex life as their symptoms are relieved (Maas, Weijenborg, & Kuile, 2003). A study by Helstrom and colleagues (1993) reported that about half of all women surveyed said sex was better after hysterectomy, mainly as a result of relief from the dyspareunia (pelvic pain during sex) experienced prior to surgery. Conversely, however, 21% of the study's participants reported that sex had deteriorated in quality since surgery. A further study by Darling and McKoy-Smith (1993) found that only 26.3% of women had improved sexual satisfaction following hysterectomy. Both of these studies suffer from a common methodological problem, which is the assumption that a woman's sexuality can be described and measured by very brief or misleading items such as frequency of intercourse. Areas such as physical sensation, pleasure or emotional meaning are rarely included.

A study that is highly persuasive in the argument that hysterectomy can improve sexual function appeared in the influential *Journal of the American Medical Association* (JAMA) in 1999 (Rhodes, Kjerulff, Langenberg, & Guzinski). It claimed that after hysterectomy the frequency of sexual activity is likely to increase while problems with sex decrease. However, Rozenman and Janssen (2000) point out that there are again problems with the measures used. For example, how do you adequately measure and compare 'strong' with 'very strong orgasms?' Additionally, it seems ten to sixteen percent of the women who had no sexual problems prior to surgery either developed problems or just stopped having sex altogether. Finally, the study makes a common error as it equates quantity with quality, which tells us little about the personal desire or enjoyment women experienced. As Meston (2004) notes, sexual willingness in women does not necessarily equal pleasure, and impairments in sexual physiology therefore require further investigation.

In considering the possible effects of hysterectomy on sexual function, there are several areas to consider. Surgical menopause can lead to decreased vaginal lubrication and weight gain (Schofield et al., 1991), while hysterectomy in general can result in a shortened vagina (Thakar & Clarkson, 1997) and diminished sexual desire (Plourde, 1998). In addition, according to the research of Masters and Johnson (1966), the cervix and uterus play a vital role in the sensations a woman experiences during arousal and orgasm. As West (2000) points out, orgasms are not either 'vaginal' or 'clitoral' as the popular press would have us believe. He explains that stimulating these areas may initiate sexual arousal, but the experience of orgasm can be felt deep in the pelvis, and uterine contractions are a fundamental component of this sensation. Without the uterus, it is difficult to understand how the experience of orgasm can remain unchanged.

In conclusion, a woman's sexuality is thought to be a complex mixture of many areas (Heiman & LoPiccolo, 1976) such as health, education, culture, values, self-esteem, body

image, relationship quality, and life stressors. In the extant literature it appears that in general medical doctors (rather than sexologists) are responsible for much of the research on hysterectomy and sex, and it may be that core human sexuality texts such as those by Masters and Johnson (1966) or Bancroft (1995) are not part of a standard medical training. Perhaps this may go some way to explaining the methodological issues that fail to encompass the task of adequately measuring female sexuality. After even a cursory reading of such texts, one is left wondering not ‘does hysterectomy affect sex?’, but rather ‘how do we explain results suggesting a woman’s sexuality is unaffected by this experience?’

The Culture of Hysterectomy

As mentioned previously, hysterectomy is practiced in the U.S. at far higher levels than any in other country. By the age of 60, for example, at least a quarter of all women in the U.S. will have their uterus removed, compared with only 9% of women in France (Plourde, 1998). As Lilford (1997) puts it, “in California barely half of all women will carry their uterus to the grave, whereas a gynecologist in Saudi Arabia may do no more than one hysterectomy a year and, often as not, this will be a lifesaving operation for catastrophic obstetric haemorrhage” (p. 160).

There have been various attempts over the years to reduce the hysterectomy rates in the U.S. In the early 1970s, these rates peaked to an all time high (Plourde, 1998). It is thought this may have been due in part to the trend of using hysterectomy for sterilization (Kane, 1990), and also as a result of a 1969 publication supporting a common belief that the uterus is useful only for reproduction and should therefore be removed as a matter of routine after the last pregnancy (Corea, 1985). While there have been congressional investigations (Mendelsohn, 1982), Senate reports (Primmer, 1997), and within-hospital review teams (Easterday, Grimes, & Riggs, 1983) focused on reducing hysterectomy rates, there has yet to be a dramatic curtailment in practice (Goodwin, Broder, & Drum, 2003).

A primary reason why hysterectomy rates in the U.S. stay so high, some argue, is not that American women are more diseased than women in other countries, but has to do with the culture of health care in the U.S. (Lilford, 1997; West, 2000). There are different themes discussed in the literature that help to illuminate this culture as it pertains to hysterectomy, and these will be explored here.

Hysterectomy and region. Within the U.S. the rates of hysterectomy vary widely according by region (Easterday, Grimes, & Riggs, 1983). According to CDC statistics (2002), almost twice as many hysterectomies are performed in the South as in the Northeast, and the average age of a woman undergoing hysterectomy is the youngest in the South (41.6 years), compared to the oldest in the Northeast (47.7 years). West (2000) argues it is unlikely this is entirely due to genetic or health differences in women as regional differences are also found for many other types of surgery. More credible explanations include different approaches to medical education and styles of medical practice (Easterday, Grimes, & Riggs, 1983), and differing physician and patient preferences (Wallach & Eisenberg, 2003). These explanations are concerning, as they suggest that a woman living in the South may agree to a hysterectomy merely as a result of pressure from peers or family, or a lack of access to surgeons who are skilled in alternative techniques. These issues would benefit from further investigation.

Hysterectomy and SES. In a 1997 study, Marks and Shinberg reported that a woman's occupational status and net worth were significantly negatively correlated with her likelihood of having a hysterectomy. Thus, a well-educated woman with a good job increases her chances of keeping her body intact. The authors' explanations for this variation include differences in health insurance, the frequency of medical screening, the level of respect from (and for?) doctors, and a higher level of confidence displayed in women who are used to dealing with authority figures. These results support earlier findings by Carlson and colleagues (1994b) who

reported that education level is a strong predictor of a woman's choice of, and positive outcome from, non-surgical alternatives to hysterectomy.

It has further been reported that hysterectomy rates are much lower among female doctors and lawyer's wives than they are for other professional women (Domenighetti & Casabianca, 1997). It would seem plausible, therefore, that female doctors may see good reasons to keep their bodies intact, and that a hysterectomy may well leave one with problems that one's husband would consider worth litigation.

Hysterectomy and race. According to existing research, among women aged 35 to 44, about 30% of those who are White will experience surgical menopause (hysterectomy with oophorectomy), compared with around 50% of Black women (Barnard & Reame, 1996). Further disproportionate figures include higher rates of morbidity and mortality, a younger age at surgery, and higher incidence of abdominal hysterectomy (more invasive and higher risk than vaginal hysterectomy) for African American women (Groff et al., 2000). Kjerulff and colleagues (1996) point out that these higher rates are usually explained by the fact that Black women seem to develop more numerous, larger fibroids at an earlier age than can be seen in a comparable population of White women.

In the hysterectomy literature there is but a hint that racism may also be an explanation for these disproportionate statistics. In a qualitative study of medically underserved women in Texas, for example, a number of African American participants mention that they view hysterectomy as a form of genocide (Groff et al., 2000). Additionally, West (2000) points out that medical residents often practice their skills on patients who are unable to pay for health care, and there are more poor Black women than poor White women, particularly in certain parts of the U.S. such as the South.

Further evidence of possible racism in the culture of hysterectomy exists in the lay literature, where hysterectomy is referred to as a form of sterilization abuse for poor women of

color (Miller Stokes, 1986). Given the history of sterilization abuses in the U.S., this is a matter for concern. In the South, for example, there was a well-documented scandal known as ‘Mississippi appendectomies’, a surgery where women (poor, and often of color) were pressured or tricked into sterilization, commonly through hysterectomy (The Boston Women’s Health Book Collective, 1998). It has also been documented that in some states sterilization abuses persist as programs have been implemented to offer financial incentives to women on welfare to use Norplant, a surgically implanted contraceptive that can last for five years (Nechas & Foley, 1994).

The fact that African American women experience the highest rates of hysterectomy is a matter for further investigation. This need is particularly poignant when one considers the literature suggesting that hysterectomized women of color are highly likely to be stigmatized by the men in their community, labeled less of a woman and sexually unappealing (Behar, 1994; Bernhard & Harris, 1997; Richter et al., 2000; Williams & Clark, 2000). These views may contribute to a culture where poorer Black women can find themselves facing a social norm of health and relationship problems.

The Decision to Have a Hysterectomy: The Doctors’ Perspective

In 1994, the American College of Obstetricians and Gynecologists (ACOG) published criteria for hysterectomy for women with uterine fibroids, detailing a list of conditions that should be satisfied before proceeding to the option of surgically removing the uterus; the required considerations and actions include checking for malignancy in the cervix and endometrium, and consideration of the level of psychological risk for the woman. A subsequent government funded study (Broder et al., 2000) found, however, that in over 70% of hysterectomy cases the ACOG criteria had not been met; and further, 6% of the pathology reports post-hysterectomy found no evidence of the fibroids that surgery had been performed to treat (Goodwin, Broder, & Drum, 2003).

A concern expressed in some of the literature on hysterectomy, therefore, appears to be whether women receive all the facts and diagnostic checks necessary to help them make an informed treatment choice. The incentives that may lead some physicians to recommend hysterectomy as the treatment of choice are well documented in the literature, as are the arguments that may be used to sway a patients' decisions, and these are examined here.

It is necessary surgery. When considering their treatment options, Payer (1987) notes that women may be told hysterectomy is necessary if they want to get better. Payer argues that to the doctor the term 'necessary' denotes a way to correct an abnormality, whereas to the woman patient it infers urgency, and a sense that her life is in danger if she does not consent. Greer (2000) supports this observation by pointing out that if it were true that all hysterectomies were necessary, then there would be little variation in rates between countries that have a comparable quality of life and health care.

While some (e.g., Greenberg & Kazamel, 1995) argue that conservation of the uterus should be a primary aim, even a cursory reading of the medical research journals reveals a bias toward hysterectomy as a necessary and preferred surgery for a variety of problems.

Hysterectomy may indeed prove a satisfactory solution for many women, but it may be worth considering whether this bias in research is fuelled in part by methodological issues, such as poor outcome measures and definitions of psychological health (Plourde, 1998), or by patients being reluctant to report anything negative about their doctors (Schofield et al., 1991). Brody (1994) points out that many women are socially conditioned not to speak out against doctors, believing that any problems are either in their head or inconsequential. When a doctor tells a patient that a surgery is necessary it may, therefore, be helpful to define what this term means.

Hysterectomy will reduce your risk of cancer. According to Tavis (1992), many hysterectomies are recommended for pre-cancerous conditions, regardless of whether the organs are currently healthy or the woman's willingness to attend regular PAP screenings.

Payer (1988) argues that the term ‘pre-cancerous’ deserves close scrutiny, as fibroid tumors are invariably benign. Fibroids that appear to be growing quickly may also attract a label of ‘possibly cancerous.’ Dionne (2001) maintains that rapidly growing fibroids are part of “the urban legend from the gynecological underworld” (p. 36) that is used to scare women into accepting unnecessary hysterectomy.

In reality, the total incidence of sarcoma associated with fibroids is very low (0.23%) and the association of rapid fibroid growth with sarcoma has not been substantiated (Parker, Fu, & Berek, 1994; Scialli, 1998). According to CDC statistics (NCI, 2003), in 1991, the incidence of prostate cancer among men was 171.4 per thousand, while for uterine cancer the rate was 24.2 per thousand. Clearly there is a place for research that would compare the treatment options offered to men and women for benign conditions of the sexual and reproductive organs, particularly where the concern of possible cancer is raised as an argument in support of radical surgery.

A uterus or two a month pays the rent. In 1998, the average cost of an abdominal hysterectomy in the U.S. was \$12,500, with an average hospital stay of 3.10 days (Mushinski, 2000). With increasing health care costs it is clear that finances can play an important role in treatment decisions. In the extant literature there are claims that some doctors will recommend the level of surgery that fits their level of skill, even if there are other viable options for the patient. This is said to be a result of strong financial incentives not to invest in further training or to refer patients on (Cloutier-Steele, 2002; Dorsey, Steinberg & Holtz, 1995; Payer, 1987). Plourde (1998) asserts that hospitals and insurance companies may prefer hysterectomy to surgical interventions such as myomectomy as it takes up much less time in the operating room, thus further pressurizing the treatment choice. Additionally, doctors who have spoken out against unnecessary hysterectomies (e.g., Mendelsohn, 1982; West, 2000) cite numerous

examples of colleagues for whom hysterectomy is a fundamental means of covering practice costs.

“A few years ago I attended a seminar on medical economics. The topic was how to care for women in order to maximize our fees. The experts who led the discussion reminded us that gynecologists make the most money by doing surgery and that the highest fees we can generate come from hysterectomy. ...With proper planning, our advisors suggested, each year of practice would produce a lucrative ‘crop’ of women ripe for hysterectomy” (West, 2000, p. 35).

The Decision to Have a Hysterectomy: The Patient’s Perspective.

In a 1983 review of hysterectomy in the U.S. (Easterday, Grimes, & Riggs), the authors state that the “decision for hysterectomy is ultimately made by the woman” (p. 211). As previously mentioned, the current trend in the hysterectomy research appears to indicate that this surgery is generally viewed as a highly effective form of treatment for benign uterine conditions, leading to improvements such as a better quality of life (e.g., Carlson, Miller, & Fowler, 1994a; Davies & Doyle, 2002). The research discussed by surgeons seems to focus largely on ways to increase the speed and efficiency of organ removal while reducing costs, but Plourde (1998) points out that outside of the lay literature the woman patient’s voice is rarely heard; as a consequence her role in the decision process of whether it is preferable to have or to avoid a hysterectomy is not clear. West highlights this issue when he states that, “I understand why doctors want to perform hysterectomies better than I understand why women agree to them” (2000, p. 23).

“The submission of the body to medical control” (Dell & Papagiannidou, 1999, p. 397) is a complex process to understand. It has been suggested that women may tend to shy away from being fully involved in information gathering or decision-making, having been conditioned to trust their doctors’ judgment (Payer, 1987; Plourde, 2003). However, where a

woman does not fully understand the problem or alternatives, Dell and Papagiannidou (1999) have argued that the concept of informed consent is called into question. Schofield and colleagues (1991) assert that many women accept hysterectomy without question, and cite a case of a woman who was in hospital for scheduled bladder surgery. Her physician told her she might as well have her uterus removed during surgery as she did not need it anymore. “When asked how she felt about this, she said that she accepted it because the doctor should know what is best” (p. 1135).

According to the extant literature, a further reason why women may choose hysterectomy over alternative treatments is that removal of the uterus liberates the body from menstruation; a monthly event that has many negative connotations (Dell & Papagiannidou, 1999). In many cultures menstruation is a taboo subject (Rich, 1986). Stubbs and Costos (2004) believe that the negative attitudes of girls and women to menstruation may well reflect a ‘disconnect’ from their bodies, as periods become something you get, “like the flu” (p. 40). In countries such as the U.S., menstruation is generally marketed as an event that requires concealment, modesty and sanitized freshness (Roberts & Waters, 2004), thus reinforcing the sense of disgust around the whole topic. Indeed, oral contraceptives that reduce the menstrual cycle to only four annual events or less look set to become popular, and products are increasingly being sold based on their ability to free women from what Greer (2000) has termed the ‘tyranny of the female body’.

According to Greer (2000), women have come to view their bodies as mysterious and naturally defective; a consequence, she argues, of hundreds of years of assaults on the female body. This sense of ignorance and dislike may result in women believing hysterectomy is their only real option. As Greer explains it:

“More worrying than the gynecologists who despise the womb, and tell women that once they have completed their family size their wombs will give them

nothing but trouble and might as well come out, are the women who will not accept that their womb is not the cause of their woes and will seek high and low until they find a practitioner who will agree to spay them. If men flee the female, we will survive, but if women themselves treat femaleness as a disease we are lost indeed” (Greer, 2000, p. 47-48).

That many physicians will tend to view hysterectomy as a definitive and normal treatment for benign uterine conditions is not in doubt. What is less clear from the literature, however, is the process women go through when choosing their treatment, and their reasons for agreeing to have their uterus removed. There are other surgical and medical treatments available, and the one that is most comparable to hysterectomy in terms of cost, invasiveness and recovery time will now be discussed.

Myomectomy

The process whereby fibroids are surgically removed, leaving the uterus intact, is known as myomectomy (Scialli, 1998). This is not a new surgery, as Dr. Alexander of Liverpool, England first described it in the 1890s (Barlow, 1992). Dr. Victor Bonney later popularized myomectomy in the early 1900s, claiming to have removed up to 225 fibroids during one operation (Payer, 1987). By 1945, Bonney had performed over 800 myomectomies with a surprisingly low mortality rate for that period of history; he had also invented the Bonney clamp, which is still used to control bleeding during this surgery today (Barlow, 1992).

In the U.S. it is estimated that only about one myomectomy is performed for every ten hysterectomies, making it a much less common surgery for the treatment of uterine fibroids (Iverson et al., 1996). Myomectomy is usually performed by abdominal surgery, particularly where there are numerous or large fibroids, although some fibroids can be removed via laparoscopy or hysteroscopy (Lumsden, 2002). According to surgeons who are skilled in performing myomectomy, there is no such thing as a case that cannot be treated with this

surgery (West, 2000), and in countries such as France it is apparently considered normal and safe to offer a woman multiple myomectomies (Payer, 1987).

Where doctors do not offer myomectomy there are several reasons that are apparent in the literature. One that is often cited is the fear that bleeding may become uncontrolled during surgery (Mayfield, 1993). There are various surgical techniques, however, used to minimize blood loss and reduce the risk of transfusion, and these include the use of clamps, tourniquets and the injection of vasopressin into the uterus (Leach & Diamond, 1998). A further common critique of myomectomy in the literature is that a woman runs the risk of her fibroids recurring, with some claiming the risk is as high as 30% (Scialli, 1998). Conversely, there is evidence that in the hands of a skilled surgeon who is meticulous about discovering and removing all the fibroids (including the ‘seedlings’), the recurrence rate may actually be around 15% or less (Payer, 1987). Factors such as pregnancy or a woman being older are thought to reduce the risk of recurrence (Lancet, 1991), while issues such as dietary and lifestyle changes, or complementary medicines have yet to be thoroughly researched. West (2000) pulls no punches when he argues that, “most of the complications of myomectomy are due to sloppy surgical attitudes and the willingness to take the remote but real risk that cutting corners represents” (p. 112).

Further reasons why myomectomy is not more commonly performed may include the facts that few gynecology residents are offered thorough training in the surgical techniques, it is a more complex and time-consuming surgery than hysterectomy for about the same fee, and it is not a standard procedure where every surgery will be fairly routine (West, 2000).

Myomectomy or hysterectomy?

In a study to compare myomectomy and hysterectomy, Iverson and colleagues (1996) reported that myomectomy compared favorably, offering a decreased risk of infection and surgically induced complications. There is a further important difference, however, which has

yet to be satisfactorily explored, as myomectomy preserves the uterus while hysterectomy destroys it. The comparison of the full emotional, psychological and physical impact of these two surgeries therefore bears further investigation.

In most cases, myomectomy is only recommended for a woman who wishes to preserve her fertility (Iverson et al., 1996; Lumsden, 2002; Scialli, 1998). Some argue this attitude seems to hark back to beliefs that the uterus is little more than a baby carriage (Goodwin, Broder, & Drum, 2003). It is, however, a pervasive argument that once a woman passes a certain age or has had children, hysterectomy becomes the treatment of choice. It is interesting that while a surgical treatment that can preserve the uterus exists, it is often reserved for younger women, and the literature fails to document any particular awareness of the resulting discrimination against older women who might feel entitled to keep their bodies intact, regardless of their childbearing status.

A primary concern when women are considering their treatment options is whether they have sufficient information to be able to make an educated decision. Dionne (2001) highlights the concern thus:

“Medical decisions are most often based on the information that is presented to a patient – information presented by the physician. What woman would choose myomectomy when a physician describes it in a way that makes seem hysterectomy seem far superior. And what is a woman to do when her trusted gynecologist of many years ONLY [emphasis in original] recommends hysterectomy and discounts all other treatment options?” (p. 27).

While we live in an age of information it is unclear what kind of information doctors present to women, how many women take the time to find other resources, or which sources of information are the most helpful.

There are other treatments for uterine fibroids which women may demand if they can find a specialist, or if they have insurance or funding to cover it; these treatments include ablation, medical therapies, holistic methods and uterine arterial embolization, the latter being a technique developed by radiologists in France in the mid-1990s to shrink fibroids by reducing the blood supply to the uterus (Lipman, 2000). While such treatments show promise, it is uncertain how they will impact women's choices in the longer term, and there is a need for continuing research to demonstrate how they compare to more established treatments such as hysterectomy.

Summary

In summary, some claim there has long been a bias in health care against women and that with the spread of medicalization the natural female body has become increasingly subject to medical control. While great strides have been taken to improve women's health care in more recent decades, there is clearly further to go in our understanding of women's diseases and in the empowerment of women patients.

A common condition that affects a majority of women is uterine fibroids. For a significant proportion of these women the fibroids will become symptomatic, causing chronic health problems, and at this point they will likely require medical attention. Despite the existence of other surgical and medical treatments to remove or reduce the fibroids while sparing the uterus, hysterectomy is still the most common treatment of choice, and the U.S. has the highest rate of hysterectomy in the world. It is important to note that the severity and prevalence of uterine fibroids appear to differ by race. The issue of the effect of race on a woman patient's treatment experiences and choices, however, remains largely unexplored.

The current trend in medical research suggests that hysterectomy is generally viewed as an efficient and definitive approach to fibroids, but there is controversy over its frequency of use for benign conditions, and the resulting problems that women may face after their surgery.

There are numerous reasons why doctors would tend to elect hysterectomy as the preferred treatment over myomectomy, a major surgery to remove fibroids while sparing the uterus. What is not so clear, however, is the role women play in this decision making process. Outside of the lay literature, relatively little research has been done to bring women to voice on these issues.

It appears that policy attempts to curtail the rates of hysterectomy have largely failed, and what is lacking is greater awareness of the process of choosing a treatment, and the role women patients play in this process. If unnecessary hysterectomies are taking place, then it may be that the pressure for change will have to come from consumers.

The aim of this study, therefore, is to bring women to voice on their attitudes to, and experiences of, surgical treatment for the benign condition of uterine fibroids. The study will compare two groups of women who have experienced either hysterectomy or myomectomy, and the sample will include African American women so their perspectives can also begin to be explored.

CHAPTER 3
METHODOLOGY
Research Questions

In brief, the issue under exploration is the process women go through when they seek medical help for symptomatic fibroids. The purpose of this study is to examine women's attitudes to, and experiences of, the surgical treatment they chose in order to build understanding of women's role in this treatment process.

The research questions to be answered are as follows:

- 1) As participants describe their process of seeking and experiencing treatment, which common areas become evident?
- 2) What attitudes do participants have to treatment and their bodies, and did these attitudes influence treatment choices?
- 3) How do the participants' responses to the first two questions differ by treatment type?
- 4) Are there any perspectives that distinguish the experiences and attitudes of African American participants?

Epistemology

When feminism enters into science, the agenda is said to be far greater than a mere study of experiences according to gender (Morawski, 2001). In order to undertake such research it is necessary to be guided by a feminist epistemology (Harding, 1986). According to Crotty (1998), to have a women's way of knowing is problematic as it sets women apart from men and infers the two will never be able to find common ground. Crotty does concede,

however, that women can “theorise the act of knowing in a different way from that of men” (p. 174), as they are likely to have experiences, concerns and insights that men do not.

Feminist researchers such as Gilligan (1982) have argued that women and men clearly have very different lived experiences, and must therefore know the world in distinctly different ways. Further, in a feminist approach there is not just a woman’s way of knowing, but “there are women’s *ways* of knowing” (Reinharz, 1992, p. 4). Thus, there are many variations among women, and it is the individual as well as the collective that must be given voice.

If one has a feminist epistemology the ‘knower’ cannot be an invisible being who claims to have objective knowledge. In non-feminist research what is generally acknowledged as ‘truth’ is in fact the product of those with social power, and so they alone define what becomes our common knowledge. Feminist research seeks to alter this balance by allowing other voices to be heard, those voices that have otherwise been marginalized (Sherwin, 1998).

Frank (1995) claims that medical journals typically speak of the skill of the intervention, or the mass suffering of a group of people who are described by statistics, while the voices and experiences of these people are ignored. In this study of women and health care, emphasis is placed on the voices of the participants as they describe their lived experiences of treatment. These experiences may help to create a different knowledge, one that is defined by those who are usually silent.

This study is guided by a feminist epistemology. It recognizes that women invariably have less power in society than men, and that they are systematically oppressed by sexism that is inherent in all areas of society, from politics and economy to religion (Humm, 1995). This oppression is deeply embedded in society, and within the self. It is not, however, natural or beyond change.

The word ‘oppression’ may seem to some extreme when one speaks of women’s experiences, to others it may be a deterrent from looking too closely at the reality of many

women's lives. In attempting to understand its use in this study, it may be helpful to consider the following words of Marilyn Frye:

“The root of the word ‘oppression’ is the element ‘press.’ *The press of the crowd; pressed into military service; to press a pair of pants; printing press; press the button.* Presses are used to mold things or flatten them or reduce them in bulk, sometimes to reduce them by squeezing out the gases or liquids in them. Something pressed is something caught between or among forces and barriers which are so related to each other that jointly they restrain, restrict or prevent the thing's motion or mobility.”(Frye, 2001, p. 49).

When one reads this quotation, it is possible to visualize aspects of the history of women's health care described earlier in this study. That women have faced barriers to optimum health care is not in doubt. That biases in the medical system have contributed to women's oppression is an opinion that will depend on one's perspective and experiences.

As stated at the beginning of this section, when one brings feminism into science, the agenda is far greater than the mere study of experiences according to gender. A feminist stance demands more than just the observation of unjust situations, as it is a political act with an agenda that compels the observer toward the empowerment of women (Sherwin, 1998). This agenda will be used to guide all areas of this study.

Subjectivity Statement. The author of this study brings her own perspectives to the research process. She is a sex therapist and researcher specializing in issues that affect women's sexuality, and their sexual and reproductive health. She has also been a sufferer of symptomatic fibroids, and it was her personal experiences of health care that led to this study.

Participants

The participants in this study were women living in the U.S., between the ages of 21 and 60 who had either hysterectomy or myomectomy within the last two years for a primary

diagnosis of uterine fibroids. It was hoped to recruit up to forty women who were either Caucasian or African American, with a fairly even split between the two groups. In the event, twenty-eight women responded to advertisements for the study, and eighteen of these eventually participated. What was disappointing, however, was that only four of these women were African American, and the reasons for this will be considered later in this dissertation. Of those who did not participate, some simply did not respond once they received further study information, and several were rejected because they either did not fulfill the study criteria, or in an effort to keep the numbers fairly balanced between the two surgery groups.

Table 3.1 provides details of participants. In this study participants are identified by their treatment type (Hyst or Myo), race (Cauc or AfAm), the state in which they live, and their age.

Participants were primarily recruited through internet support groups that agreed to advertise the study. This method was intended to reach women across the U.S. who had a variety of experiences and doctors, rather than approaching just one treatment center where the experiences would have revolved around the same group of doctors. The information that was used to advertise the study is included in the appendices.

Two internet support groups helped in recruitment and these were Hyster-Home at www.ezboard.com, (over 500 members) and the Uterine Fibroids Research and Support Group (NUFF) at <http://groups.yahoo.com/group/uterinefibroids> (about 4,000 members). Both groups provide information and support to women before, during and after the treatment process. Many members may leave the groups after treatment, but a proportion remain active on the listserv in order to provide continuing help to others. Hyster-Home posted the advertisement for the study in their notice-board section, which meant it was accessible for a longer period of time, whereas the Uterine Fibroids Group allowed the advertisement to appear only as a member posting. Some of the women members of these groups will have had extremely

positive experiences of treatment, others will not. Both perspectives were apparent in the final sample for this study.

Participants in this study were paid for their time. Those who were recruited through Hyster-Home were paid \$10, and a \$10 donation was made to the group for every member who participated in the study (although the moderator of the group was not active in recruiting). Some of the participants requested that their \$10 payment be sent to Hyster-Home as a further donation. Participants who were recruited through the Uterine Fibroids Group received \$20 for their time, and no donation was made to the group.

Two of the participants in this study were recruited by word of mouth rather than through the internet; both were African American, and it may be that this less formal method would prove fruitful to help in recruiting a more racially diverse sample in future. Each of these women received the full \$20 payment.

The online support groups used in recruitment are not formal organizations or institutions and as such did not require their own Human Subjects approval. Approval for this study was given in October of 2005 by the Institutional Review Board of the University of Georgia, and the project number is: 2006-10046-0.

Procedures

According to Rheinharz (1992) there is no one feminist method as “feminists have used all the existing methods and have invented some new ones as well” (p. 4). What is common to all methods used by feminists, however, is that they “become channels and instruments of women’s historical mission to free themselves from bondage, from the limiting of human possibility through culturally imposed stereotypes, lifestyles, roles and relationships” (Crotty, 1998, p.182).

Table 3.1: Study Participants

Participant Identification	Occupation	Education Level	Marital Status	Children	Menopausal Status	Organs Retained
HystAfAmAL33	Student	Doctoral	Single	None	Pre	Ovaries Cervix
HystAfAmNC37	Paralegal	Bachelors	Single	None	Pre	Ovaries Cervix
HystAfAmSC47	Unemployed	Masters	Single	One	Uncertain	None
HystCaucCA49	Engineer	BSEE	Single	None	Surgical	None
HystCaucNC44	Military	High school	Married	Three	Pre	Ovaries
HystCaucNC48	Self-employed	Bachelors	Married	One	Surgical	Ovary(1)
HystCaucPA43	Account co-ordinator	Some college	Married	One	Pre	Ovaries
HystCaucPA49	Administration	Bachelors	Married	Two	Pre	Ovary(1) Cervix
HystCaucTX31	Sales support	Associates	Married	One	Pre	Ovaries
HystCaucTX43	Education administration	Bachelors	Divorced	One	Pre	Ovary(1)
MyoAfAmVA42	State employee	Masters	Cohabiting	None	Pre	All
MyoCaucCA37	Film industry	Masters	Single	None	Pre	All
MyoCaucCA48	Retired teacher	Teacher training	Married	None	Pre	All
MyoCaucCO41	Financial planning	Some college	Married	Two	Pre	All
MyoCaucIA34	Student	Doctoral	Single	None	Pre	All
MyoCaucLA40	Hair stylist	Technical degree	Married	Two	Pre	All
MyoCaucMA42	Technical writer	Masters	Married	Two	Pre	All
MyoCaucOK37	Administration	Some college	Divorced	None	Pre	All

As the primary aim of this study was to bring women to voice on their experiences and attitudes, a qualitative interview approach was used, an approach that tends to be favored by feminist researchers. A qualitative approach “involves listening to and theorizing about what

emerges when people use their own words to make sense of their lived experience” (Maracek, Fine, & Kidder, 2001).

The procedures of the study were as follows: Potential participants read about the study through their online support group (with the exception of the two participants who heard about it via word of mouth). If they were interested in participating they were invited to email the author of this study, who then mailed them a packet containing a letter explaining the study, two copies of the consent form, a contact sheet, a list of questions (these items are attached as appendices), and a stamped self-addressed envelope. The questions were mailed ahead of the interview so participants would have time to recall their experiences, and in order to build trust. It also gave potential participants an opportunity to make an informed decision about whether or not they wanted to participate.

Those women who were willing to take part in the study returned one signed consent form, with their contact sheet to indicate their phone number and times they were available to be contacted for interview. After exchanging emails to confirm the preferred interview time, the study author telephoned each participant for the main interview. Each interview was audio-taped with the participants’ permission, and special equipment was purchased to allow clear recordings to be made of the phone interviews. Interviews typically lasted for about one hour.

The questions were designed to be open-ended in order to elicit detailed narrative about each woman’s experiences and attitudes. Prompts were used to help the participants recall relevant information and they were told that they could feel free to go ‘off-track’ if they felt there was other information that was important to share. Each participant was asked the same questions in the same general order to ensure that a comparison could be made between their narratives.

After each interview the study author transcribed the recordings. These transcripts were all produced immediately after interviewing to ensure the information was accurately recalled.

The author chose to do her own transcription to build familiarity with the data. As the interviews were being transcribed, the study author also made notes to record her impressions and possible themes arising from each interview, and these notes were helpful in the later analysis.

Once a transcript was completed it was sent to a participant as an email attachment. Participants were requested to check the transcript for accuracy, and to add or delete information as they felt appropriate. This helped to ensure that participants were active members in the research process. Each participant then emailed the study author to confirm that she was satisfied with the transcript, and to note any changes that should be made. Several of the participants used the track changes facility in Microsoft Word to alter their transcripts, and the study author saved these revised versions over the original files. Once this process was completed participants were sent a check with a thank-you letter.

The participants were in general extremely enthusiastic about their support for fibroids research, and all will receive a brief report of the results from this study, which will be sent via email. This will help to maintain their sense of partnership in the whole process.

A financial award was obtained from the University of Georgia Graduate School, which helped to defray research costs. These costs included the recording and transcribing equipment, audio-tapes, phone calls, postage and participant payments.

Reliability and Validity

According to Kvale (1996), “In modern social science the concepts of generalizability, reliability, and validity have reached the status of a scientific holy trinity. They appear to belong to some abstract realm in a sanctuary of science far removed from the interactions of the everyday world, and to be worshipped with respect by all true believers in science” (p. 229).

For some qualitative researchers, the very terms ‘reliability’ and ‘validity’ are an anathema, as they are associated with an approach to science that embraces such ideas as there being true objectivity and only one external reality (Trochim, 2001). By contrast, qualitative research relies on strong impressions, induction, self-reflection, and further, it acknowledges that bias is inherent in all observations, be they qualitative or quantitative (Maracek, Fine, & Kidder, 2001).

According to Silverman (2000), however, if a researcher cannot show that the methods used were reliable and led to valid conclusions, then there is little point in undertaking the research in the first place. Using Silverman’s definitions, this study interprets validity as referring to whether or not the results accurately represent the phenomena under consideration, while reliability refers to the level of consistency in the observations and coding.

In the first instance, validity is ensured in several ways. These include the use of member checks, where participants read their own transcripts and confirm or disconfirm their words. Secondly, tabulations or counting of instances are used to give the reader a “flavor of the data as a whole” (Silverman, 2000, p. 185), and a sense of how common a given theme is across participants. Finally, the constant comparative method is used. This involves the close inspection of all areas of the data so that emerging categories can be compared across cases to ensure they are a good description of the group as a whole.

In the second instance, reliability, it is necessary to document all procedures, and to ensure that another observer can confirm the assignment of themes. In her qualitative study of young girls’ sexuality, Tolman (2002) observed that reaching agreement on every choice of words was “neither feasible nor sensible” (p. 212). Instead, she proposed that an interpretation was reliable if a second reader could follow and confirm it. For this current study, therefore, a second person was asked to read a random sample of transcripts to confirm that the coding for

those sections is credible. This person was a male professor with extensive experience in qualitative research.

Ethics

In qualitative research, particular ethical dilemmas are raised as the researcher may often be allowed access to very intimate details of a participant's life (Silverman, 2000). In such cases, the researcher should strive to be overt about how the data will be used and protected. For the purposes of this study, participants gave informed consent to the recording of interviews, and they had the opportunity to read through the resulting transcripts to ensure they were an accurate portrayal of what was said. The recordings will not be used in any way that has not been agreed to, and they will be erased once the study is completed. At no time will identifying information about participants be revealed.

In her previous qualitative interview studies with women, the study author has observed that participants appear to find the telling of their life experiences to be a positive experience. Kvale (1996) notes that careful listening by the interviewer can make the process a unique experience that benefits both participants and interviewer alike. In an effort to adhere to the ethical principle of beneficence, the study author is a highly experienced therapist, and as such she was able to build trust with participants, and to display sensitivity during the interviews. If, on reflection, participants felt they regretted revealing some information, they were allowed to delete the relevant words from their transcripts. In actuality, no participants chose to do this.

Analysis

In qualitative research analysis, one's task is to "search through transcripts or field notes for the glimmer of a pattern" (Maracek, Fine, & Kidder, 2001, p. 35). This process is by its nature highly inductive (Silverman, 2000) as it involves meaning-making and the identification of themes. However, as Constanas (1992) has pointed out, the themes or categories do not emerge from the data, but rather they reflect the choices of the researcher. In order to

make this process more transparent, Constat suggests that researchers produce tables to document the process of developing themes. To this end, table 3.2 below details where the themes in this study originated and how they were named (from topics the participants raised, from existing research and conclusions in the literature, or from the views and experiences of the researcher). In addition, the point during the research process where these themes arose is detailed, and this is either before or after data collection, or as part of a tentative process of development throughout the research (iterative). In the final list of themes on page 48, it can be seen that the participants' experiences follow a timeline of before, during and after treatment. This is a system the author of this study has used before, and it follows the order of the questions used to elicit narrative from the participants.

One of the primary issues with larger qualitative studies is the management of data. Even with just a few transcripts it can be overwhelming to try and identify patterns while keeping track of relevant quotations from participants' narratives. To this end, N6 software (QSR) was used to assist in the management of the data. N6 enables the researcher to be immersed in the data, while keeping track of all interpretations as they are made. These interpretations can then be organized and coded into themes with relative ease.

Through the process of transcribing the tapes, the study author was able to build a strong familiarity with the data. Additionally, she took notes as she transcribed, so that her strong impressions of each interview were additionally used to help identify key themes. During the coding of each interview, use of the constant comparative method meant that emerging themes would generate continued re-reading and coding of previously coded transcripts. This allowed a comparison to be made across transcripts so that cases could be described as a whole. As previously described, a second reader was requested to read a random sample of transcripts to ensure that coding was credible.

Table 3.2: Development of themes

Component of categorization	Temporal Designation		
	A priori	A posteriori	Iterative
Origination (where authority for creating category resides)			
- participants			10, 11, 12, 14
- investigative	2	5	3, 9,
- literature	1, 6, 7, 8, 13	4	
Nomination (source of the name to describe category)			
- participants			13
- investigative		3, 4, 5, 10, 11	2, 7, 9, 12, 14
- literature	1, 8	6	

Category label key (themes):

1. symptoms	8. sex and sexuality
2. insurance	9. information
3. choices	10. attitude to body
4. experience of doctor	11. influence of family and friends
5. experience of hospital	12. attitude to doctors
6. benefits and complications	13. growing back
7. self-image	14. recommendations

CHAPTER 4

RESULTS

The following themes are drawn from the transcripts of eighteen interviews, ten of these were with women who went through a hysterectomy, and the remaining eight participants had a myomectomy. Quotes from the transcripts are used illustrate the final themes and bring richness to this section. The participants are identified by a code that denotes their type of surgery, their race, the state they live in and their age.

Table 4.1: Final themes identified from interviews

Experiences	Attitudes
Before treatment:	Information
Symptoms	Attitude to body
Insurance	Influence of family and friends
Choices	Attitude to doctors
During treatment:	Growing back
Experience of doctor	Recommendations
Experience of hospital	
After treatment:	
Benefits and complications	
Self-image	
Sex and sexuality	

Experiences

Before Treatment: Symptoms

The symptoms that participants experienced associated with their uterine fibroids varied. However, it was clear that in terms of bleeding, the group of women that eventually chose hysterectomy seemed to experience much more profound symptoms. Eight of the women in the hysterectomy group talked about this level of bleeding, compared with only three in the myomectomy group. The following quotes describe the level of problems women in the hysterectomy group experienced with bleeding:

“I had friends at my job and I remember sitting in one of my friend's chairs and I got up and there was blood on the chair, and she fussed at me about it. I couldn't help it. I remember going to church and getting up and blood was there and I felt ... I mean...I don't even know what to say. That made me not even want to come out in public. I felt that if I bleed, if this happens, then nobody is going to understand, and then I thought people were going to talk about me”
[HystAfAmAL33].

“Actually in February, even before I had got time to see the doctor, I went on a cruise, and I was panicking because I found I had to wear both a tampon and a pad, and even that wasn't necessarily sufficient on the heavy days. I had both of those on and we got on a bus, and we were just out for an hour, and by the time we got to our first stop I had to change the tampon and the pad was already getting stained. So yes, I didn't feel like I could go out for long periods of time without knowing where the nearest bathroom was going to be” [HystCaucCA49].

“I was on a helicopter and I had two tampons, two pads and bled through, and how embarrassing to get off the helicopter. You know, you are in the middle of a foreign country in a war zone and I am getting off saying could somebody take me to the hospital here, because I knew I needed some help controlling the bleeding. At that point they gave me quarters, and told me not to do anything vigorous, so I had to stay in my little room” [HystCaucNC44].

“My son was actually with me when I was doing a show in someone's house and I began hemorrhaging on their white carpet, so he had to pick me up, wrap me up in a blanket and get me home. You know, come home, get a me a change of clothes. He saw the embarrassment and suffering himself. So it is hard to live with two men and go through this, but what choice did I have?” [HystCaucNC48].

Clearly the level of bleeding was causing other problems, and the women described their shame and embarrassment, the limits they faced in trying to work or take part in other activities, and the isolation they sometimes chose during the times when the bleeding was at its heaviest:

“ ... so, it just became where I was more in pain, and my periods were longer, and they were already long enough. I mean I was on 3 or 4 pads at a time, the overnights, and I was still having an issue with leakage. I couldn't go out of the house sometimes for the first two days, well I can't miss work every month like that. It was just very, very, very bad” [HystCaucPA43].

“ There were trips that I wouldn't go on. My son is training to go Olympian, and there are many high level tournaments that he competes at, and there were times that I couldn't go because ... mommy was having a bad period (laughs). And he

would look at me like, well there are other mothers sitting out there bleeding too, why can't you go? How do I sit there and say well I am having big clots and I don't want to sit there and have to run to the ladies' room every 20 minutes?"
[HystCaucPA49].

"I didn't know anybody and I was afraid to meet people because at any point everything could come down. I wanted to come to class and go home. It was not being anti-social, it was because I did not know what was going to happen with my body. To get up from my chair and not see bloodstains was a successful day. To be able to walk and not stain my clothes, that was a successful day. From 2001 to 2003, I didn't make friends very easily, it was an isolating process"
[HystAfAmAL33].

In contrast, while three of the women in the myomectomy group talked about problems with bleeding, these descriptions were fairly brief. Symptoms such as pain, swelling, bowel and bladder problems, and a feeling of pressure or fullness were more frequently mentioned, and these were discussed by seven of the eight women in the myomectomy group:

[Interviewer] *"Okay. So, tell me about the pain and pressure, did you get it in your back, your abdomen?"*

"Oh yeah, terrible ... it was primarily on my left side. And it would bring you to your knees, that's all I can tell you (laughs). Oh, it was terrible"
[HystAfAmSC47].

"Well, it got to where it started to affect my quality of life. It was sitting on my spine, and I have a lot of back problems, and it was leaning on my bowel. So it just made my IBS worse, and it just gave me a lot of pain, I had kidney stones, and

a lot of weight-gain. Even though I don't see it all come off right now, it wasn't weight, it was the size of the fibroids, so it was pressing against everything”
[HystCaucPA43].

“They were huge, and I had one that was attached to my bladder, and it had actually established a blood supply to my bladder. Now that one did cause me symptoms that I should have noticed and didn't, like when I went to the bathroom sometimes it would feel like someone was sticking me with a knife”
[MyoCaucLA40].

“Okay, I had fullness, and pressure on the abdomen, I had bladder issues where I would frequently urinate like five or six times during the night, shooting pains in the legs, like shooting from my back down my leg, back pain ... and that is really about it. I didn't notice my periods being heavier” *[MyoCaucOK37].*

The primary differences between the symptoms of the two groups of women appeared to be whether they experienced a level of bleeding that was sufficient to reduce their quality of life, or whether they suffered with other symptoms. Those that eventually chose hysterectomy primarily talked about a level of bleeding that was at times incapacitating.

Before Treatment: Insurance

This theme refers to the level of insurance the participants had, and whether this affected their ability to make choices about treatment. In both groups of women (hysterectomy and myomectomy) there were reports of problems related to insurance, however, there were some slight differences observed between the groups. In the hysterectomy group, one woman reported that her insurance was very good, two said they went out of pocket to cover some

medical costs, and three women believed they had either been treated differently or their choices had been limited by their insurance:

[Interviewer] “And your health insurance at the time you had your surgery, did you feel like you had good health insurance?”

[Participant] “Good? No. I only had the state funding like Medicaid and Medicare.”

[Interviewer] “Okay, so that's government health insurance?”

[Participant] “Right.”

[Interviewer] “And was that good enough to help you make choices?”

[Participant] “Yeah, but sometimes I feel as though you get treated differently. They don't come out and say that” [HystAfAmSC47].

[Interviewer] “So your insurance didn't allow you to make a full choice then, because you also had to dismiss the laser treatment?”

[Participant] “Right, well that would have been too new so they wouldn't have approved that yet. I hadn't found anyone else that did the myomectomies apart from Dr [Dr's name], but my hairdresser had been to him and she raved about him for that.”

[Interviewer] “Actually his name rings a bell as being a myo specialist.”

[Participant] “Yeah, he is supposed to be quite good, but again, I am just really wary about getting out of the insurance realm” [HystCaucCA49].

For the third participant, problems with her insurance meant that she had to consult multiple doctors over a period of time; this lack of continuity of care may have impacted the choices that were ultimately available to her:

“ Probably I have seen about 5 different doctors, just because of changing insurance, with each job comes a new insurance company, with different

providers, so yeah I would say I have gone to 5 different gynecologists”

[HystCaucNC44].

In the myomectomy group, common themes were that three of the women said their insurance was particularly good, while all of the eight women felt their choices were not hindered by their insurance. In order to have a range of treatment options though, three said they had gone out of pocket fairly significantly so the doctors of their choice could treat them. The amounts they paid varied from about \$1,500 to around \$6,000:

[Interviewer] And the health insurance that you had at the time of your treatment, did you feel it was sufficient to help you make choices?”

[Participant] “No, it wasn't, but the thing is the fibroid specialists, the people that you really want to go to for your surgery, none of them accept ... well there were three that were really good that I was considering, two were here in California and they do not accept any insurance because they feel like the insurance company payment plan is based in the 1980s, and it is not up to date and they couldn't afford to keep up their practice” [MyoCaucCA48].

It may be that in order to have the less mainstream surgery of myomectomy, some women may have to be able to afford to pay out of pocket. In the event, two of the participants in this latter group incurred debt to have the treatment they wanted.

Before Treatment: Choices

In addition to any problems that may have been encountered with medical insurance, the theme of choice was one that emerged from the interviews. This theme was particularly notable in the hysterectomy group where six of the ten women said they did not feel they had a full choice in their type of treatment. For one participant this was the result of a diagnosis of uterine cancer, while a second woman believed she was in danger of cancer, but her diagnosis was less certain:

“And then, erm, surgery [subtotal hysterectomy] went well, but then it was June, I think around the 7th or 8th, that I went back into see my doctor for a follow-up, and she had gotten the pathology report, and they had found Stage Ib endometrial adeno-carcenoma. So then things took a different turn and I went in to a gynecologic oncologist, and ended up having a second surgery on June 30th, which was the total hysterectomy and bilateral oophorectomy” [HystCaucCA49].

“Well, she talked about the hysterectomy, but also I had a bad PAP that came back with abnormal cells. That's why she came in with the hysterectomy part. She said normally she would not have done it, but because of the bad PAP and once she got inside ... she said once she got inside and could see what was going on, because she already saw the bad PAP before she went in, she said she was probably going to have to do a hysterectomy. So I had already signed for it before they put me under” [HystAfAmSC47].

Three further participants in this group said they were given no choice of treatment by their doctors as they were told their fibroids were too big for there to be any option other than hysterectomy:

“ And I went for my exam, and he was like 'you know, this is a problem now, because I can feel it by your belly button, and your uterus is now enlarged to between a 5 and 6 month pregnant woman'. Instead of being somebody who was 3 to 4 months pregnant, so right away he sent me for the ultrasound, and then when it came back and I went in to talk to him, and he was like 'well now the fibroid is too big to do an embolization or a myomectomy, so the only course of action is a hysterectomy'" [HystCaucPA43].

“Yeah, she said hysterectomy was the only way to go to get rid of that fibroid, because it just demolished my uterus” [HystCaucTX31].

“And then the fibroid wouldn't have been so big, and then I would have had more choices. But as it was I was told 'too big, no choices'" [HystCaucTX43].

For the sixth woman in the hysterectomy group who had limited choices about her type of treatment the story was particularly tragic. This woman was only in her early thirties and had trusted a doctor to do a myomectomy. The doctor had stopped practicing medicine soon after he had treated her, and this participant was uncertain what kind of surgery he had undertaken on her, or even if the fibroids had actually been removed, but the consequences were catastrophic as she subsequently had to be taken to hospital for emergency surgery. When she came out of surgery she discovered she had been given a hysterectomy:

“... and I was by myself, and I went to the bathroom and something was ... it was like this big thing coming out! And I didn't know what to think, and you probably think I am crazy but I was like, well I know I am not pregnant! Because something was just coming out and I didn't know what it was.”

[Interviewer] “Literally you could see it?”

[Participant] “I could feel it, I mean it was flesh like, so I said oh my God, I know I am not pregnant, so what is this coming out?”

[Interviewer] “And you were bleeding with this?”

[Participant] “Yes! A lot of blood, all over the place. And I couldn't hardly walk so I had to crawl to the door to unlock it, and I didn't leave the door open so when the ambulance came I didn't know they couldn't hear through my door, so I am laid out on the floor bleeding, and they can't hear me saying come in, so I am still having to crawl back over there” [HystAfAmAL33].

In the myomectomy group there was only one woman who said she had not been given a choice about her need for surgery. As she still wanted the option of children available to her, her doctor advised her that myomectomy was the treatment of choice, following a course of medical treatment to first try and shrink the fibroids:

“ I actually started hemorrhaging one morning, and had to be taken to the ER and they kept me there for 24 hours, elevated, trying to stop the bleeding. My ob/gyn was called in and they did the MRI while I was in the Emergency Room, and they got the bleeding stopped that day, put me on bed rest for about a month, and started treating me with Lupron and things like that, and it was four months later when I had the surgery” [MyoCaucLA40].

In this particular case, it was interesting to note that the participant was still ambivalent about having had a myomectomy rather than a hysterectomy. If it was not for the fact that she wanted to keep trying for a child, she was sure that she would have demanded a hysterectomy.

During Treatment: Experience of Doctor

This theme refers to the ways in which the participants talked about the doctors who performed their surgeries. In general, most of the women seemed to display positive feelings toward their doctors, but this was more apparent in the myomectomy group, all eight of whom held their surgeon in high regard. They particularly commented on characteristics of a doctor they deemed important, such as being respectful, easy to talk to, listening, taking time, being gentle, thorough or a perfectionist. Six of the ten women in the hysterectomy group used similar phrases to describe their doctors, but four spoke about less positive experiences; one woman whose experience was previously described, found that her doctor had not performed her first surgery correctly, and others talked about their doctor being rushed, humiliating, intimidating or abrupt:

“ But I asked a lot of questions and I think the more questions you ask ... some doctors don't like to be questioned. As long as you come in there and don't say anything, or don't come in there and act like you have been on the internet, because they don't like you to go on the internet for some reason (laughs), I don't know what it is. It is like you are challenging their authority with that internet thing” [HystAfAmSC47].

“So he was very, very ... he really surprised me, he cut me off, like I had this whole list of questions and he said 'oh you don't need to ask those questions because you don't have any choices'. And I said what? And he said 'you have no choices, the fibroids are so big, and your anemia is so bad, and your bleeding and your clotting is so bad, and you have to have a full abdominal hysterectomy, the cut will be a long the bikini line, but it will be a very long cut because your uterus is 17 centimeters, and your uterus is so big I can't get it out any other way, and it is going to be a difficult surgery, it is so big, blah blah blah'. He just kept saying it like that. I remember my mother was just staring at him with her mouth open (laughs), like just stunned.

“ So the doctor brings the assistant to meet me, the anesthesiologist, and he was like standing in the walkway, not even by my bed, like five feet away and says 'so, why haven't you signed the consent?' And I said well, I realized we had never talked about keeping an ovary, and I have had this very strong feeling all morning that I never even thought of all these weeks, about keeping one ovary. I said is that possible? And he said (raises voice) 'I don't care! It is up to you, these are your ovaries', he started yelling at me and I started sobbing, and of course everyone is still looking at me, and I felt like a little girl being yelled at by some

mean coach or something (laughs). It was horrible, and the nurse wouldn't look at me, and my mom was embarrassed, and I remember thinking I don't want him cutting on me, he is in a bad mood" [HystCaucTX43].

It is encouraging to see that so many of the participants were pleased with their doctors. At the same time, however, a few of the women had experiences that were concerning. While a number of those with good outcomes had also had previous experiences with doctors that were highly negative, they had felt empowered to move on and find different specialists. This will be detailed later in the results section, under the theme of Attitude to Doctors.

During Treatment: Experience of Hospital

During the coding of the interviews it was observed that there were qualitative and quantitative differences in the way the participants talked about their treatment experiences in hospital, according the type of treatment they received. The myomectomy group, for example, had briefer narratives where they perhaps talked about some nervousness before surgery, but there was much less discussion about pain or complications, even where the surgery was particularly long or complex. This group tended instead to use words to describe their surgery such as: outstanding, excellent, amazing job, blown away, smooth and wonderful:

"The hospital was excellent, the nurses I had were excellent. There were some that were lazy, because I was in the hospital for three days so I got to know the staff, but all of that was outstanding. And after six weeks, after the surgery you have a follow-up with your surgeon, and so I had my follow-up and I felt like I was doing well, and he felt like I was doing well, and he was satisfied and he released me, after six weeks. So I was done and free to go on and live my life. And he said just do whatever I want to do, so he was pleased with my recovery"
[MyoCaucCA48].

The hysterectomy group was distinguished by its noticeably longer and more detailed narratives when describing the hospital experience. Additionally, while most of the women in this group said their experience was positive overall, they also used words and phrases that did not appear in the myomectomy group, and these included more detailed descriptions of pain, post-operative problems and a higher level of fear prior to surgery:

“ My night nurse, we had a few issues, and I have subsequently taken care of that because she had no business being a night-nurse, in a ward where women have just lost their organs. And you know, I had a little problem with her. I had run a fever, 101.5, in a 47 year old female that just had surgery, that is diabetic ... it's serious. And they let me go home that same day. I know that is shocking, but at 4 in the morning I ran that fever and at 12 o'clock they released me from the hospital. So that is scary. You know, in a way they did me a favor because I got to come home and rest, and I was right outside the nurses' station, you know the noise was incredibly loud through the night. The surgical care, I felt it was excellent. The anesthesiologist was excellent, and the pre-op - very good”
[HystCaucNC48].

The reasons why the two groups of women would tend to tell a different kind of story about their hospital experiences are unknown and can only be speculated upon. According to this sample, however, the way treatment was recalled tended to differ according to whether or not organs had been removed.

After Treatment: Benefits and Complications

All of the participants were asked about any possible benefits and complications that had resulted from their surgery. As with some previous themes there were differences between those women who had hysterectomy and those who had myomectomy.

In the hysterectomy group, nine of the ten women talked about the benefits of their surgery. For one of these the most positive factor was that her endometrial cancer had been detected early, thus affording her an excellent prognosis. For the remaining eight participants the primary benefit of surgery was overwhelmingly the chance to be free from bleeding and periods. It should be remembered, however, that these women had experienced debilitating levels of bleeding prior to surgery:

“ I have always hated periods. So that was the best thing, even though I know it's a natural process I always thought it was just nasty and I hated it”
[HystAfAmAL33].

“Well the most positive is that I don't have the heavy bleeding anymore (laughs). And not having a period, period, is magnificent. I mean I had no idea this is what your life could be like” [HystCaucNC48].

“ And I love, I love not having a cycle. I should have done it years ago, which of course a lot of my friends that have gone through it have said the same thing, which is true” [HystCaucPA43].

In the myomectomy group, three participants mentioned that being without fibroids was a benefit, and four talked about the relief from pain, swelling and bladder problems. While in the hysterectomy group freedom from periods was a primary benefit, in this group the women still had periods, but three talked about how their periods were now light and easy to live with:

“ ... the good part is that they are out, I wanted them out. I did not want to wait until they deteriorated over a period of time, I did not want to change my underwear and see a clump of the fibroids fall in the toilet, I didn't want to do all

that. I wanted them gone, and that was the best thing is that they were gone”
[MyoAfAmVA42].

“ And the most positive thing is that I am fibroid free. I don't have pain with intercourse, I don't have heavy bleeding, my periods are so normal. Let's see, what else, oh I can do sit-ups without it hurting. More freedom”
[MyoCaucCA48].

One woman in the myomectomy group had an uncommon, but nevertheless interesting, benefit that she identified from the process of having been through treatment:

“It made me feel stronger for fighting the system (laughs). You know, just doing what was best for me and my body. And that is the positive part”
[MyoCaucCO41].

When it came to complications from surgery, the myomectomy group was associated with fewer problems. One woman talked about temporary abdominal swelling, and another was frustrated that her periods and cramping had not improved as much as she had hoped:

“Of course you know since then there have been times where I thought oh, I wish he would have just taken it all out (laughs). Because it really doesn't get rid of the pain every month. You have pretty bad cramps after you have a myomectomy, still every month my cramps are really bad, some months worse than other months. But every month I say I wish he would have taken it all out” [MyoCaucLA40].

In the group of participants that had hysterectomy there were more reported problems and complications following surgery; for two women these included hormone related issues such as fatigue, mood swings, night sweats and sexual problems; one had had her ovaries removed, and the other had retained one ovary but it had apparently ceased functioning immediately after surgery. In addition, two women said they had temporary problems with

their bladder, and other identified problems included post-operative pain and bruising, a blood transfusion, scar tissue or keloids, and difficulties with staples being used to close the incision:

“It has been very good except for, like I said, those first few weeks. Now it is much much better than it was. But when I had to go back for the staples, about a week after I got out of the hospital, one of those staples was growing into the flesh or something, I don't know what it was, but they had to call in ... she wasn't there to take the staples out, she said a nurse or someone would be taking the staples out. But she couldn't get them out, so she had to call in some other man, whatever. And he had to ... I mean, look, he had to nearly pry them out because the flesh had grown up around it” [HystAfAmSC47].

“ So that is something I have been struggling with, and actually we just only recently got it to where it is a normal level. But I had the estrogen patch, it is what I was given the day after surgery, so I have had that on. But then, when was it? It was mid-July, so surgery was June 30th, erm, mid -July, no it was later, it was the first week in August that I complained about fatigue, and fatigue is a big issue. And so, I saw my gynecologist and she said 'you are not getting enough estrogen at this point', so she gave me four samples of different strength, what's that stuff called, starts with a 'c'? See, another thing is you start having these senior moments (laughs)” [HystCaucCA49].

“ For a little while I felt I was having problems with leakage ... sometimes it felt like I was leaking. And I went to see the doctor about that, and they said my bladder wasn't in the normal position, and just to give it a little bit of time and see what happened, and it seems to have eased up considerably, so it doesn't seem to

be a problem anymore. But that was probably ... you know, for six months I was kind of concerned about why it was doing this” [HystCaucNC44].

“And it is really more on one side, and that is the one problem I have had is I have had a lot of pain on the left side, and that's where I didn't have an ovary. I woke up with a lot of pain on the left side and there was a huge bruise on that side, and that is where I am continuing to have pain, so I don't know what is going on there, if it is just a lot of bruising from blood collecting or what” [HystCaucPA49].

The primary difference between the two groups under this theme was that while most of the women experienced benefits from their surgery, the hysterectomy group had greater levels of morbidity. Such was the severity of symptoms before surgery that the benefits may well have outweighed the problems for some women. However, one participant described the situation thus:

[Interviewer] “So how would you describe your level of satisfaction overall? On a scale of 1-10, like a patient satisfaction questionnaire.”

[Participant] “Erm, probably a 6.”

[Interviewer] “Even though you got rid of that horrendous bleeding?”

[Participant] “Yeah, the trade-offs you know? You just trade one thing for another” [HystCaucNC48].

After Treatment: Self-Image

This theme arose as some of the participants talked about how they felt about themselves since surgery, and how this had been impacted by the emotional experience of what they had been through. Two women (one in the myomectomy group, one in the hysterectomy

group) found a benefit as they had previously been very body-shy, but going through the process of treatment had changed this:

“... I have always been somewhat body shy, but having all these strange people walk in and flip up my covers and have a look at my crotch in the hospital (laughs) ... really got rid of my body shyness” [MyoCaucIA34].

Conversely, some of the women in each group talked about how the surgery experience had left them with a negative self-image:

[Participant] “Yeah, they stapled it. My gynecologist told me it looked like I had a zipper (laugh), so they can open it up and go in again, it will make it a lot easier.”

[Interviewer] “So the scarring has changed how you feel about yourself?”

[Participant] “Yes, yes” [HystCaucCA49].

“Erm, the scar, the scar tissue, I look like a train wreck on my stomach, you know I have always had a flat nice stomach. They had to make the incision from my navel down to my pubic bone” [HystCaucTX31].

“Erm ... the way I feel about my body ... I think I am self-conscious because of the way my scar is so big. I know that I am very self-conscious about that. So if you are meaning the way I feel I look, you know, I don't have any self-confidence in that because my scar is so bad. And my stomach really didn't go down that much as far as ... (sighs), I don't know, I guess I thought I would have a flat stomach but it didn't turn out like that. So as far as self-confidence goes, no I really don't have any as far as the way my stomach looks” [MyoCaucLA40].

In total, three women in the hysterectomy group and two in the myomectomy group talked about how the incision on their abdomen had had a negative impact on their self-image. A more common theme that occurred only in the hysterectomy group was the experience of grief and loss, which seemed to stem from changed feelings about being a woman, as well as the sense of finality that came with the surgery:

“Well, even though for me I don't mind it being final, I just ... want to find out because ... let it be final how I want it to be final. You know it's like don't let it be final because some doctor in some hospital who really doesn't know me as a person says it's final” [HystAfAmSC47].

“I guess just the fact of having a hysterectomy and knowing it is such a permanent thing, you can't change it, you can't reverse it, and knowing what is done is done, and I can't look forward to trying to get pregnant again, or having another baby, that is what is really hard on me” [HystCaucTX31].

“But sometimes I think about that I really do want to have children, and then I don't feel like a complete person. When I think about what I really want for my life I don't feel complete, there is just something missing because of this, and it causes me some distress at times because I know that you can't go back and change things, there is nothing you can do about it. It is over” [HystAfAmAL33].

“My body - I feel like, I don't know ... a deep-seated feeling that something is missing. You know, deep in my psyche I feel like something is missing” [HystCaucNC48].

“... and all of a sudden I realized ... especially when I was having my last period before the surgery, and I got very emotional about that. I said I am sitting here having what is probably my last period and for some odd reason I am very sad about that” [HystCaucPA49].

“Yeah, mentally wise because, you know, I only have one baby and now that's all I have, and I would have loved to have been able to have another baby, to have two kids, and I am still dealing with that” [HystCaucTX31].

In total, six of the women in the hysterectomy talked about feelings of finality, grief and loss and how these feelings affected their experience of themselves as women. In this area the online support groups and close family members had been invaluable for some of the women.

After Treatment: Sex and Sexuality:

This theme arose from the literature and reflects the uncertainty about the effects of uterine surgery on a woman's sexuality. In the myomectomy group the women did not talk about sex to a great extent during their interviews, which is probably due to the fact that myomectomy is not usually thought to affect sexual sensation. Where the subject was touched on, one woman said sex had improved since the pain from her fibroids was gone, and four cited the possible sexual side effects as a reason to be cautious of hysterectomy:

[Participant] “Because one of my doctors said that if I had a hysterectomy the sex that I have will not get any better (laughs), and it may even diminish. He said my sexual response or whatever, once you have a hysterectomy you are not going to have better sex. I mean you won't have painful sex, like if you are having painful intercourse because of your fibroids, but your sexual life is not going to be better. He was pretty straight.”

[Interviewer] “And did that have an effect on you?”

[Participant] “Did it? Well I was already under the belief that nobody was taking my organs, I would die with my fibroids” [MyoCaucCA48].

In the hysterectomy group, the picture was slightly different. Six women mentioned that information on this topic from their doctors had been either lacking, or reactions were insensitive:

“ The only thing he did was say to go and have sex. He didn't say this may result from it, or this might be different. The only way I learned there may be a difference was from other people who had hysterectomies, not from a doctor.”

[Interviewer] “Were you with a partner at that point?”

[Participant] “No.”

[Interviewer] “I am wondering where he thought you were going to have sex then?”

[Participant] “(laughs). That's why I think it was crazy. I wasn't with a partner throughout the whole process, because I felt nasty, I mean I really literally felt nasty so I wasn't with a partner throughout that whole process. And that's why I was like, well how do you think I am going to have a baby? And then after the hysterectomy, do you think I am just going to go out and grab somebody and have sex with them?” [HystAfAmAL33].

“ ... and he was like 'well you know, how was the experience?' And I said painful, and he asked me questions and said 'that's because you need to relax and be creative, and you are a creative person, so next time you come in I want you to tell me that you were creative and things are better'.” [HystCaucPA43].

In terms of the experience of sex, of the participants in the hysterectomy group one did not talk about sexuality, three said there had been no change in sex since the surgery, two

women who were not currently in a relationship said they were uncertain about the effects, one married woman said it was too early to say, and three women had a less certain outcome. One of these was without a partner and had experienced some difficulties trying to assess her sexual response after surgery, while two talked about the fact that they had developed sexual problems:

“A couple of weeks ago, only like three weeks out, I got so nervous about that I actually masturbated because I wanted to know if I was going to feel anything (laughs). I mean I kind of see it like a therapy because it was ridiculous what I did, I think it took two hours. I mean it was work, it was physical work, and I think I was way too new after the surgery to have done that, but I did have an orgasm and it did feel okay.

“ This is so ridiculous to say, but I remember thinking yeaay! Every little response I got from my body, I was so relieved I cried. I sobbed that night, I think I sobbed myself to sleep” [HystCaucTX43].

“Well, I still have some concerns ... I have to keep remembering that being healed on the outside with incisions and scars, it is not quite as quick on the inside, and it just takes time and it takes not worrying about it, and it takes a little more time sometimes for everything to kick back in. So where I thought oh, this is not the same, and I don't feel like I did before as far as being in the mood, that has slowly started to fix itself as well, as time goes on” [HystCaucPA43].

“ And I have had extreme sexual dysfunction up until fairly recently, yeah, extreme sexual dysfunction. And I am not embarrassed to talk about it because I have read a lot of books on this (laughs).

“ And then you know of course we tried a couple of times and it was absolutely out of the question, I was just screaming out in pain, and I thought oh my God, did he sew me shut? I literally thought he sewed me shut. So I went back in June and said did you sew me shut? I can't get anything in there, what's going on? I do feel differently physically. Particularly in the sexual area, the sensation is so different and not in a positive way. The orgasm is so much different. I can't pinpoint ... I haven't had that many (laughs) to be honest, simply because I was unable to have sex. Orgasm is still easily achieved but the intensity is decreased significantly.”

[Interviewer] “And what are your feelings about that?”

[Participant] “I am so disappointed. I had a great sex life before the bleeding started, and if I had to rate it ... it's half what it used to be, half!” [HystCaucNC48].

What was apparent from these interviews was that prior to the surgery information on this aspect of these women's lives had been lacking, and improvements in their sex lives were far from guaranteed.

Attitudes

Information

With this theme, the study author was concerned to know what type and level of information participants had been exposed to prior to surgery, and how this may have affected their decisions about treatment. The first striking feature of this section was that with the exception of one woman, all remaining seventeen participants had done their own research; the most common sources of this information were books and the internet:

“But like I said I read the whole shelf of books at the library, and then I got on the internet, and that's how I found you, and I found two sites: Hysterhome and

Hystersisters, and got support and information on recovery milestones from them” [HystCaucTX43].

Indeed, one woman felt so strongly about the right of women to access information that she talked at length about her efforts to educate other women:

[Interviewer] “... you have been very proactive in terms of getting information out there to women.”

[Participant] “Yes, because I think most doctors don't give people enough information, and also because even though this group is great for beginning information, people come and go and so the people who have got the experience to inform the people who don't have the experience tend to leave after they have had their treatment, so they don't stick around to answer other people's questions. So that is one of the reasons I do continue on in the group, because people ask the same questions over and over again, and they have the same concerns, and I see so many questions that the doctors ought to be answering that people either don't feel comfortable asking, or else the doctors aren't answering them for whatever reason, you know, they are not giving them enough time or whatever”

[MyoCaucMA42].

Some participants commented that their doctor had given them minimal information, perhaps just a pamphlet, and even where they were invited to ask questions they may have lacked sufficient information to know which questions to ask. Despite their efforts to educate themselves, the interviews revealed areas where information had been lacking. In the myomectomy group two women said they would have liked more knowledge of how to prepare for surgery and the recovery period, and one found it difficult to find information on her options when she was diagnosed with large fibroids during pregnancy.

In the hysterectomy group, seven women appeared to lack information about their options or their condition:

“Maybe I should have asked more, maybe I should have done more, maybe she should have told ... did she tell me everything, did I ask the right questions? But then ... I am saying this after the surgery, after all the pain sets in, and I knew there was going to be pain, but it is just the length of the pain” [HystAfAmSC47].

[Interviewer] “... but did they leave your cervix?”

[Participant] “Apparently not, no.”

[Interviewer] “Did they talk to you about that before you went in?”

[Participant] “He wasn't sure what he would find when he went in there. He did tell me that if he saw something ... I think he did tell me that he was going to take the cervix, I can't really remember all the details as far as that, I can't remember if he told me, I'm pretty sure he did” [HystCaucNC44].

[Interviewer] “And he took your cervix as well?”

[Participant] “Yes.”

[Interviewer] “Did he say why?”

[Participant] “Do you know I was just asking my husband that the other day, I said did he ever tell us why he took my cervix? And he said no, I don't think so. And I said when I go at Christmas for my check up I am going to ask him, because I don't think I know. I don't know the answer to that, and I would like to know” [HystCaucNC48].

“ And even I said beforehand, while we were talking and he was asking me about the cervix, and I was like, I don't even know what it does, I don't even know it is there, so how am I going to know it is not there, am I going to miss it? And he goes 'yeah, you are going to miss it because you are not going to have any pain'”
[HystCaucPA43].

[Interviewer] “Did they tell you anything about how big they were or if they were causing other problems?”

[Participant] “No, they never mentioned the size. I think on paper they wrote down the size, but I never paid attention to it, I never thought of pursuing that, but looking back now I wish I had of, maybe it could of saved me from having a hysterectomy.”

[Interviewer] “So, they left your ovaries but they took your uterus and your cervix?”

[Participant] “Yes.”

[Interviewer] “Did they talk to you about why they were going to take your cervix also?”

[Participant] “Erm... she just thought it was best to go ahead and take it”

[HystCaucTX31].

What is concerning here is that while nearly all of the women were proactive in seeking information, for some there were clearly gaps in their knowledge that impacted the type of surgery they received. What was lacking was education about fibroids, about treatment options, and about female anatomy and physiology. Interestingly, six women (three in each of the two treatment groups) talked about their surprise at discovering how many women around them had already been through a similar experience:

“You know, when I was emailing all my friends all over the country, like oh guess what, I am going to have to have a hysterectomy, I mean I had no idea that some of them had already had it. And I said is this a government secret? It's like they are ashamed or something, or it's not a topic of everyday discussion. And people I have known for years, I did not know they had a hysterectomy and I am kind of a busy-body, I want to know everything about everybody. And I was shocked”
[HystCaucNC48].

“Well actually I did, but I didn't even realize it. My cousin had had a hysterectomy, and she never talked about it until after I told her about my myomectomy, and I think maybe she regretted it, but she never actually said that. She said we should have talked about it before she had the hysterectomy”
[MyoCaucMA42].

In addition to problems caused by the level of privacy that surrounds many women's gynecological health problems, there may be instances where women just prefer to avoid information. In this sample, for example, four women (two in each group) talked about how they did not want to hear more information:

“Well, she didn't really go into all of that, but I told her I had read all the stuff on the website and I was aware of all that, so I kind of headed her off at the pass, because I really felt pretty informed about that. I just didn't want to hear anything negative, I just wanted to move on with it, because I had waited so long, and I was just in so much pain” [HystCaucPA49].

[Interviewer] *“If you were thinking about a hysterectomy in the future, would you go ahead and do research on it like you did with the myomectomy?”*

[Participant] “Erm ... maybe a little bit, but not a whole lot, because I wouldn't want it to scare me, you know if I read more than I wanted to read, because you know you always read the horror stories” [MyoCaucLA40].

In sum, many of the women sought their own information to make up for shortfalls in what their doctor was able to offer. However, some women were still left with gaps in their knowledge, and perhaps this left them unsure what questions to ask or unclear about what to expect.

Attitude to Body

This theme refers to the attitude participants had to their bodies, and how these opinions influenced treatment choices. Five of the women in the hysterectomy group clearly identified the uterus as an organ useful for reproduction only, with the rationale that as they did not want more (or any) children, a hysterectomy was therefore a natural choice:

“ So when I went back in January he gave me the results from my ultrasound, and told me what my options were, and I said you don't even have to tell them to me, because like I said, for me, I don't plan on having any kids, don't want any, I got a niece and nephew and I like to take care of them and that's enough for me”
[HystAfAmNC37].

“Well, the fact that I was 48 years old, I had a 16 year old and a 19 year old, and I basically had decided I wasn't going to have any more children. I had been planning my life around my periods for the last 16 years, and I was basically tired of doing that. And I said I think my uterus has served its purpose”
[HystCaucPA49].

While some women in the myomectomy group said they had decided to keep their uterus so the option of fertility would remain open to them, there was another attitude that had clearly influenced the choices of six of these eight women:

“ You know I figured the uterus is there for a reason other than giving birth, I mean it is holding up something, I don't quite know what it is, but I did not want to have a hysterectomy, I was quite adamant about that, unless it was to save my life. And he was okay with that” [MyoAfAmVA42].

“I believe that every organ serves a purpose. I wouldn't give up any organ in my body. I mean they say that your appendix doesn't serve you any longer, there is no need for it, but I don't know if I would even want to give that up, I mean I don't know if I totally believe that. So it is more like my belief system that all your organs are there for a purpose. One of the doctors that I saw said 'yeah, but the purpose of your uterus is to give birth and at your age' ... I was 47 at the time, he goes 'you are not going to give birth, so it doesn't serve the purpose that it was predestined for' or whatever. So I said I still think it does something for your body” [MyoCaucCA48].

“ I really don't like the idea of amputating pieces of the body that are healthy, and that is what I see a hysterectomy for fibroids as being.

“I think mostly it's ... I am an ecologist, I have got a lot of biological training, and I think about ecosystems as a whole, how one piece of it affects the whole thing, so when I think about my body I think of it as just a smaller scale ecosystem, so how does one organ affect the rest of the body? And so I think that probably had a

lot of impact on how I viewed my treatment options and what I wanted to do, and particularly my thoughts on removing organs” [MyoCaucIA34].

From these quotations we can begin to understand more about how women’s attitudes to the female body will influence treatment choices. Many of these themes show some overlap, for example, the level of information women had about their bodies was important in forming their attitudes and choices.

Influence of Family and Friends

In both groups of women it was apparent that the opinions and experiences of close family and friends had some influence on participants’ choices:

[Interviewer] “So it doesn't sound like you knew anyone who had a hysterectomy that had anything bad happen?”

[Participant] “No! You see I got lucky, because all the people I know were happy about it. And my aunt, that second time, she was like 'I was so glad that was over, I wished I would have had it done the first time instead of just having the removal'. (Exhales loudly). So for me, that was just the way to go”

[HystAfAmNC37].

[Participant] “He [partner] wanted me to have an operation, but he did not want me to have a hysterectomy.”

[Interviewer] “Did he say why?”

[Participant] “He felt that I would be crazy-er. And I would go into menopause and I would be crazy-er (laughs). That was his exact word. I would go into menopause and get freaked out. I am already moody as it is, he just couldn't take another reason to be moody-er.”

[Interviewer] “(Laughs). Did that have any influence on your decision to have a

myomectomy?”

[Participant] “It had some, I listened to him, and then I had to research it, but yes, I did listen to him, I thought his opinion was valid” [MyoAfAmVA42].

“ ... you know I hear all the horror stories about being on hormones when you get your female organs taken out, you have to go on this hormone replacement therapy and I am really against that. I was raised by my mother who is very natural, she doesn't take prescription drugs unless she absolutely has to. I mean she recently had a heart problem so she had to, but I didn't have aspirin until I was 12 years old (laughs). So, I am just not one to take medicine and drugs, that sort of thing” [MyoCaucOK37].

In total two women in the hysterectomy group, and five women in the myomectomy group, talked about how the experiences and attitudes of others close to them had influenced their choices. There were no particular differences in these narratives to distinguish these two groups under this theme.

Attitude to Doctors

One of the most striking themes to emerge, and one that grew from the interviews rather than the literature or set questions, was that of the attitude the participants had to doctors. The interview process was first carried out on the women who had a hysterectomy, and during the later stages of the study, when the myomectomy group was being interviewed, it became clear that this group of women was talking about doctors in a qualitatively different way:

“The gynecologist that did my surgery and the ob/gyn that I went to see initially are in the same office, but they have different mannerisms. And the ob/gyn that I went to see initially, he was pretty bing bang boom abrupt, you know it's no big

deal, I can give you surgery and we can schedule you in two weeks, not a problem. I was like no, uh uh, you don't do that. I was very uncomfortable with his mannerism” [MyoAfAmVA42].

“ I don't know ... maybe it dates way, way back to when I was a teenager or something, but I just never had a very good attitude towards doctors. I just think that they are kind of stupid. And I have always been able to relate to them just as people. I feel like of course some doctors have a lot better skill than others, you know skill level, or just have been trained in different areas, it depends on their training and what they do and how experienced they are, but some of them just have bad personalities, and some of them have good personalities but that doesn't mean they are a good doctor” [MyoCaucCA48].

“ I think I am different from a lot of people in that I don't think doctors are ... a lot of people I think put doctors on a pedestal and think they know everything, and I don't have that opinion” [MyoCaucCO41].

“ So I went to this surgeon and I really liked her, so she is the one that ended up doing my surgery for me. I just walked in and said I want an abdominal myomectomy.”

[Interviewer] “So you didn't go back to the original gynecologist that you had seen, the male?”

[Participant] “No, no I didn't like him, and since my friend had given this woman such a glowing recommendation, I decided to give her a try and I was just so much more at ease with her, and I just got a better impression of competence from her.

“ If I felt like the doctor wasn't competent enough ... I know that people who have studied stuff don't always know everything, and I would be willing to find somebody who maybe is a little more familiar with this particular area, because every doctor has a specialty. I would have gone looking for one who specialized in this type of thing” [MyoCaucIA34].

“ I have an investigative license here in the state, and so I did some background stuff and some of it is public anyway that people can pull up, but I started doing some research on this doctor and she had several malpractice suits, and I mentioned her name to a friend of mine, and she was like 'oh no, she is horrible'. And that is when I went ahead and switched to this other doctor and it was like night and day between the two” [MyoCaucOK37].

What was interesting here was that seven of the eight women who had a myomectomy had ‘shopped around’. These participants had been extremely proactive in finding the right doctor for them, even if it meant traveling a great distance; one woman drove 800 miles and another actually flew from Colorado to Pennsylvania to have surgery with the doctor of her choice. In addition, four of the women in this group displayed an attitude to doctors that was not overly respectful -- in the views of these women a doctor is like any other professional, some are more skilled at their job than others, and patients should find the right fit for them.

By contrast, the hysterectomy group tended to display an attitude that was less discriminating. Six of the women in this group had surgery with the doctor in their usual gynecology practice:

“I went to my primary gynecologist, who I trusted very much. I had been going to him for several years and we had been watching the fibroids carefully every six

months, and they got to the size and problems that we couldn't manage anymore. So he was my primary point of contact” [HystCaucNC48].

“Erm ... well the gynecologist who delivered my daughter actually found them, and I saw him until he retired and then I went to his partner, and that is who I see now, so really just the two of them. I mean I didn't have to go to any other specialists because it was a gynecologist who found them to begin with” [HystCaucPA43].

[Interviewer] “So what was it that stopped you going to get a second opinion?”

[Participant] “I don't know. I think, like I said, the anemia, and somehow the finality, it felt good, like something was going to happen” [HystCaucTX43].

Four of the women who had hysterectomy talked about concerns that they should have perhaps consulted more doctors before making a final decision. This theme is therefore important as it raises questions about how enabled women feel to challenge doctors' authority, and whether a woman's attitude to the medical profession may have an influence on the type of treatment she eventually has.

Growing Back

The theme was raised as a number of participants talked about the possibility of fibroids growing back after surgery. Their attitude to this possibility was a decisive factor for some in their treatment decisions. In the hysterectomy group, for example, four of the ten women said fears of re-growth had in part led them to seek a definitive treatment:

“And I had read and heard that once you get them there is always the possibility that they will come back, and like I said, not only did I not want the kids, I didn't

want to have to deal with them coming back, so I said please, just take it out”
[HystAfAmNC37].

“Well basically I was discouraged from having any kind of surgeries or anything to remove them, because most of the gynecologists I talked to said they would just grow back” [HystCaucNC44].

“So you know, I had bought all these books on hysterectomy, and I ran home and read up on it, and I thought well, you know what, there is no guarantee that they won't come back, and I just decided against it, that was a personal decision on my part. Do I regret it? I don't know” [HystCaucNC48].

“And I had done a myomectomy and they grew back. I was just, like I said, tired of dealing with the heavy bleeding, and what was the point of doing a myomectomy and then two years later having them grow back” [HystCaucPA49].

In these instances the fear of re-growth was important in the decision-making process. With the last participant it was interesting to note that she had already been through one myomectomy; however, at the age of 49 it was likely that she would have been in menopause before any significant re-growth could take place, and at this point any fibroids would have shrunk. She did not, however, talk about this point.

With the myomectomy group, the attitude to the possibility of re-growth was different. Six of the eight women in this group talked about this natural concern; however, this seemed to be a chance they were willing to take:

“ And I am also quite confident they can come back, I realize that. I want to keep a better tab on them now, and even though this may sound backward for some

people, because he was like 'you are having the surgery first but you want to know if you can have the UFE later', and I am like yeah, I want to cut off and get out as many as possible, so if they do grow back then I want to take the least invasive surgery at that time, because it will be a whole lot less for the pellets to address, do you know what I am saying?" [MyoAfAmVA42].

[Interviewer] "Did he talk to you about how you might manage that if it starts to grow?"

[Participant] "You know he didn't, he just said he really didn't think it would be a problem. I think he told me that he has only had one woman that had to come back and have a repeat myomectomy after he did a surgery, and she was in her thirties I think when he did it. So who knows? He didn't have a crystal ball" [MyoCaucCO41].

"A lot of women that I have seen on the list say they are worried about fibroids growing back, and that is why they are strongly considering hysterectomy, but with the number of women who actually have fibroids and don't even know it, or have them and know it but have no symptoms, it seems to me that even if they grow back it may not be a problem, it may not need treatment" [MyoCaucIA34].

"The second fibroid ... I went for a follow-up ultrasound a few months after the second baby was born and they said it had actually shrunk a bit. And it is pretty tiny, so they are not worried about it, and I am not really either. I am just gonna keep an eye on it" [MyoCaucMA42].

For a woman who is prone to developing symptomatic fibroids, as these responses indicate, it may well be a common concern that fibroids might grow back if the uterus is not removed. In the case of a majority of the women who chose myomectomy, the attitude appeared to be that this chance was worth taking, as even if there was re-growth it might not be symptomatic, and with careful monitoring and early treatment there would still be options available. For the women who chose hysterectomy, there was relief from having to remain concerned about fibroids growing back.

Recommendations

This final theme was another of those that was somewhat surprising. Participants were asked one last question that they did not see beforehand, and this was intended to reveal their spontaneous attitudes to hysterectomy, anticipating perhaps a split between those who were either positive or negative about it after experiencing one or other surgery. However, what actually happened was that all the participants used this as an opportunity to discuss how other women should approach their treatment options. Regardless of which treatment group participants were in, the common sentiments expressed were the importance of examining all the options, the need to consult a variety of doctors, and the help that comes from sharing experiences with other women:

“And I would try to find out the reputation of the doctor first, and get more than one opinion before I committed to anything, because I made a lot of mistakes along the way, but I just didn't know, I had never been sick before”

[HystAfAmAL33].

“ But I think that is probably the most important thing I would say, you know, are you sure that is what you need? Have you gotten another opinion about that?”

What do you think about the surgery and what does your doctor think about the surgery, and what kind of options do you have? [HystAfAmNC37].

“I would tell her that there are other choices, and she did not have to have a hysterectomy if she did not want to. But if you want to have one, go and do the damned thing (laughs), do what you want, but it has to be what you want, it is not what your doctor is telling you” [MyoAfAmVA42].

Regardless of the type of surgery and outcome participants had, there was a common sentiment that women should be empowered to explore all their options and make the choice that was right for them.

In the above results, a fairly extensive amount of space is devoted to quoting from participants' interviews. This was done to address one of the primary aims of this study, which was to bring women to voice on their experiences, in addition to providing a rich illustration of the themes that emerged from the data. In the following section, there will be a discussion of these themes as they relate to the study questions and the extant literature.

CHAPTER 5

DISCUSSION

The aim of this study was to explore women's attitudes to, and experiences of, surgical treatment for the benign condition of uterine fibroids within the U.S. medical system. Using a qualitative interview approach to help give voice to the participants, and to value their role in the creation of knowledge, two groups of women were interviewed and compared: those who experienced myomectomy and those who went through a hysterectomy. The sample consisted of women who were either Caucasian or African American, with the initial intent of being able to compare perspectives according to racial background; however, it did not prove possible to recruit a sufficiently diverse sample for any clear conclusions to be reached on this issue.

Eighteen women (eight had myomectomy and ten had hysterectomy) were interviewed for an average of one hour each, and these interviews were then transcribed. In total, 278 single-spaced pages of transcript were generated, and a thematic coding was carried out using N6 software. The themes were reported using frequency counts, which were intended to illustrate patterns in this sample, but not to infer that these patterns could be generalized to the wider population of women that undergoes such surgeries. The discussion will now center around the original research questions for this study.

Research question one: As participants describe their process of seeking and experiencing treatment, which common areas become evident?

There were four questions guiding this study, and the first of these examined the experiences that were common to the participants in the process of seeking and experiencing treatment. Themes that emerged in this category were divided into the three time periods of before, during and after treatment. These themes were as follows: (before) symptoms,

insurance, choices; (during) experience of doctor and hospital; (after) benefits and complications, self-image, sex and sexuality.

Research question two: What attitudes do participants have to treatment and their bodies, and did these attitudes influence treatment choices?

The second study question examined the attitudes of participants to their treatment and bodies, in an attempt to discern whether there were values held by the women that influenced the kind of treatment they eventually pursued. The themes that arose in this category were: information, attitude to body, influence of family and friends, attitude to doctors, growing back, and recommendations. It was clear from the first five of these themes that women did make treatment choices based partly on some of these attitudes. For example, if a woman believed that her uterus served a function other than childbearing, if she had a mother or partner who believed in a more holistic approach, and if she was mistrustful of doctors, then she was more likely to have a myomectomy. This leads into the issue of defining the group of women who chose to go against the system and have a less traditional surgery, and this will be discussed further in this section.

Some of the themes in answer to both of the first two questions arose from the interview schedule, or from the literature review, and others arose from participants' words. In the latter category this was particularly important as studies that take a qualitative approach to examine women's perspectives on uterine surgery are still in the minority, and to date they have tended to focus mainly on experiences of hysterectomy (e.g., Groff et al., 2000; Mingo, Herman & Jasperse, 2000; Williams & Clark, 2000). The qualitative approach can yield information that may not normally be found in quantitative medical outcome research, and this is the first qualitative study to focus on a comparison of hysterectomy and myomectomy.

Research question three: How do the participants' responses to the first two questions differ by treatment type?

The third research question for this study addressed a comparison of treatments and whether any of the participants' attitudes and experiences differed by treatment type. One of the first issues to arise was that of finances and medical insurance. A woman's financial situation is an important factor in a medical culture where the quality of care is often dictated by one's level of insurance. In this sample, there were at least two women who talked about their choice of hysterectomy being driven by financial concerns, while three of the women in the myomectomy group had to make financial sacrifices as their insurance did not cover all the costs of their treatment. It was clear that money was an important consideration for many of the participants, and some of those in the hysterectomy group seemed to be the ones whose choices were most limited in this way. While some studies have paid attention to the decision-making process for hysterectomy (Wu, Chao Yu, Yang, & Che, 2005), the issue of finances in a medical system such as that in the U.S. remains a factor that requires further investigation. It is concerning to think that women may elect to have organs removed based primarily on this issue, or that alternative treatments may be rejected if specialist services are not covered under many insurance policies.

A further factor that may strongly influence the choice of treatment is the opinion of doctors. It has been argued that women are often led to believe hysterectomy is necessary where there may in fact be other options; one persuasive argument being the possibility of avoiding cancer (Greer, 2000; Payer, 1987), and this may be particularly true if fibroids have grown large or if their growth is rapid (Dionne, 2001; Payer, 1988). Worryingly, there may be financial incentives for doctors to perform hysterectomy (Mendelsohn, 1982; West, 2000), and the large number of physicians who reportedly proceed to recommend this surgery before meeting the ACOG criteria for such a diagnosis (Goodwin, Broder & Drum, 2003) can only exacerbate this concern.

With the sample in this study, a clear difference between the two groups of women was that six out of the ten women in the hysterectomy group said they had limited choices about their surgery, while those in the myomectomy group felt they had more options. For one woman, her more radical second hysterectomy was dictated by a pathology report of endometrial cancer, and for another an emergency hysterectomy was performed to stop life threatening hemorrhaging resulting from what may have been a myomectomy. In the remaining four cases the doctors persuaded participants that hysterectomy was their only option because of abnormal cervical cells (one woman) or due to the size of their fibroids. While this study is not generalizable to the wider population, it is concerning that five of the women (27% of the sample) experienced organ removal when they might possibly have had other choices. While the U.S. Department of Health and Human Services has funded studies to review the recommendations for hysterectomy (Broder, Kanouse, Mittman & Bernstein, 2000), further research may be needed to determine the extent to which doctors still recommend hysterectomy as the only course of treatment, and whether these recommendations can be replicated by a fibroids specialist. Although this study was primarily intended to focus on the woman patient's perspective and how this might influence the treatment process, clearly one cannot escape the importance of attending to policy; issues such as insurance and doctor preferences may need to be attended to if a real change in the hysterectomy rates in the U.S. is to be effected.

In terms of the woman patient's role in the treatment process, this study suggests that values and attitudes of the woman and those close to her will be important in shaping choices. Under the theme of symptoms experienced before surgery, it was striking to note differences in the women's descriptions of what drove them to seek treatment. While both groups of women talked about a reduction in the quality of life and associated problems, the level of bleeding experienced by those in the hysterectomy group tended to be more profound, and brought with

it a strong sense of isolation, inconvenience and shame. A need to experience relief from such bleeding has been reported as a primary benefit of hysterectomy (Schofield, Bennet, Redman, Walters & Sanson-Fisher, 1991), and it may have been an important factor in what drove these women to request a more definitive treatment; as one participant put it “it was just like ugghh, let’s just turn it off, turn the faucet off. And again at that point I was more open to doing a hysterectomy” [HystCaucCA49]. In this sample, relief from debilitating periods was the primary benefit reported by the hysterectomy group. However, some women in the myomectomy group also reported relief from heavy bleeding as a benefit of surgery, and, with the exception of one woman, periods were subsequently viewed as lighter and far more manageable.

Roberts and Waters (2004) have discussed how popular culture reinforces the need for women to keep their bodies sanitized and feeling fresh. Stubbs and Costos (2004) have described the sense of disconnect from their bodies that women can experience as they come to associate menstruation with qualities that are shameful, disgusting and in need of concealment. For women with symptomatic fibroids that lead to extremely heavy bouts of bleeding, it is understandable that this disconnect can lead to a desire for more drastic interventions, particularly where the problem has been ongoing for years.

The attitude that women have to their bodies may provide more clues as to the distinguishing factors of women who choose hysterectomy over other interventions. In this sample, it appeared that a woman’s attitude to, and level of information about, her body was an important factor in her decision process. Half of the women in the hysterectomy group identified the uterus as an organ required only for fertility, and as they had no wish for any or more children, they believed hysterectomy was the better option. By contrast, six of the eight women in the myomectomy group talked about the other roles the uterus plays, and the importance of keeping the body whole. In the late 1970s, Sloan (1978) used the term “useless

uterus syndrome” to describe the pervasive opinion of doctors that a uterus was of little purpose once it had served its childbearing function. This attitude may well persist in many doctors today, but perhaps for some doctors and their patients this view is shifting. Clearly it may be an important factor in the decision making process, and therefore requires further investigation.

The attitude that participants displayed to doctors was one that particularly distinguished these two groups of women. Those who chose hysterectomy seemed more likely to receive surgery from their usual gynecologist, someone they had perhaps consulted and trusted for a number of years, while the myomectomy group displayed a strong preference for ‘shopping around’ to find surgeons with particular skills for treating fibroids. It is debatable how many women would be financially able to do this, and in fact there was evidence of high levels of sacrifice in this latter group, in terms of paying out of pocket and being prepared to travel great distances.

It is uncertain why these women seemed to behave differently; perhaps they had accessed different kinds of information or it may just have been their values about the female body. Certainly they did not seem more educated or more self-confident. With the exception of a minority of those in the hysterectomy group, the majority of the women in this study said they felt happy with the relationship they had with their doctors. In the myomectomy group, however, the participants were clear about how quickly they had moved on from doctors they did not like, and four of the women went as far as to say they neither trusted nor revered doctors in general. Some studies have found that a proportion of women patients have either a “flagrant distrust” of (Richter et al., 2002, p. 438), or a negative attitude to, the medical profession (Groff et al., 2000), but it may be this kind of attitude is actually an important factor in driving women to find the right treatment options for them.

The level of information a woman patient has prior to surgery is an issue that has been raised in other studies. For example, doctors may fail to interact on a more emotional or compassionate level, or they may discourage women from doing their own research and talking to people who might give them a less than positive view about the treatment being offered (Richter et al., 2002). Additionally, there may be a lack of information on the pros and cons of a treatment, particularly in a surgery such as hysterectomy where there can be a trade-off of one set of problems for another (Chapple, 1995; Schofield, Bennett, Redman, Walters & Sanson-Fisher, 1991).

In this study all but one of the women had been proactive in seeking information, primarily from the internet. It should be remembered, however, that all but two of the women were recruited via the internet, so this may have been a particularly technology savvy group of women. What had driven this search for information was often dissatisfaction with the level of information provided by the doctors; but despite these efforts, some women appeared to lack information that later proved to be important. This was particularly so with the hysterectomy group, where seven of the ten women had not been fully prepared for the outcomes, or perhaps were not even sure what parts of their anatomy had been removed or why. In addition, some women said concerns about fibroids growing back had contributed to their decision to have a hysterectomy, compared with six out of the eight in the myomectomy group who had researched this issue and decided it was a risk worth taking.

A number of the participants were surprised by the fact that women they knew well had also undergone uterine surgeries, but had not talked about it. Part of the problem seems to be that women tend to be very private about their gynecological issues, and so internet support sites may be the only option available to those who want to learn from other's experiences. Clearly, this study adds to concerns in the literature that women continue to be lacking in the information required to give informed consent on their gynecologic surgeries. More work

needs to be done to find ways to help women gain access to current research, particularly where results are mixed such as in the case of the effects of hysterectomy on sexuality. Additionally, it appears that women who have been through treatment may be a vital source of information and support for those who are considering their options, and greater attention needs to be paid to ways to help women access this valuable resource, either through the internet or hospital based support groups.

In terms of the participants' experiences of treatment, there were again some marked differences between the two treatment groups. It was noted that the descriptions of hospital experiences were longer, more detailed, and included more negative types of words in the hysterectomy group. This may have been due in part to some of the problems that resulted, perhaps coloring memories of the experience. The reported benefits from surgery were consistent with the literature in that most of the women in the hysterectomy group reported being satisfied with their treatment as they were now symptom free, but there was also a less positive side. Those in the hysterectomy group talked about problems resulting from surgery such as hormonal issues and prolonged post-operative pain, and in particular there were emotional difficulties they faced that were not apparent in the myomectomy group. There were powerful feelings of grief, loss and finality that affected the hysterectomy group, and it was moving to listen to some of these feelings during the interviews; there was a sense that these women were perhaps not fully prepared for this part of the surgery experience, nor adequately counseled after treatment. While women may work through such emotions in time, it may be that these issues are under-represented in the literature. Studies that conclude hysterectomy is a treatment of choice as a result of the use of a limited selection of questionnaires (e.g., Davies & Doyle, 2002), for example, may fail to paint the whole picture. While research may suggest a majority of women do not display symptoms of depression after surgery, this does not mean there is an absence of strong emotions that could benefit from some form of intervention.

In terms of sexuality and hysterectomy, the picture was as unclear in this study as it is in the extant literature. Even the current literature is either in support of hysterectomy as having no effect on sexuality (Kupperman et al., 2005; El-Touckhy, Hefni, Davies & Mahadevan, 2004), or it claims the surgery can lead to sexual problems (Cloutier-Steele, 2006; McPherson et al., 2005). The mixed reactions from the women in the hysterectomy group from this study support the need for further investigation of the possible effects hysterectomy might have on a woman's sexuality. In the meantime, as Katz (2005) suggests, medical staff could play a greater role in talking with patients about sex before they undergo surgery to remove their sexual and reproductive organs.

Research question four: Are there any perspectives that distinguish the experiences and attitudes of African American participants?

The final research question for this study was concerned with any perspectives that might distinguish the experiences and attitudes of African American participants from those of the Caucasian women. With only just over 20% of participants being of African descent, it was unfortunately not possible to discern any definite trends in the themes. The only area that was suggested was that of finance and insurance as it affects choice. One participant from rural Alabama, for example, had good insurance, but her location meant that one of her nurses practiced in a small rural clinic. This clinic's patients were primarily poor women of color, and the participant described the place as "disgusting" and "horrible". The one participant in this study who was in receipt of government health insurance was African American and unemployed. While she reported she was pleased to be free from her symptoms, she did complain that her doctor seemed very rushed and she questioned whether other options might have been available to her had there been time for discussion or counseling.

Concerns about the treatment of poorer women of color were elaborated by an African American participant from Virginia who had a myomectomy: "if we don't have insurance and

a hysterectomy is cheaper than a myomectomy, which from I understand it is, it is quick and dirty, you know, you get in, take it out, call it a day. Well, it's cheaper so we are economically driven on that point." While some attempts have been made to explore the perspectives of hysterectomy based on race and ethnicity (e.g., Mingo, Herman & Jasperse, 2000), the levels of African American women affected by fibroids mean this is an area in need of further investigation.

Implications

While much of the literature has focused on experiences of hysterectomy, this study has attempted to expand the picture by including women's perspectives as they influence treatment decisions, in addition to providing a comparison with another surgical technique that treats the problem of fibroids. There are several themes that have arisen from this study that require further investigation. The first of these is the extent to which women make treatment choices based on finances and medical insurance, and how much choice women of lower socio-economic status have, particularly those of African descent. While many doctors undoubtedly strive to have productive working relationships with their patients, this study also raises a concern about how willing some gynecologists are to refer women patients to the pool of specialists in the field of fibroid removal. Clearly the removal of larger or multiple fibroids is outside of the skills base of many gynecologists, and there needs to be more investigation of how accessible myomectomy from a surgeon specifically trained in this area is, in terms of cost, availability and access to unbiased information. In terms of choosing a doctor, this study also highlighted the need to educate women about the importance of shopping around, getting multiple opinions and not trusting a doctor's opinion just because he or she has been treating you for years. Regardless of outcome, all of the women who took part in this study emphasized the need for women to get other opinions and explore all the options.

The differences between the women that were less tangible bear further investigation. What was particularly interesting in this study were the women who went against the general tide of opinion to have a myomectomy. They were more likely to be discriminating in their choice of doctor, as well as more likely to want to fight the system. Why they were like this is not clear. A study that used mixed methods and a larger sample might, for example, be better able to identify and quantify the characteristics of these women. This information is important, as it could help to guide interventions intended to empower women in their health care experiences.

A further area of interest would be to explore how women's symptoms influence their treatment choices, and whether their education and values about the female body also play a major role in the decision process. A primary need that was apparent from these results was that of awareness and education. Clearly women continue to lack important information about their bodies, the diseases that affect them, and the pros and cons of the treatments available. While doctors may believe they are disseminating information to their patients, there is a gap that remains to be bridged between doctors' biases and what they think patients need to know, and what women actually need to hear. Women may either lack the information to know what questions to ask, or in the case of topics such as sex, they may not know how to approach the issue in the first place. In such areas it is important that doctors accurately reflect the uncertainty of the research literature, as well as emphasizing possible risks and trade-offs. Perhaps it is time for a campaign to raise awareness of these issues as they concern fibroids, as one participant said: "I really think that if people were more willing to talk about it, if it were one of those health issues that they talked about on the news occasionally or something like that, I think a lot more women would be more informed about what choices they do have." [for example] "You have a Run for Life for breast cancer, but you never have runs for fibroids."

A further tool that may help women in their decisions is a model or decision-making tree. One study (Wu, Chao Yu, Yang & Che, 2005) has attempted to build such a model based on interviews with 32 women deciding whether or not to have a hysterectomy. The options that it provides, however, are arguably limited and it would benefit from the addition of some of the themes raised in this study, such as financial situation, level of education, values about the female body and influence of family and friends.

Limitations and Problems

While this study did attempt to begin to compare hysterectomy with a viable surgical alternative, it relied on a small sample of just eighteen women, and so any themes and patterns can only be a suggestion of areas in need of further investigation. The sample also lacked sufficient diversity as it was primarily composed of White, educated women who regularly use the internet as a source of information and support. It was unclear why so few African American women responded to the adverts for the study. It could be that they do not frequent the internet support groups where the study was advertised in such large numbers as Caucasian women, or perhaps they are less willing to be involved in research that affects them for a variety of reasons. Regardless of the cause, there was a problem recruiting African American women for this study, and future research on the issues raised in this study should find ways to address this imbalance. In particular, it would be useful to develop this study further by repeating it with a sample of women from racial minorities with lower SES, and to compare their experiences and attitudes to those women who participated in this current study.

In general, though, it did not prove a problem to attract Caucasian women to this study, and it is perhaps useful for future researchers to know that many women with fibroids seem keen to help expand knowledge in this area. Also, recruiting from across the country was seen as beneficial, and preferable to limiting responses to women who attend just one or two hospitals in the same region. While this sample was not large enough to reflect patterns in

regional differences, it is clear from the literature that experiences and attitudes concerning treatment can vary widely according to where a person lives. National samples are therefore important to represent the differences in women's cultural values and experiences of health care.

Reflections

The stories these women told were powerful, at times moving, disturbing and humorous. It was not always easy to stand outside of my therapist self, or to distance myself from my own experiences of having been a fibroids sufferer. At these times it was important to remember to let the participant do the talking, and to journal notes during the transcribing process so I could separate my 'stuff' from theirs. In retrospect, the fact that I had been through similar experiences was important in helping me to know which questions to ask, and when to probe further for more detailed information. It may have also helped in recruiting, as women knew I had empathy with, and understanding of, their situations.

One of the striking features of this study was the different type of impression or energy that came with the myomectomy interviews. The hysterectomy interviews at times felt draining and sad, perhaps I was sharing their sense of grief and loss from the perspective of being a woman. In contrast, the women in the myomectomy group left me feeling empowered, and re-energized my enthusiasm for this study. Seven of the eight women in this group were very definite about their determination to get what they wanted from the medical system. The eighth woman was less so, and her interview felt as though it belonged in the hysterectomy group; interestingly she seemed very ambivalent about the fact that she had a myomectomy and I suspect she may have a hysterectomy in future if she is unable to have a child in the next year or two. For this woman, her problems with heavy periods, her culture in the deep South and the fact that her primary female relatives had had a hysterectomy, are all factors that will probably drive her decision in the end.

The total experience of this dissertation has actually been compelling. It has never felt like a chore to work on it, and I have enjoyed immersing myself in it. The women in this study were brave to relate their most intimate experiences to a stranger, but they entrusted me with this information in the hope that it might make a difference somehow. My hope is that in some small way this research might become a stepping-stone in the process of empowering women to become better-informed consumers of health care.

Conclusions

The purpose of this study was to examine women's attitudes to, and experiences of, the surgical treatment they chose for uterine fibroids, in order to build an understanding of their role in the treatment process. Eighteen women participated in the study, and a qualitative long-interview approach was used. The themes generated from the analysis reflected differences between the groups of women who chose myomectomy and hysterectomy, and from this sample there were suggestions that women's treatment decisions are affected by a variety of factors. These include the type and severity of symptoms from the fibroids, a woman's financial situation and level of health insurance, the level of empowerment she feels when facing authority figures, the attitudes she and those around her have toward the female body, and her level of information about topics such as fibroids, treatment options, and female anatomy. The opinions of doctors may well be an important factor in treatment decisions, but much greater attention needs to be paid to the women patients and their influence on outcomes.

While there is no shortage of research and literature on hysterectomy, there are still areas such as the effect on sexuality that need further exploration. Equally, myomectomy is a well-established alternative to hysterectomy that remains under-valued and under-researched, particularly from the woman patient's perspective. In general, the subject of fibroids is one that many women have heard of, but do not fully understand. Given the prevalence of symptomatic

fibroids and the fact that the most common treatment is removal of the sexual and reproductive organs, a campaign to raise awareness and educate women is past due.

In the 1970s, Sloan stated, “An informed patient is a free patient. We owe our women patients nothing less” (p. 605). As attempts to improve women’s health care progress, it is vital that steps are taken to ensure women are educated about their bodies and treatment options, in addition to being empowered consumers who are in control of their health care choices.

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APPENDICES

Appendix A: Interview Guide

1. Background information:
 - a) Age
 - b) Race/ethnicity
 - c) Occupation
 - d) Education level attained
 - e) Which U.S. state currently living in
 - f) Marital Status
 - g) Number & ages of children
 - h) Level of health insurance
 - h) Menopausal status: premenopausal/natural menopause/surgical menopause
 - i) Any previous significant health problems requiring medical treatment
 - j) Treatments received for uterine fibroids to date
 - k) Number of/speciality of doctors consulted over fibroids to date
2. Describe the symptoms you experienced from your fibroids.
3. Tell me when you were first diagnosed with fibroids, and what you can recall of this diagnostic process and the initial information you were given.
4. Describe the treatments you considered, and the process you went through to find the information you needed before deciding on a treatment.
Did you feel fully involved in the decision-making?
Did you feel you were given choices?
5. Tell me about the surgical treatment you received for your fibroids, and what you recall of your treatment experience.
6. Tell me about your experiences of doctors & nurses you have seen about your fibroids.
7. Tell me about the sex of your doctor/s and your views on how/if this affected your experience of treatment.
8. Tell me about the people closest to you in terms of their reactions.
9. Describe the emotional experience of your treatment.
10. Describe the attitudes doctors & nurses had to your body and your sexual and reproductive organs.
11. How did the doctor talk about your sex life and sexual feelings, and the effect treatment might have on this part of your life?
12. Talk about whether your feelings and attitudes to your body have changed since treatment – for better or worse.
13. Tell me about the most positive and most negative parts of this whole process, and how closely the treatment matched your expectations.
14. Describe any complications or benefits you have felt as a result of your treatment.

15. Tell me about anything you felt you needed that you didn't get from this whole experience.
16. How would you describe your level of satisfaction with your treatment overall?
17. What else would you like to tell me that I haven't already asked you?

[one more question they won't see beforehand: If your adult daughter/best friend/sister had symptomatic fibroids and was told she needed a hysterectomy, what your reaction be? What would you tell her?]

Appendix B: Online Advertisement for Study

What it's about: Participants are needed for a study to help build understanding about the surgical treatment experiences of women with uterine fibroids. There is plenty of medical research published about the statistical outcomes of hysterectomy, however, as yet there is no research in the scientific literature that compares the common surgical treatments for fibroids, and gives voice to the women who have experienced these treatments. It is time to let your views be heard!

Who is doing it: The researcher is a doctoral candidate in the final year of her PhD at the University of Georgia. She is also a fibroid sufferer. Her published research focuses on issues of women's sexual and reproductive health.

What would be required of you: If you want to go ahead and be part of the study you will be interviewed by phone at a time convenient to you (the cost of the call will be covered by the researcher). You will have received the questions ahead of time to help you think about your experiences. The interview will be recorded and transcribed by the researcher and you will receive a copy of the transcript to read. The researcher will call you one more time for your feedback on the transcript. After that you will receive a check for \$20 to thank you for your time. [note: this line was altered for women recruited through Hyster-Home]. This study has been approved by the Human Subjects Office of the University of Georgia, and your confidentiality will be assured.

Why would you want to be in the study: To help build understanding of what women go through when they receive surgery for benign uterine conditions. If there are areas where improvements are needed, then your voice may help pave the way for changes to take place. Also, we know that African American women tend to have more numerous and larger fibroids, as well as higher rates of hysterectomy, but as yet there has been little attention given to their views. We need women who are willing to help change this situation.

Who can be included in the study: Any African American or Caucasian woman between the ages of 21 and 60 who has received surgery (either hysterectomy or myomectomy) for uterine fibroids within the last two years. Ideally, all the interviews will take place before early January of 2006. *If you are interested in taking part in this study, please email:*
julesa@uga.edu

Appendix C: Introductory Letter to Potential Participants
(to be on University of Georgia headed paper)

Dear

Re: Study to explore the treatment experiences of women with uterine fibroids

Thank you for expressing an interest in participating in this study! The primary aims of this study are, firstly, to help bring women to voice on their treatment experiences so their views can be heard in the scientific research literature, and, secondly, to begin to ascertain which areas of the surgical treatment process for uterine fibroids are in need of improvement.

Initially I hope to recruit about 30 women to my study, with a fairly even split between those who have experienced hysterectomy and myomectomy. The women should be between the ages of 21 to 60, either African American or Caucasian, and should have had their surgery within the last two years.

To date, medical research has tended to focus on statistical outcomes of these surgeries, but little attention has been paid to women's actual experiences. While some qualitative research has helped to highlight the thoughts and feelings women have about hysterectomy in general, there has as yet been no attention given to comparing the two most common surgical treatments experienced for benign uterine fibroids. As a fibroids sufferer myself, I have been made well aware of what some women experience as they make choices that could have irrecoverable effects on their body.

This study will be a qualitative interview study and if you were a participant, you would have a telephone interview with me. This would last up to about an hour, and I would use the questions enclosed with this letter to help you recall your experiences. This conversation would be audio-taped so I could transcribe it, which is necessary for the analysis. Once I have produced the transcript I will send you a copy to read, so that you can add to or delete your comments as you see fit. You can then email me to confirm whether you want any changes to be made to the transcript. Once this is completed you will receive \$20 to thank you for your time and input. The enclosed consent form explains the confidentiality process for this study. At no time would your identity be revealed.

If you would like to take part in the study, please read and sign one copy of the enclosed consent form (retain one copy for yourself) and return it in the prepaid envelope with the details of when you are available to be interviewed. All interviews need to be completed by early January 2006. If you have any questions, or know of someone else who might be willing to take part in the study, then please don't hesitate to call or email (contact details are at the top of this letter).

With best wishes,

Julie Aske w, MSc
Doctoral Candidate, University of Georgia

Appendix D: Appointment for Interview Form

When would be the best time to call you for the first interview? (Please allow time for me to receive your form)

(Please complete this form and return it with one signed copy of the consent form)

	<u>Date</u>	<u>Time</u>
Monday
Tuesday
Wednesday
Thursday
Friday
Saturday
Sunday

Your name:

Your telephone number:.....

Your email address:

Appendix E: Consent Form

An exploration of the treatment experiences of women with benign uterine conditions: uterine fibroids Consent Form

I agree to take part in a research study titled 'An exploration of the treatment experiences of women with benign uterine conditions: uterine fibroids, which is being conducted by Julie Askew, (Department of Child and Family Development, University of Georgia, telephone: 706 338 2982). My participation is voluntary: I can stop taking part at any time without giving any reason, and without penalty. I can ask to have information related to me returned to me, removed from the records, or destroyed,

Reason/Purpose

The purpose of this study is to help the researcher understand more about the experiences of women who undergo treatment for uterine fibroids.

Benefits

The benefits that I may expect from it are a reimbursement of \$20.00, which will be paid to me in full once I complete the interviews.

Procedures

If I volunteer to take part in this study, I will be asked to do the following things:

- Sign and return a copy of this consent form to the researcher in the prepaid envelope.
- Take part in a telephone interview where I will discuss my experiences of treatment for uterine fibroids. This should take no more than one hour at most. The interview will be tape-recorded and transcribed.
- Receive and read the transcript of my interview.
- Take part in a second, brief, telephone interview where I will be able to give feedback on the transcript. During this interview I can add to or delete any of the information. This second interview will also be audio-taped. This interview should take approximately 20 minutes.
- Receive payment to thank me for my time.

Discomforts or Stresses

No discomforts or stresses are expected.

Risks

No risks are expected.

Confidentiality

The only people who will know that I am a research subject are the researcher. The audio-tapes of my interviews will only be heard by the researcher and faculty members who are part of her dissertation committee. After they have been transcribed and analyzed the audio-tapes will be erased.

Further Questions

The researcher will answer any further questions about the research, now or during the course of the project, and can be reached by telephone at 706 338 2982 or by email at: julesa@uga.edu.

Final Agreement and Consent Form Copy

My signature below indicates that the researcher has answered all of my questions to my satisfaction and that I consent to volunteer for this study. I have kept a copy of this form.

_____ Name of Researcher Telephone: 706 338 2982; Email: julesa@uga.edu	_____ Signature	_____ Date
_____ Name of Participant (please print)	_____ Signature	_____ Date

Please sign both copies, keep one and return one to the researcher in the prepaid envelope.

Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542 3199; Email Address: IRB@uga.edu