# DECISIONS, DECISIONS:
# EXPERIENCES OF WOMEN WHO HAVE UNDERGONE AN ELECTIVE HYSTERECTOMY IN THE NORTHERN INTERIOR HEALTH REGION OF BRITISH COLUMBIA

by

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# Abstract

The lived experiences of women are often not heard or are dismissed, especially within the realm of health care. This is a fundamental flaw of the system since lived experience reveals a great deal about the context, relationship and structure of women lives and the health care decisions that they may need to make. Such information would be of benefit to health care providers who seek to provide quality care and service to women and who wish to promote partnership and shared decision making.

This study explores and describes women's lived decision-making experiences of elective hysterectomy. Elective hysterectomies are performed on countless numbers of women in Canada every year. However, there remains much controversy about the necessity for the surgery given the advances to medical treatments and more conservative surgery options available. Decision making thus becomes a challenge.

This study was conducted from a feminist phenomenological perspective. It takes place within the boundaries of the Northern Interior Health Region of British Columbia. Purposive sampling was used to select the eleven women. The interviews were audio-taped, transcribed and data were analysed to uncover the essential themes or "essence" of the experience.

The fundamental theme describing the decision-making experience was: "You need to do what's right for you". Supporting or connecting themes that emerged were: setting the stage, experiences of the body, involvement with doctors, alternatives and choices, knowledge is key, figuring it out, reflections of the North and outcomes.

The study found that women's decision-making experiences within the Northern Interior Health Region were indeed challenging, complex, and multi-layered. Issues related to relationships with doctors, locale, and access to information and resources emerged. The implications for social work practice include education, support and advocacy for women, their partners and doctors.

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# CHAPTER ONE

## RESEARCH QUESTION AND PURPOSE

### INTRODUCTION

Decisions, decisions. Women make them continually in their daily lives, for themselves and often for others in their immediate or extended families. Some decisions may be about the so-called small things in life, like what to wear. Others may involve weightier matters like career choices, finances or whether to put an elderly mother into a nursing home. Whatever the decision to be made, it represents use of cognitive skills and emotional sensibilities.

In the case of women's health, there is continuing emphasis on women taking charge of their own health care and thus decision making about what action and treatments are best for them (Greenberg, 1993; Linton, 1996; Stensrude, 1996). However, in order to make informed decisions, all women need to feel and believe that they are in partnership with health care providers. This is a different approach and perspective than has traditionally been the norm, both from women and health care providers (McBride & McBride, 1994). This new perspective also means promoting a shared definition and understanding of the meaning of women's health. Within the context of this thesis, the following definition is used to convey that shared meaning:

> Women's health involves women's emotional, social, cultural, spiritual and physical well-being, and it is determined by the social, political and economic context of women's lives as well as by biology. This broad definition recognizes the validity of women's life experiences and women's own beliefs about and experiences of health. Every woman should be provided with the opportunity to achieve, sustain and maintain health, as defined by that woman herself, to her full potential (British Columbia's Women's Hospital and Health Centre Society, 1995, p. ix).

Within that broad meaning, the focus of this research is on the decision-making experiences of women regarding a surgical procedure specific to women, namely hysterectomy. Hysterectomy affects countless numbers of women every year (Greenberg, 1993; Laurence & Weinhouse, 1994; O'Leary-Cobb, 1993; Stokes, 1986; West, 1994). It is the number one elective surgical procedure performed on women in Canada (Statistics Canada, 1995). In 1991-1992, the latest year for which figures are available, 58, 495 hysterectomies were carried out (Statistics Canada, 1995). However, more than 90 percent of hysterectomies are performed for benign conditions and only a small percentage are done for malignant conditions (Carlson & Eisenstat, 1995). An article, "Hysterectomies - Cure or Controversy?" (BC Woman, August, 1996) reports that of the numbers of hysterectomies performed in Canada between 1988 and 1990, only 8.7 percent were done for cancer, whereas 91.3 percent were performed for non-malignant conditions. Any non-malignant or benign condition would be considered non-life threatening and therefore would come under the realm of elective surgery. Elective surgery implies that the individual has had the time and opportunity to decide that the benefits of surgery outweigh the risks, and has consented voluntarily to the procedure. In the case of hysterectomies, the figures suggest that a significant number of women have voluntarily and perhaps unnecessarily made the decision to undergo surgery, therefore I wanted to examine the experience of decision making. What do women who have had this elective surgery have to say about the experience of deciding? What can be learned from this experience?

## IMPETUS FOR THE RESEARCH

This exploratory study takes place within the Northern Interior Health Region, one of twenty health regions in the province of British Columbia (Appendix A). I selected this region, because it is where I live and work as a medical social worker. It is also the region where I underwent the experience of deciding to undergo a hysterectomy at the age of thirty-five. My own experience of deciding was a struggle: Should I or shouldn't I? What will I feel like following surgery? Will my pain be totally eliminated or still continue to bother me? How will I feel and respond sexually? How do I know if what the doctor is telling me will apply to me? Who can I talk to about this? What will it be like to go into instant menopause? Will I feel relieved or sorry to have this done? Essentially, my experience of "deciding" was trying to consider what would fit best for me in my particular circumstances. Could other women have had similar experiences and observations making their own decisions?

Because much of women's research does start from the personal (Reinharz, 1992; Roberts, 1981; Robinson, 1993) I engaged in conversations with other women about the experience of hysterectomy and also drew on my work experience, specifically on a general surgical unit. It was not unusual to discover during a conversation at coffee break or lunch just how many women have also experienced a hysterectomy, or how many know of someone who has experienced one, or how many women have been contemplating the surgery themselves. As well, I saw almost on a daily, certainly weekly basis, numerous women who came to my place of employment in the Northern Interior Health Region to have this surgery performed. I began to wonder about the frequency of the surgery and in what way women are involved in the decision making of this procedure.

I embarked on my inquiry by searching for statistical information to see if my perception of frequency had any basis in fact. According to the Provincial Health Officer's Annual Report (British Columbia Provincial Health Officer, 1996) featuring women's health, the rates of hysterectomy vary in the province up to two-fold within the twenty health regions, with low rates in the Lower Mainland and high rates in the North. The report states that the Northern Interior Health Region had the second highest rate of hysterectomy per 100,000 women age twenty and over in British Columbia in 1993/94. In 1994, the average age of women in the Northern Interior Health Region was 30.8 years (British Columbia Division of Vital Statistics, 1994). The Provincial Health Officer indicated that the hysterectomy rates seemed too high and should be examined. He recommended that action be taken to "improve the consistency in hysterectomy rates, through the use of clinical guidelines and quality review" (p. 146).

As statistics are only one aspect of any phenomenon, I proceeded to review some of the popular literature on hysterectomies in an attempt to broaden my perspective. This inquiry revealed that there is much debate and controversy, both from women and doctors, about the necessity of hysterectomy (Cutler, 1988; Gross & Ito, 1991; Hufnagel, 1989; Laurence & Weinhouse, 1994; Payer, 1987; Rachlis & Kushner, 1989; Ross, 1996; Sheehy, 1995; Stokes, 1986; West, 1994). While much of this information was primarily statistical in nature, some of it began to put a personal, social, economic and political face to the issue. I then attempted to find research on decision-making experiences from women who live in northern areas of Canada or British Columbia and discovered that there was none. Consequently, my curiosity was further fuelled and I decided to explore the issue of hysterectomy decision-making with women who live throughout the Northern Interior Health Region.

## SIGNIFICANCE OF THIS RESEARCH

Rosser (1994) suggests that the personal experiences of women are often neglected in research and consequently sufficient information about the problem being studied is not provided. She further notes that this is particularly true of the experiences of menstruation, pregnancy, childbirth and menopause which are all exclusively female experiences. I would suggest that hysterectomy be included in this category. There is a preponderance of clinical research about women's experiences of hysterectomy however it is written from the point of view of various health care professionals. Much of the research focuses on outcomes of the surgery (Carlson, Miller & Fowler, 1994; Kinnick & Leners, 1995), impacts of the surgery on women's sexual functioning (Helstrom, Lundberg, Sorbom & Backstrom, 1993; Williamson, 1992), psychological outcomes related to depression (Ryan, Dennerstein & Pepperell, 1989) and the like. However, studies on hysterectomy which place women in the centre of the research and examine the issues from the perspective of women as "knowers" of their own experience is limited, but growing (Chasse, 1991; Harris, 1993; Linenberger, 1996; Lockett, 1995; Webb, 1984).

There is no research on the phenomena of hysterectomy in the Northern Interior Health Region. Therefore, my intent through this research is firstly, to add to the growing collection of research which takes the "lived" experiences of women into account. Secondly, the exploratory nature of the research focuses on a single aspect of hysterectomy, namely decision-making and offers descriptive insights within the context of a specific geographic location. Thirdly, the intent of the research is to offer awareness and information about women's decision-making experiences to those who will have contact with women who are trying to decide, namely family and friends and the many health care providers; doctors, nurses, medical social workers and counsellors. It is anticipated that this research may provide these professionals with a more informed appreciation of the complexity of the experience for women and thus the opportunity to incorporate that knowledge into their respective practices. Lastly, it is also hoped that the descriptions of the experience will hold meaning for other women who have had this experience, but more importantly, will assist those women who are trying to decide.

## CONDUCTING THE RESEARCH

The intent of any research endeavour is to produce knowledge and contribute to the discourse in particular areas. However, the way in which the knowledge is produced and communicated is dependent upon the approach or methodology chosen by the researcher. The methodology is considered the framework which guides or directs the process of defining the research question, collecting, analysing and interpreting the data and finally writing the conclusions (Marshall & Rossman, 1995). A methodology is also a reflection of beliefs, values or commitments to a particular philosophy or way of viewing the world. My worldview comes from being a woman, a feminist and a medical social worker. As such, it was important to me to conduct this research both from a woman's perspective and her perception of her experience, because I believe and others have shown (Fisher, 1994; Lorber, 1997) that women's health care experiences are often discounted or are simply dismissed by the medical system. Therefore I chose to combine two frameworks, phenomenology and a feminist perspective, because both allowed me access to the "lived" experience of this particular phenomenon in the lives of women who have had this surgery. Phenomenology, which is the study of lived experience, offered an approach to inquiry that is continually aiming to understand the nature or essence of human experience (van Manen, 1990) such as the decision-making experience. A feminist perspective also considers the world as it is lived and experienced by women. However, feminist analysis focuses upon the need to challenge and redefine the prevailing notions or concepts of women's lives, as they have been defined from a male viewpoint or one that ignores gender, and not from the "lived" experiences and knowledge of women. Because such prevailing concepts, particularly in the health field, continue to oppress women, a feminist perspective allows for alternative ways of viewing and changing this thinking. I also chose these frameworks because both share my value of the intrinsic worth of the person, and my belief that one's personal experience is of value in the search for meaning and understanding about the world and how we know it. I also believe that to understand any human experience, one must be open and receptive to all aspects of the phenomena, as there are many truths which are equally valid and deserve voice (Bricker-Jenkins, 1991). Both of these frameworks support that belief. Finally, I believe that context and social structures or institutions are part of human reality and cannot be ignored in the discourse created about women's lives. Both phenomenology and a feminist perspective aid that belief because both acknowledge that perceptions are manifest within one's personal experience and reality. Thus, the question posed by this research, "What is the "lived" decision-making experience of women who have undergone the elective surgery of hysterectomy in the Northern Interior Health Region?" was explored from a feminist phenomenological perspective, which will be discussed more fully in Chapter Three.

## SUMMARY

The Northern Interior Health Region is an area where a high number of hysterectomies are performed. There are no research studies from this area which address any aspect of the phenomenon, therefore the aim of this research is to explore and describe through the "lived" experiences and voices of women, the decision-making experience of having an elective hysterectomy. Accordingly, this study is presented in five chapters. Chapter Two presents a review of the literature on hysterectomy, particularly the controversies that surround the surgery. It also reviews literature on women's medical decision making and how this relates to hysterectomy decision making. Chapter Three details the process of conducting the study. Chapter Four presents the description and analysis of the participant's decision-making experiences. The final chapter summarizes the thesis and provides concluding remarks and recommendations.

# CHAPTER TWO

## REVIEW OF THE LITERATURE

### INTRODUCTION

Hysterectomies are typically elective procedures, but the decision to undergo the surgery can be difficult. According to Kinnick and Leners (1995), "a doctor may recommend the surgery, yet popular literature and media in the last decade consistently tell women that too many unnecessary hysterectomies are being performed and the outcomes may be undesirable" (p. 133). Therefore, in order to understand the decision-making experiences of women who have undergone a hysterectomy, it is essential to outline what a hysterectomy is, the common medical indications for the procedure and some of the alternative treatments. Next I will review the controversies that surround this surgery. Lastly I will present literature about decision making itself with respect to women's health care issues, and specifically to hysterectomies. I will do this through the review of popular books, articles and research studies that pertain to the topic, and offer some perspectives on decision making. The popular books were chosen because they are likely to be some of the main sources of information most women would have access to either through libraries or bookstores. The research studies are the information sources that many health care providers might consult. I have attempted to restrict the use of books and articles as much as possible to the last ten years to ensure relevance. I have also attempted to include as much information from Canadian sources as possible given the Canadian context of this study.

## THE SURGERY

All of the literature confirms that hysterectomy ranks as one of the most frequently performed surgeries in Canada and the United States (Cutler, 1988; Greenberg, 1993; Gross & Ito, 1991; Hufnagel, 1989; Laurence & Weinhouse, 1994; Linton, 1996; Payer, 1987; Rachlis & Kushner, 1989; Sheehy, 1995; Stokes, 1986; West, 1994). There are differing opinions and hypotheses as to why this practice continues with such frequency and these controversies will be reviewed in the next section. However, in order to begin to understand these phenomena and how they relate to women's decision-making experience, it is important to define what is meant by this surgical procedure and to outline the common medical diagnoses which indicate a hysterectomy.

Hysterectomy is, by definition, the removal of a vital female organ, the uterus (Cutler, 1988; Greenberg, 1993; O'Leary-Cobb, 1993; Strausz, 1993; West, 1994). A total hysterectomy usually involves cutting away the cervix, which is the mouth of the womb, as well as the uterus; a subtotal, or partial hysterectomy, leaves the cervix intact (Ross, 1996). Often a hysterectomy involves removal of one of the ovaries, a procedure known as oophorectomy. For many women, the surgery may also involve the removal of both ovaries, fallopian tubes and the cervix, technically known as a hysterectomy with bilateral salpingo-ovariectomy.

Hysterectomies are frequently recommended and performed for such common non-malignant conditions as fibroids, pelvic pain, uterine prolapse, stress urinary incontinence, abnormal bleeding, endometriosis and cervical dysplasia (changes in cervical cells that may progress to cancer) (Laurence & Weinhouse, 1994, p. 171). These conditions are also cited as reasons for hysterectomies in 1993/94 in British Columbia (British Columbia Provincial Health Officer, 1996).

Abdominal hysterectomy is the most common surgical approach (Strausz, 1993: West, 1994). Vaginal hysterectomies account for about twenty percent of surgeries and are increasing in popularity because as a general rule they cause less postoperative pain than abdominal procedures and require shorter lengths of hospital stays (West, 1994). The newest approach to hysterectomy is laparoscopic-assisted vaginal surgery. The advantage of this type of surgery is that the small incision means even shorter hospital stays, less pain and more rapid recuperation (West, 1994). However, as O'Leary-Cobb (1993) points out there are few surgeons skilled in this procedure and it will not suit all women. She also cautions that as laparoscopic-assisted vaginal surgery becomes more common, women may be more easily persuaded to this surgical rather than non-surgical alternative and that we will see an increased incidence of hysterectomies and oophorectomies.

According to Greenberg (1993), Hufnagel (1989), and O'Leary-Cobb (1993) there are also medical alternatives such as medications, diets and exercise to alleviate the symptoms of most of the gynaecological conditions and thus reduce the need for hysterectomies. As well, according to Women's Health Matters (1995) there are surgical alternatives to specific conditions that would decrease or eliminate the need for hysterectomy. For instance, in the case of fibroid tumours, a myomectomy, a surgical procedure that results in the removal of the fibroids without removing the uterus, can be performed. However, depending upon the size, number and location of the fibroids, a myomectomy may be a longer, more complicated, riskier procedure than a hysterectomy and for that reason, it may be difficult to find a surgeon with the necessary skills.

A myomectomy also requires more operating room time which many Canadian hospitals may not have the capacity or resources to provide.

Another surgical alternative for women who want to reduce long and heavy periods and who no longer wish to become pregnant, is endometrial ablation ("Women's Health Matters," 1995). This procedure involves the removal of all of the three layers of the endometrium (uterine lining) using an electric source or lasers. Endometrial ablation has an 80 percent success rate, preserves the uterus and avoids a surgical incision. Uterine bleeding may not stop entirely but it will be much lighter. The latest procedure for women who are experiencing excessive uterine bleeding because of hormonal changes which precede menopause, is uterine thermal balloon therapy ("Women's Health Matters," 1995; Gray, 1996). A small latex balloon catheter is inserted into the uterus, filled with sterile water and heated to 87 degrees Celsius. The uterine lining is blanched and sheds. The procedure is performed under general anaesthesia on an outpatient basis and women can usually return to work the next day.

Hence, given the advances to both medical and surgical alternatives, it is surprising and perhaps distressing, that such large numbers of women continue to have their uteruses removed. A review of the controversies surrounding this surgery provides a frame of reference for the discussion and the dilemmas which confront women during the decision-making process.

## THE CONTROVERSY

Advocates of women's health care (Cutler, 1988; Hufnagel, 1989; Laurence &Weinhouse, 1994; Payer, 1987; Reider, 1994; Sheehy, 1995; Stokes, 1986; Strausz, 1994; West, 1994) argue that hysterectomy is an unnecessary surgery. These arguments inform the discussion and consequently the process of informed decision making. So what are the controversies that women will hear about as they try to decide?

One aspect of the controversy surrounding hysterectomy is the fact that having this surgery for any of the aforementioned gynaecological conditions is generally unnecessary. Some women's health experts argue that, with the exception of emergency surgery, cancer may be the only justification for a hysterectomy and even that may be further qualified (Laurence & Weinhouse, 1994; Reider, 1994; Strausz, 1993; West, 1994). Cervical cancer, for instance, if caught in its earliest stages may be responsive to more conservative strategies such as laser treatment and cone biopsy, rather than necessitating a hysterectomy (Greenberg, 1993; Ross, 1996). As mentioned in the previous section, alternative medical and surgical procedures are available for consideration before deciding to undergo a hysterectomy.

Another aspect to the controversy is whether a hysterectomy will improve or enhance a woman's quality of life. The Maine Women's Health Study was a prospective study to assess the effect of hysterectomy for non-malignant conditions on women's symptoms and quality of life and to identify adverse effects one year after the surgery (Carlson, Miller & Fowler, 1994). The study population of 418 women aged 25 to 50 years was primarily white, employed and medically insured. The authors used three measurement indices, the Mental Health Index, the General Health Index and the Activity Index to assess quality of life just prior to the surgery and at three, six, and twelve month intervals following the surgery. The study concluded that hysterectomy was highly effective for relief of symptoms associated with the common non-malignant gynaecologic conditions and that symptom relief was associated with marked improvement in quality of life. No mention however, was made to what, if any, alternative measures had been tried by the women prior to deciding to undergo a hysterectomy.

Another study by Kinnick and Leners (1995) of thirty women undergoing elective hysterectomy also concluded that women's quality of life increased significantly post-operatively as the physical problems they had been experiencing were relieved, thus making a real difference in their lives. The authors cautioned however that because the subjects in this study were a highly educated group and tended to be from the middle to upper socio-economic class, additional prospective research needed to be done from different economic and cultural perspectives to further support this claim.

Henderson (1995) found in her retrospective study of 370 women, ages 20 to 79, who had undergone a hysterectomy for non-malignant conditions, that 82 percent felt that their life was much better or a little better as a result of the hysterectomy. The main benefits cited by the women were relief from pain and from heavy bleeding. However, even though most of the women reported improvements in symptoms experienced post-hysterectomy, many had symptoms or problems which had been caused or made worse by the hysterectomy. The main problems and symptoms identified were hot flashes, dry vagina, weight problems, decreased interest in sex and low energy levels. Henderson suggests that these results highlight the need to look more closely at the decision-making processes of both the physicians and their women patients, about the benefits and risks of a hysterectomy.

Another aspect of the controversy surrounding hysterectomy involves the importance or value of the uterus. There is increasing clinical evidence to suggest that this organ performs a significant role in the ongoing health and well-being of a woman (Cutler, 1988; Greenberg, 1993). The uterus produces substances that affect brain function and reduce the risk of cardiovascular disease. As well, the uterus and ovaries together are responsible for maintaining the various hormonal cycles of estrogen, progesterone, androstenedione, testosterone, FSH and LH (the gonadotropins) and the beta endorphins (Culter, 1988). These hormones play an important role in the healthy functioning of the female body.

Stensrude (1996) suggests that the medical profession still equates the value of the uterus with that of reproduction and downplays or dismisses evidence that the uterus has some function within the nervous system and with sexual response. West (1994) states "prevailing medical wisdom holds that the uterus is a disposable organ that serves no useful purpose once a woman has all the children she wants. What's more, it is regarded as something of a nuisance" (p. 18). Women in their forties and fifties often feel the pressure to undergo hysterectomies and oophorectomies because of this thinking. Sheehy (1995) uses the term "hysterectomy trap" to describe the dilemma faced by women when presented with the message from doctors that hysterectomy is one way to survive cancer of the uterus or ovaries once women are beyond childbearing age. She suggests that doctors do not warn women sufficiently about the lifelong effects of instant menopause, that may place a woman at risk for depression, loss of sexual desire, osteoporosis and heart disease. Sheehy challenges women to be empowered and knowledgeable consumers in the face of a medical community continuing to define and assert their beliefs about the value of women's reproductive organs.

Another contemporary example of this belief appeared in the Hastings Center Report (Dwyer, Cerfolio, Murray & Rosenthal, 1996). Two sets of doctors (each set comprised of one male and one female) were asked to comment on a case study of a thirty-nine year old woman diagnosed with fibroids who did not wish to undergo a hysterectomy even following a second opinion. Instead, she wanted an alternative surgery called a myomectomy (a surgical technique to remove fibroids) in order to preserve her uterus. The doctors' debate centred on whether or not the woman had the right to insist on a surgery which the doctor had not recommended. One set of doctors reframed the issue and stated that it was important to first understand what losing a uterus would mean to this woman and that " a patient's willingness to undergo a particular therapy is not an isolated, technical choice, especially when the consequences of the decision signal dramatic changes to a person's life story" (p. 29). The other set of doctors' responses was to pathologize the woman's case and essentially suggest that it is the doctor alone who determines what is a reasonable procedure or option. This article suggests that doctors continue to be very influential when it comes to women's health care decision making, both about the value of the organ being considered for removal and for the decision of how surgery will be performed. West (1994) refers to this as "doctor's style" and characterises it as the doctor's beliefs and attitudes about what is in the best interests of their female patients and how they approach changes in knowledge and treatments for women that are communicated to women when they are trying to make decisions about their health care.

Another issue in the controversy about hysterectomy is the variation in rates across geographic areas in North America and other countries (British Columbia Provincial Health Officer, 1996; Rachlis & Kushner, 1989; Roos, 1984; West, 1994). Sources from the United States contend that if you are a woman living in the South or on the West Coast, you are more likely to have a hysterectomy than if you live in the Northeast or Midwest (Ross, 1996; Strausz, 1993; West, 1994). In Canada, rates vary from province to province. The rates performed in eastern Canada are significantly greater than the rates in western Canada (Abramson, 1994). Abramson (1994) observed for example, that if you live in Newfoundland you have a 61 percent greater chance of having a hysterectomy compared to a woman living in Saskatchewan. That particular statistic was not always the case. As Rachlis and Kushner (1989) report, between 1964 and 1971, the provincial rate for hysterectomies in Saskatchewan jumped 72 percent, even though over the same period the number of women over fifteen increased only by about eight percent. At the request of the provincial health minister, the Saskatchewan College of Physicians and Surgeons set up a surveillance committee to establish criteria to justify hysterectomies and they in fact monitored decision making in seven hospitals. The result of this surveillance was a one-third drop in the total number of hysterectomies in Saskatchewan between 1970 and 1974 (Rachlis & Kushner, 1989). Finally, rates vary within areas in provinces, which is certainly confirmed in British Columbia (British Columbia Provincial Health Officer, 1996). For example, in 1993/94, the Vancouver Health Region had the lowest number of hysterectomies at approximately 320 per 100,000 women, whereas the Northern Interior Health Region had the second highest number of hysterectomies, at approximately 710 per 100,000 women. Only the Peace River Health Region had more, approximately 720 per 100,000 women. A study in Ontario showed that while the overall age-adjusted rates had declined from 1985/86 to 1994/95, the variations from county to county were large (Cohen, 1994). A woman living in the county with the highest rates was eighteen times more likely to have a hysterectomy than a woman living in the county with the lowest rate (Cohen, 1994). This analysis also illustrates the difference between hysterectomy rates performed in areas of northern Ontario as compared to southern Ontario (Cohen, 1994; Linton, 1996).

Strausz (1993), Travis (1988) and West (1994) all argue that the variations in rates can be explained by a gynaecologist's interest in surgery, rather than suggesting alternative, non-surgical methods. Surgeons do not earn a living unless they do surgery. However many of the newer techniques require specific training and skills and many physicians are not trained in these procedures and therefore they do not offer them as options to their patients. Strausz (1993) further argues that when clinical guidelines are not clear as to which conditions necessitate surgery and which do not, ambiguity favours the doctor and the surgery is often performed. According to Dr. John Wennberg, a professor of epidemiology from Dartmouth Medical School in Nova Scotia and the director of the Centre for Evaluative Clinical Sciences, perhaps as many as half of all elective surgeries are inappropriate because patient preferences are not properly taken into consideration in the decision-making process (Rachlis & Kushner, 1994). Carlson, Nichols and Schiff (1993) also assert that professional uncertainty about the appropriateness of hysterectomy was the primary cause of variations in rates. They further suggest that the uncertainty was thought to stem from difficulties in diagnosis, lack of information on the probable outcomes of hysterectomy and alternative treatments, and differences between physicians' judgements and patients' preferences for treatment.

A study by Bernstein, McGlynn, Siu, Roth, Sherwood, Keesy, Kosecoff, Hicks and Brook (1993) compared the appropriateness of hysterectomy across seven health care plans in the United States. The study was in response to reports in the professional and lay literature that there was a potential overuse of hysterectomy surgery in the fee-for-service sector, but also concern that perhaps there may be an underuse of the surgery for economically disadvantaged women in either fee-for-service or the managed care system. A list of indictors for the surgery was developed and rated for appropriateness by a panel of managed care physicians. The authors reviewed 642 patient records and concluded that fifty-eight percent of the patients underwent hysterectomy for appropriate reasons, twenty-five percent for uncertain reasons and sixteen percent for inappropriate reasons. The proportion performed for appropriate indications was forty-four percent in the 21 to 40 year old age group compared to eighty-three percent in patients aged 60 years and older. The study concluded that the inappropriate rates were similar to those for other procedures. However, this information was valuable in terms of making improvements to surgical care and to inform consumers so that they could better decide which health care coverage to use.

Laurence and Weinhouse (1994) and Travis (1988) posit that the incidence of hysterectomies in the United States do vary by race and class: poor women, women without a college education, and African-American women are all more likely to have the surgery. Ross (1996) concurs by citing a study conducted by the University of Maryland School of Medicine, which reported that women with less education and lower incomes were more likely to receive hysterectomies than women of higher education and greater incomes. However, the study found no difference in rates due to race (Ross, 1996). The study suggests that one reason for higher rates of hysterectomies among women of lower socio-economic class is that these women are less likely to receive regular gynaecological check-ups and actual medical problems are not as likely to be caught in the early stages when hysterectomies can be avoided. This study lends support to the view of Clancy and Massion (1992) that women's health care in the United States is "a patchwork quilt with gaps" and that access to health care still has many barriers for women.

In Canada, a study by Roos (1984) in Manitoba focused on the practice of hysterectomy across thirty-three hospital catchment areas, encompassing ninety-two percent of the province's population. The study found that hysterectomy rates varied five-fold across the hospital areas, however no systematic variation in rates was found according to level of education of women aged twenty-five and over, or in any variety of income measures used. The study did suggest however, that ethnic and cultural factors needed to be considered, as the area with the highest number of surgeries represented three very specific ethnic groups within that province, namely Catholic French, Polish and Italian women.

In terms of ethnicity, Behar (1993) provides an ethnographic account of a young Mexican American woman's experience of hysterectomy. The story of Marta portrayed how a woman's life experience, her medical history, her culture and her class are all entwined. The account also showed how difficult it is to withstand the power and influence of the medical system which represented an androcentric perspective and displayed little interest in understanding her from the perspective of what a hysterectomy would mean to her. Instead the system viewed her housing a body part in need of removal and that body part, the uterus, was seen as a commodity. Marta, wanting to be a good wife, mother and American citizen, put her faith in an institution that she believed was there for her health and well-being and thus had a hysterectomy that was later found to be medically unnecessary. Behar contends that what happened to Marta can happen to any woman, of any age and ethnic background, and challenges women to speak out about their experiences so that other women may have the benefit of learning from them.

A final issue in the controversy regarding hysterectomies is whether or not fees or fee structures factor into the equation. West (1994) suggests from studies done in the United States that financial motives on the part of doctors cannot be dismissed. He contends that there is no doubt that hysterectomies are performed less often under prepaid health plans than when doctors are compensated directly for the surgery (West, 1994). The majority of doctors in Canada are paid on a fee-for-service basis, "a system that provides payment for each billable service a doctor provides" (Rachlis & Kushner, 1994, p. 165). As Rachlis and Kushner (1994, 1989) suggest, it would be naïve to assume that the fee schedule has no influence on the way doctors practice medicine, as the fees differ widely for specific services. In general, invasive procedures, such as surgery, fibroscopic endoscopy, catheterizations, and so on, pay the most (Rachlis & Kushner, 1994). Thus, they suggest that doctors are rewarded more for cutting and prodding than they are for listening and thinking and, because gynaecologists are surgical specialists, many will derive their incomes from performing hysterectomies.

In an area such as the Northern Interior Health Region, the numbers of hysterectomies performed are likely to reflect all of the controversies suggested in the literature. Which controversies may be more influential in the decision-making experience may be illuminated in this study. However, these controversies which are made up of issues related to values, economics, geographic location and doctor's style, suggest to me that the decision-making experience for women must truly be a challenge.

## WOMEN'S HEALTH CARE DECISION MAKING

Within the realm of literature on women's health care decision making and specifically in relation to hysterectomy, there are differing thoughts, experiences, approaches and hypotheses about how this process can be shared between women and health care providers. To begin the discussion of women's decision making, I will provide a definition of the term. The Concise Oxford Dictionary (Thompson, 1995) defines decision as "an act or process of deciding; a conclusion or resolution reached, especially as to future action, after consideration; a settlement of question; a formal judgement; a tendency to decide firmly; resoluteness; a choice" (p. 348). Decision making then is the process an individual undertakes to make a choice. In the case of any health care concern, decision making may range from the simple to the complex depending upon the degree to which the woman perceives the risks or benefits of any action or treatment to her body integrity and personal situation. However, in order to make a decision it is necessary to have access to a full range of information, provided in a meaningful and understandable manner. Then the individual must possess the ability to apply that information to one's own circumstances and communicate the action to be taken. Within health care this is generally known as providing informed consent. Informed consent is defined as:

> The consent given by a person after receipt of the following information: the nature and purpose of the proposed procedure or treatment, the expected outcomes and the likelihood of success, the risks, the alternatives to the procedure and the supporting information regarding these and the effect of no treatment or procedure, including the effect on the prognosis and the material risks associated with no treatment. … Informed consent promotes individual autonomy, protects patients, avoids duress, encourages introspection by health care professionals, and involves the public in promoting autonomy and controlling biomedical research. (Thomas, 1997, p. 433).

So how do women ensure that they have all the facts and are part of the process for informed decision making?

Kaplan (1994) suggests that there may be greater patient involvement in the decision making process if the focus of medical decisions is directed to functional patient outcomes based on health and well-being, rather than the biomedical disease model based on signs and symptoms. While most patients are understandably concerned with the short-term consequences of procedures, it is generally the long-term benefits that most want to achieve when they agree to undergo procedures. He states that there have been substantial studies on the aspects of mortality and the short-term morbidity with respect to hysterectomy, however the long-term benefits have still not been conclusively established. He suggests that the need for further studies, focusing on quality of life and the effects of the surgery on the day to day lives of women, will likely be of more interest and substantive benefit to them in their decision making.

Hodne and Reiter (1994) and Hodne (1995) assert that "models of medical decision making and informed consent are becoming more oriented to patients' expectations, as they have been influenced by health consumerism, the health component of the women's movement and the research on patient-physician communication"(p. 162). They suggest that compared to traditional models, "patient-centred models include greater rights and responsibilities for patients and highly interactive patient-provider communication and decision-making" (p. 162). The authors present two emerging patient-centred models for consideration. Firstly, Gambone and Reiter's PREPARED ™ informed consent mnemonic model allows a patient to explore a health decision in a systematic manner: (1) the Procedure; (2) the Reason for the procedure;

(3) the Expectations for benefits; (4) the Probability of benefits occurring; (5) the Alternatives; (6) the Risk; (7) the Expense; (8) the Decision (p. 163). The second model devised by Ballard-Reisch includes three phases with eight stages.

> Phase 1: Diagnostic: stage 1: information gathering; stage 2: information interpretation
>
> Phase 2: Exploration of treatment alternatives: stage 3: exploration of alternatives; stage 4: criteria established for treatment; stage 5: weighing of alternatives against criteria
>
> Phase 3: Treatment decision, implementation and evaluation: stage 6: alternative selection; stage 7: decision implementation; stage 8: evaluation of implemented treatment (p. 163).

The authors suggest that both of these decision-making models offer the opportunity for improved satisfaction in decision making for patients as they encourage interaction and taking control of one's health. The models are meant to improve communication and understanding, as well as facilitate a process whereby the doctor and patient can assess their progress on the decision. While both models provide useful frameworks, the authors acknowledge that other social and contextual factors play a role in women's health care decision making. Contextual factors include gender of the doctor, cultural and social differences of the doctor and the patient, and patient-doctor communication. Social factors such as the woman's present illness, other stresses in her life, her individual coping style, and social support systems will also influence participation in decision making. However, the authors contend that these types of models are an improvement with respect to shared decision making, and they encourage women and health care providers to continue to use and refine them.

Travis (1988) asserts that there are a number of factors which tend to interfere with women being able to make health care decisions, however the physician-patient relationship is an especially significant one. She contends that this relationship, which is generally a male–female relationship, is fraught with issues of control, authority and power. Her analysis suggests that because the institution of medicine, through its educational process, continues to "mirror the subordinate status of women in society" (p. 26), it perpetrates negative stereotypes about women. This form of oppression does not allow women to exercise their rights to information, autonomy and self-determination. Travis further suggests that "women who take up physician time, ask questions, or demand to be counselled on treatment issues are identified as problem patients and become likely targets for sedation" (p. 27). Thus she puts forth the hypothesis that sexism, racism and classism may exist in medical decision-making since all hysterectomized patients are women and the vast majority of surgeons are men. Travis suggests that this hypothesis is supported by such "radical perspectives, represented by Daly in her book *Gyn / ecology* (1978), … that male surgeons use the respectability of a medical degree to legitimize a sort of ritual violence against women" (p. 193). This perspective suggests that it is men who benefit from this surgery, both economically and structurally by maintaining control of women's bodies. Travis points out that historically, black women have had the highest rates of hysterectomies in the United States. One explanation is that black women have higher rates of conditions, such as fibroids, but that cannot be the whole story. Travis suggests the potential of racism and classism exists because black women, women from other ethnic and racial minorities, and women from lower socio-economic classes have all been subject to having hysterectomies performed as a result of the social issues surrounding contraception and sterilization. For Travis, decision making is no where near the level of shared responsibility to which many women's health advocates aspire. However she continues to encourage women to practice consumer awareness, demand informed consent and take charge of their bodies (Travis, 1988).

In Oregon, in response to complaints that women were not being adequately informed about the effects of recommended hysterectomy surgery, the Oregon state legislature considered enacting a bill that would require a woman to sign a form stating that she had been informed about the procedure, the risks and alternatives (Rose, 1992). However, after several legislative committee meetings it was determined that such a requirement would not ensure that a woman's overall knowledge would be increased. Rather it was determined that an educational approach was a more appropriate strategy. As a result, an educational booklet was produced with input from consumers and doctors. The information emphasised the woman's right to ask questions and that the final decision was hers. Booklets were mailed to doctors, hospitals, clinics, women's health care agencies and to individuals (Rose, 1992). Rose indicates that there is no evidence, as yet, that the booklet had been effective. However, it is anticipated that this material will help to reduce complaints of inadequate information and demonstrate that this type of collaboration between public health, doctors and consumers is a better way of protecting consumer health than a law.

A descriptive study by Harris (1993) regarding women's decision making about an elective hysterectomy suggests that there are several complex interrelated variables or factors which influence the decision. Harris offers five defining characteristics of decision making: personal attributes, knowledge, choice, power and resolve, all of which need to be present in order for a decision to have been made. Harris concludes that of the fifty-six premenopausal women with benign disease, who underwent elective hysterectomies, only thirty of the women had all five defining characteristics of decision making. The twenty-six of the women who did not have all five characteristics felt that they had no choice or were not given alternatives. The findings of the study indicate that patients do not necessarily play an active role in their own decision making and that there is a need for more prospective research into patient's information preferences and the impact of information disclosure by physicians on the decision-making process.

A retrospective study by Ward and Heidrich (1989) which considered factors that women take into account when deciding about the type of surgery for breast cancer, reported that the twenty-two women involved preferred "people" sources of information rather than written or videotape materials. The authors thus cautioned that relying too heavily on this type of informational and educational material, especially in financially constrained times, does not take consumer preference and expectations into account. The study also touched on the issue of information disclosure by physicians. Of the twenty-two women interviewed one to two weeks postsurgery, several noted that the surgeon's opinion was an important consideration in their choice. This was an interesting finding since the surgeon had not expressed an opinion at all, but had only presented the facts of each of the surgery alternatives. In other words, some of these women "heard" an opinion, interpreted a preference by the surgeon for one surgical alternative over the other, and made a choice or decision to go with the surgery they thought that the surgeon preferred. The authors suggest that this poses an interesting dilemma, specifically when there is no evidence to support one alternative being better or more preferable than another.

Hence, they conclude that advanced communication skills on the part of health care providers, whether they are doctors, nurses or social workers are necessary to facilitate the decision-making process. The same could be said to hold true for health care providers involved with women who are making the decision about hysterectomy. However I would suggest that the male-female doctor patient relationship advanced by Travis (1988) may provide a more meaningful analysis.

Haas (1992) claims that there are six reasons why there is no consensus regarding when a hysterectomy is appropriate or indicated, thus rendering decision making a difficult task. Firstly, there is failure to conceptualise the problem adequately because the various symptoms of gynaecological conditions are complex and overlapping, making it difficult to determine which symptom is to be treated. Secondly, there is a long history and tradition in gynaecology that supports the belief that removing the uterus will offer the "one time cure all" (p. 866). Thirdly, there is a lack of consensus on the definition of symptoms that warrant surgery. In other words, how much bleeding or pain is too much and for how long. Fourthly, there is inadequate clinical research on the outcomes of hysterectomy, particularly quality of life issues. Fifthly, most of the studies in the current literature evaluate the outcomes of hysterectomy retrospectively and do not distinguish between women who have undergone oophorectomy with their hysterectomy. And finally, there is a tension among the various stakeholders of this surgery, namely the patients, the doctors, the insurers and society. Haas maintains that a better way to consider this issue is to ask the question, "How do we make the decision to do a hysterectomy?" (p. 867). She challenges doctors to consider a framework that reviews and evaluates aspects from a physical, psychosocial and preference approach. These aspects can then be plotted on a decision tree for both the doctor and woman to discuss. The ultimate decision Haas (1992) concludes, rests with the woman. However the doctor has the responsibility to ensure that accurate medical information has been provided and that questions that will lead the woman to define her values have been asked.

An exploratory study by Chapple (1995) explored the experiences of women who were seeking information and alternatives to hysterectomy within the context of the British National Health Service and the private paying system in Britain. Forty-five women in total were interviewed. The majority were seen by consultants working for the National Health Service and received treatment free of charge, while the others were privately paying patients. Half of the women were well educated and the other half had the equivalent of a Canadian high school education. The study concluded that doctor-patient communication was one of the most important factors in seeking information, however the current practice in providing information to women was seen to be inadequate. Not surprisingly the women who were seen by private consultants expressed the most satisfaction with their overall experience because the doctor did not appear to be pressured by time. However, that satisfaction did not necessarily translate into the women being more informed and knowledgeable about possible alternatives or complications of hysterectomy. Similarly, women seen by National Health Service doctors did not receive adequate information because they were rushed, had little privacy and were not encouraged to ask questions. The author recommends that, given the current structure of the National Health Service, consideration be given to hiring professional counsellors who would have the time, knowledge and communication skills to assist women with questions, concerns and the decision-making process. She also suggests that the opportunity to be seen by a professional counsellor be an option for private paying clients as the adequacy of the information for women in that structure was somewhat questionable.

Reider (1994) suggests that women who have been advised to have a hysterectomy might have some difficulty sorting out the benefits and the risks due to their physical illness and stress. She advises that this may leave women vulnerable, feeling pressured to "get it over with" and thus decrease their ability to be active information seekers and decision makers. Reider (1994), Linton (1996), and O'Leary-Cobb (1993) all state that taking control of your health means persistence and suggest the following as advice for women in making the right decision: (a) take a partner, friend or health advocate when discussing the information and decision with the doctor; (b) talk with other women who have had a hysterectomy; (c) seek out a second opinion; (d) seek out current information about this procedure; (e) do not automatically reject other treatments; (f) try to reduce stress; and (g) know that you have the right to refuse or withdraw from treatment at any time (Reider,1994).

A study by Logothetis (1991) on women's decision making about estrogen replacement therapy (ERT) is applicable to the discussion of hysterectomy because of the divergent and controversial nature of this therapy or treatment on the lives of women. It may also be relevant to the decision-making experience because many women who decide to have a hysterectomy involving oopherectomy will have to grapple with whether or not to consider ERT. The author suggests that the health belief model, which tests for the perceptions of four constructs, namely, susceptibility, seriousness, benefits and barriers, would be a useful model to understand the influences on women's decisions about whether or not to use ERT. From the information gleaned from the survey results of 252 women, Logothetis reported that the most important factor in the women's decision making about ERT was their perceptions about the benefits weighed against the barriers. Women commented most upon the need for more accessible and reliable information about both ERT and menopause in order to make this personal decision. Women also suggested that more research in this area of women's health was necessary. The author suggests that health care providers should take up this challenge as they are instrumental in promoting informed decision making.

A study by Chasse (1991) to explore the process of recovery following a hysterectomy found that women could not just focus on recovery, but that they also needed to put the experience into perspective by describing the events surrounding the hysterectomy. This description included the decision-making process. The author found considerable variation in the way that the women made their decisions. Some of the women made the decision themselves; others consulted with their doctors and partners. One woman stated that the decision was made for her by her doctor and husband with no consultation with her about her thoughts and feelings. Another woman left the decision entirely to her doctor because of her worry that her health problem might be cancer. Many of the women decided to have the surgery when they realized that they could no longer cope with their symptoms. One woman expressed that she had to come to terms with losing a part of her body before she could decide to go ahead with the surgery. Another woman struggled with the decision-making process because it meant that she and her partner had to give up their plan of having another child. Thus the process of decision making involves relational, emotional and cognitive aspects. But it was the recovery experience itself that seemed to indicate to women, whether or not the decision to have a hysterectomy had been the right one for them.

A grounded theory study by Lockett (1995) also explored women's experience of hysterectomy. Under the process called "shaping the hysterectomy experience" the women identified several factors which could be considered essential to the decision-making process. The factors included: aging, evaluating reasons for the surgery, acknowledging personal feelings surrounding the surgery, interpreting timing of the surgery, incorporating sequencing and experiencing contextual purity. The ten women in the study concluded that the hysterectomy experience was definitely a process and how they felt about their hysterectomy changed over time. There was a recognition and a voicing that having a hysterectomy involved more than just having a body part removed.

And finally, Linenberger's (1996) phenomenological study of women's lived experience of hysterectomy described the recovery experiences of women at one week, eight weeks, six months and one year after the surgery. Sixty-five women from a metropolitan area in South Central United States were recruited for the study. From the study four common elements or concepts were derived including decision making, which provided a description of women's recovery after hysterectomy. The study found that at one week, the women were unsure about the decision to have a hysterectomy as they continued to heal. At eight weeks the women were pleased with their decision as their energy and activity levels resumed. At six months, the decision was internalised and many described having a better quality of life. At one year, most of the women had assessed their decision as good for themselves and the experience was now merely a part of their history. Four women who were childless, however, expressed regret about not being able to have a child.

The literature on women's health care decision making involving hysterectomy reveals an array of viewpoints and issues about the process and about the notions of shared decision making and informed consent. What was most apparent to me was that making the decision to have a hysterectomy is not a straight-forward proposition, either for doctors or women. This complex phenomenon involves issues of communication between doctors and women, issues of access to relevant information and knowledge, and issues related to social and contextual factors. While the models presented in Hodne and Reiter (1994) and Hodne (1995) are useful guides in the decision-making process for women and doctors, the process itself requires more examination. Several of the studies provided examples of women either not being involved or perceiving that they were not involved in decision making. This suggests that further approaches are necessary to ensure that women are provided with an atmosphere and opportunity to take charge of their own health care decisions. The challenge for women and health care providers will be to work in partnerships to explore the decision making process and develop strategies to meet the goal of informed decisions.

The literature both on hysterectomy and hysterectomy decision making displays the interest and vigour by which women, health care advocates, and doctors continue to debate this practice. What is evident is that there is no right or wrong way by which to make a decision about having a hysterectomy. However , the opportunity and ability to take part in the decision-making process is likely to differ for women depending on their locale, their circumstances and the medical system's willingness and ability to respond. Women must therefore continue to be vocal in this debate, pursuing information, knowledge and experience that will help to ensure safe, informed and reasonable decisions.

Thus the importance of this study is its focus on women who live in a northern geographic setting of Canada, where no research on the topic of hysterectomy has previously been done. It will also make an important contribution to feminist health research because it asks women directly about their "lived" experience, rather than relying on health care providers to speak for and about their experiences. This research is unique in that the voices of these women will be the voices of pioneers because they are the first women to explore and describe the "lived" decision-making experience of elective hysterectomies for the Northern Interior Health Region of British Columbia. Hence, this research is a valuable addition and contribution to the knowledge base on hysterectomy and to women's health care decision making in northern, remote areas.

Chapter Three outlines the methodological approaches and methods that I used to conduct the study. I take the reader through the process of the research and indicate my logic or rationale for the various decisions that I made while carrying out the study. The chapter concludes with a discussion of the criteria by which qualitative research is evaluated.

# CHAPTER THREE

## METHODOLOGY, METHODS AND DATA ANAYLSIS

### INTRODUCTION

The purpose of this chapter is to explicate the methodology and methods which I used to conduct this study. I will begin by explaining the choice that I made to undertake a qualitative inquiry and will also present an overview of phenomenology and a feminist perspective as the dual framework of the study. I will describe the specific methods employed in the gathering of the data. Finally, I will discuss the treatment of the data regarding the decision-making experiences of the women who have undergone elective hysterectomies in the Northern Interior Health Region, using a phenomenological method of analysis proposed by Colaizzi (1978).

As previously stated in Chapter One, the majority of research studies on the topic of hysterectomy are quantitative in nature, undertaken from an outsider or etic perspective, and tend to emphasise medical and/or psychological outcomes. Quantitative research is deductive and views the world from the perspective of cause and effect through controlling and manipulating variables to test theories or hypotheses (Leddy, 1993; Leininger, 1985). Statistical testing and measurement (counting, numbers) are basic to quantitative research (Ramer, 1989). Because my intent from the very beginning was to explore, understand and describe the essence of this surgical decision-making phenomenon from the point of view of those who were closest to it or embodied it, namely women, I knew that a quantitative research methodology would not suit my inquiry. Hence I chose a qualitative approach which is largely characterised by three features:

the emic (insider) perspective, the holistic perspective and an inductive and interactive process of inquiry (Morse, 1992). All of these characteristics suited my aim, because I wanted to understand this experience from women who would have intimate knowledge of it, to understand it within the context of their lives, and to engage in a face-to-face interview approach in order to elicit the experiences. Munhall (1989) also suggests that qualitative research is appropriate when there is little known about a phenomenon or problem and the research question concerns understanding or describing. With that in mind, I looked for qualitative research designs that would attend to the question being asked. Thus, exploratory designs such as ethnography, grounded theory, participatory action research and phenomenology were reviewed. Finally, I chose to use a phenomenological inquiry (Bergum, 1991; van Manen, 1990) combined with a feminist perspective (Reinharz, 1992; Sigsworth, 1995; Stanley & Wise, 1990; Webb, 1984) because it would allow me to explore and examine the "lived" experience of women, to put into words how that experience is "lived" and in so doing, provide a permanent documentation of the voices of women who have experienced this phenomenon. In other words, feminist phenomenological inquiry would help to elucidate the decision-making experience of having an elective hysterectomy in the context of a north region.

## PHENOMENOLOGY

Phenomenology is a philosophical perspective, a method of inquiry and an approach to analysis (Beck, 1992; Linenberger, 1996; Morse & Field, 1996; Oiler-Boyd, 1993; van Manen, 1990). Lauterbach (1993) states, " as a research methodology, phenomenology is grounded in existential philosophy and seeks to uncover meaning and "essences" in experience so that understanding is facilitated" (p. 136). Phenomenology's approach to the world is a keen interest in gaining a deeper understanding and meaning of the everyday lived experience of people. According to Bergum (1991):

> To understand lived through experience is to go beyond the taken-for-granted aspects of life. It is to 'uncover meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized or sentimentalized'(p. 56-57).

Thus conducting a study from a phenomenological perspective supports the researcher's interest in understanding how the world is experienced and understood by human beings; in other words, directing one's attention "to human realities as opposed to the concrete realities of objects" (Oiler-Boyd, 1993, p. 79).

As a philosophy phenomenology argues that knowing and understanding the world is manifest from subjective experience. We view our world because we experience the world. Phenomenology places emphasis on the individual's perceptions and meanings of the world as they live and experience them. Morse and Field (1996) state that "experience is considered as one's perceptions of one's presence in the world at the moment when things, truths or values are constituted" (p. 125). Morse and Field (1996) and van Manen (1990) also state that there are four existentials that guide phenomenological reflection: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality) (p. 125). Perception of an experience therefore is "not as a thought, but as it is lived" (Morse & Field, 1996, p. 125). Thus in using this methodology, " the researcher is trying to understand how people attend to the world, remembering that in all individual description there is also interpretation" (Morse & Field, 1996, p. 125). Phenomenology recognises the uniqueness, humanness and wholeness of the individual. (Oiler-Boyd, 1993; Ramer, 1989; Ray, 1985; van Manen, 1990). Within this philosophy "people are thus centered in qualitative research in recognition that reality is constituted in human perspectives" (Oiler-Boyd, 1993, p. 79). The profession of social work also values uniqueness, individuality and acceptance of a person's perceptions of their experience, yet it is also interested in collective experience as a means to understanding and contributing to social knowledge and change. Thus phenomenology fit congruently within my framework of values and beliefs about people in general and women in particular.

As a method, phenomenology provides a systematic approach for inquiry into human experiences (Linenberger, 1996). It continually asks the question "What is this or that kind of experience like?" (van Manen, 1990, p. 9). The method involves using broad, open-ended questions which allow the participants to tell their stories. Phenomenology does not attempt to conceptualise, to categorise or classify the phenomenon, rather it attempts to bring to consciousness that which we have experienced (van Manen, 1990). By bringing the experience to our awareness, phenomenology attempts to explicate the meanings as we live them, within the context of the everyday lifeworld. Within this study then, one could ask, what meaning does the experience of deciding to have a hysterectomy have in the context of a woman's everyday life situation?

In order to recover original awareness (perception), a process called reduction is necessary. The researcher is asked to set aside "our ties to the world in roles, knowledge, belief, habit, common sense, and the like ... in order to make them apparent" (Oiler-Boyd, 1993). In other words there is an attempt to put aside all of one's values, biases and prejudgements about the phenomena. Bracketing is the technique used in phenomenology to aid this process. Beck (1992) suggests that bracketing is like peeling away the layers, such as peeling away the layers of paint, before one can view the surface or the phenomena under study. This peeling away does not eliminate the perspective, rather it brings it into closer focus and the original experience is revealed (Beck, 1992). The concept of bracketing however, creates tension from a feminist perspective. One of the tenets of feminist research practice is the inclusion of the researcher's point of view and biases, stated explicitly, as part of the research data (Sigsworth, 1995). Thus, to overcome this tension, yet attempting to remain true to both methodologies, I reframed the method of bracketing to include one's viewpoints and biases as a matter of opening one's eyes to the possibilities of varied perceptions and interpretations of the experience.

Phenomenology asks for the very nature of a phenomenon, for that which makes a some-"thing" what it is - and without which it could not be what it is (van Manen, 1990, p. 10). As a method, phenomenology attempts to uncover and renew the experience in such a way that the essential structure or essence of the phenomena can be described. To get to the very nature of the experience means that the researcher has reflectively and intuitively grasped the particulars of the phenomena so that the universals have become apparent. Spiegelberg (1994) suggests that:

> [intuiting] is one of the most demanding operations, which requires utter concentration on the object intuited without becoming absorbed in it to the point of no longer looking critically. Nevertheless there is little that the beginning phenomenologist can be given by way of precise instructions beyond such metaphoric phrases as "opening his eyes," "keeping them open," "not getting blinded," "looking and listening," etc. (p. 682).

In order to grasp the essentials of the phenomena, a process of analysis takes place. Oiler-Boyd (1993) states that "the task of phenomenological analyzing is a matter of identifying those elements of a phenomenon that entail a relation which, if omitted, would annihilate the phenomena; that is, that which is essential for the phenomena to be isolated." (p. 111). The whole of the phenomena is continually analysed along with the parts and compared in order to reach an understanding and a description. Various methods of describing the process of analysis have been developed by Colaizzi, Giorgi and van Kaam (Oiler-Boyd, 1993; Ray, 1985).

Finally, to do phenomenological research is to construct a possible interpretation of the nature of a certain human experience through written language (Spiegelberg, 1994; van Manen, 1990). The description which occurs attempts to enrich the "lived" experience by reflecting on it, providing meaning to it and thus directs the reader or listener to hear his/her own experience, whether actual or potential (van Manen, 1990). However, as Spiegelberg (1994) suggests, it is impossible "to exhaust all the properties, especially the relational properties of any object or phenomenon", therefore description is selective and as such, reflects a particular perspective or interpretation of the phenomena under study (p. 694).

Therefore, by undertaking a phenomenological inquiry, I have sought to understand and describe the essential structures of the decision-making experience. I have continually asked the women to go beyond the surface of their experience and to relive and re-experience what the phenomenon was like for them. As I used the phenomenological method, the women's perceptions of this experience were reflected through "lived" space, time, body and human relation. Finally through the process of analysis, the "essence" of the experience was intuited, reduced, and described through their voices and interpreted through mine. Chapter Four will present the findings and analysis of the experience.

## FEMINIST PERSPECTIVE

I have chosen to combine a feminist perspective with that of phenomenology in order to seek knowledge about women from women. Phenomenology, as stated previously, allowed me a mode of inquiry into women's perceptions of their experience and, coupled with a feminist perspective, recognises these experiences and perceptions as truth (Fogel & Woods, 1995). In other words, a fundamental principle of feminist research is that women are "knowers" of their own experience and therefore this approach seeks to construct knowledge using that experience as valued and valid (Reinharz, 1992; Sigsworth, 1995; Stanley & Wise, 1990). However, as Maynard (1994) suggests there is "no such thing as 'raw' experience rather [women's] accounts of their lives and experiences are culturally imbedded, as are their descriptions and interpretations of their lives" (p. 23). The challenge therefore, of feminist research, is to begin with women's experience and to then link or make connections of those experiences to the structures and organizations that are a part of women's everyday world (Maynard, 1994). Within this study, I have perceived hysterectomy as a social construction rather than a purely medical phenomenon. In other words, I looked beyond the physical aspects of the phenomenon and looked for descriptions which connected the decision-making experience to the specific locale, to the various relationships significant to this phenomenon, and to women's perceptions of this experience as it affected their everyday life. How might family, work, the medical system and gender play a role in the decision-making experience?

Another principle of feminist research is to question the traditional approaches to scientific inquiry which have been based on a male or androcentric perspective. Spender, quoted in Reinharz (1992) offers this insight:

> At the core of feminist ideas is the crucial insight that there is no one truth, no one authority, no one objective method which leads to the pure production of knowledge. This insight is as applicable to feminist knowledge as it is to patriarchal knowledge, but there is a significant difference between the two: feminist knowledge is based on the premise that the experience of all human beings is valid and must not be excluded from our understandings, whereas patriarchal knowledge is based on the premise that the experience of only half the human population needs to be taken into account and the resulting version can be imposed on the other. This is why patriarchal knowledge and the methods of producing it are a fundamental part of women's oppression, and why patriarchal knowledge must be challenged and overruled. (p. 7).

This is especially true of research into women's health matters. As Rosser (1994) points out, most medical research questions have been framed from an androcentric perspective essentially because it is overwhelmingly men who appropriate funding for projects and men who have carried out the studies. Therefore, conducting research from a feminist perspective is to reframe the questions and provide an approach which clearly takes gender into account. As well, research from a feminist perspective recognizes that women do not all share the same experience because issues of class, ethnicity, age and sexual identity provide for the diversity of women's experience and these issues must also be taken into account (Maynard, 1994; Stanley & Wise, 1990).

This study, which approaches the decision-making phenomenon from the experience and perceptions of women, and having been funded by a women's health organisation[1] will produce knowledge that is informed by women's experience and not by institutions such as medicine.

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[1] This research was funded by the BC Centre of Excellence for Women's Health, Northern Secretariat.

For although medicine has clearly been influenced by the women's health movement and research, it is still informed by male notions of women's health and well-being.

A feminist perspective is associated with and most frequently conducted using qualitative approaches (Maynard, 1994; Reinharz, 1992). These approaches allow women to tell the stories of their lives, a process which is difficult to achieve through quantitative methodologies. This is not to suggest that quantitative research does not produce useful and valid information, only that the process of conducting the research limits our understanding and analysis of the context in which women live their lives. Generally quantitative research does not provide for interaction which supports, informs and educates both researcher and researched. It was my preference to use a qualitative approach, in particular feminist informed phenomenology, in order to gain a deeper understanding of the decision-making experience through my preference of one to one dialogue and interaction.

The methods employed by feminist researchers vary widely depending upon the particular research aim (Reinharz, 1992). According to Sigsworth (1995), Stanley and Wise (1990) and Webb (1984), feminist research capitalises on the "personhood" of the researcher in that the use of emotions, experience and social context are explicitly stated and serve to guide the research. This does not mean that feminist research is not concerned about rigour and standards of scholarship, rather it contends that its rigour is more precise because it is explicit in its bias, its process and its analysis (Sigsworth, 1995; Webb, 1984). Throughout this research, I have attempted to reveal my own experiences, biases, values and beliefs about hysterectomy decision making. This self-scrutiny or active reflexivity (Mason, 1996) meant that I was continually examining my own knowledge and experience regarding this issue in order to examine my role in the research process.

In addition to the inclusion of self, a method which has become synonymous with feminist research, is the interview strategy which makes use of unstructured, semi-structured and/or structured questions to gather data. I chose to use an informal conversational interview style, coupled with open-ended questions, because it is one that I am most comfortable with given my twenty years of clinical social work practice focusing on individual healing, problem-solving and empowerment. For the purpose of this study, I also knew that the informal conversational style would allow me to develop rapport and that the women would be free to describe their experiences as fully as they wished.

Essential to a feminist perspective is analysis and critique aimed at bringing about alternative ways of viewing the problem or issue at hand and raising the consciousness about it, both for the researcher and the researched (Webb, 1984). However, as Kelly, Burton and Regan (1994) point out, not all research will transform the condition of women's lives, but not to attempt to bring an analysis of women's experiences to the forefront would perpetuate women's oppression. Thus, feminist research makes visible, through the language of written text, that which was invisible in the lives of women. With that in mind, I used the words of the women as much as possible to illustrate or describe a particular theme as it is important to ensure that documented research is easily accessible to all women. In addition, I have attempted to articulate the connections of the descriptions to the literature and studies in words or concepts that most women would understand and recognize.

The intent of the research, to examine and describe the decision-making experience of hysterectomy, is framed by combining phenomenology and a feminist perspective. Hence, the design allowed me to put women's experiences and voices at the centre, to document the experiences and perceptions, to frame an analysis through a gendered lens, and to anticipate that these experiences would be used to inform health care practices and policies. The remainder of this chapter explains how I conducted the research.

## LOCATING MYSELF IN THE RESEARCH

As stated in Chapter One, I underwent an elective hysterectomy for the condition of endometriosis when I was thirty-five years old. At the time I remember feeling that it was quite unfair that I should have to have this surgery performed because I was still young in terms of my biological functioning. My issue was not one of reproduction, as my partner and I had made the decision not to have children; rather it was that my body would be transformed into "instant" menopause with all of its unknowns. Menopause happens as you get "older", a natural, gradual process for which women generally have time to prepare. Surgical menopause meant that I had to forego that natural experience and decide for myself to enter into this next transition, or phase, of my body and life. Meanwhile, the debate to have or not to have surgery centred on how long I could survive the ever-constant pain that I was experiencing. Would I be able to "adapt" to a body that would no longer produce the very essential female hormones that I had come to enjoy and despise at the same time? I didn't know what to think or do.

My experience was also coloured by the fact, that aside from my partner, I was without my familiar support systems because I had recently moved to Prince George from another province. I didn't know my new family doctor very well and experienced a struggle to be referred to the gynaecologist of my choice. This was an unfamiliar experience for me, as my previous family doctor and I had always partnered in choosing treatment options or choosing a specialist that I would be comfortable with, even if that meant a longer waiting period for an appointment. What I came to realize in this context was the substantial authority and power that some doctors exhibit as a means of control over patient's choice and access. I also hadn't yet established many close relationships with other women in order to feel comfortable having an intimate discussion about all the facets of hysterectomy. I did converse with my friends from "back home" and with my family. I did go to the library and read all I could get my hands on. I did consider asking for a second opinion but that would have meant going to Vancouver, which overwhelmed me because of distance, cost and continuity of care. I could not conceive of having to be so far away from home, from my familiar support system of partner and family doctor, at a time when I felt that I would need their help and support the most. As a social worker, I had intimate knowledge of the anguish and loneliness that "out-of-town" patients can experience. Finally, I did not think it was fair that I should have to pay for a health service that I felt I should be able to access in the north. Ultimately, eliminating the physical pain won out and I decided to have the surgery.

Since that time my reflections have made me wonder about this experience within the context of living in northern British Columbia. I am not trying to second guess myself or regret the decision that I made, nonetheless it is hard not to conclude that perhaps women in this area are limited in their choices and ultimately their decisions by virtue of their geographic location. As well, my own experience caused me to question the role of doctors as the "gatekeepers" of the medical system in the decision-making relationship and what kinds of partnerships are forged with them. If taking control of one's own health is the goal, does this experience exist for women in northern British Columbia? It seemed to me that by conducting exploratory research into a phenomena with which I had some experience, I could begin a dialogue about women's health care issues from a different perspective than that of the medical establishment. As well, by starting with my own experience, I am able encourage other women to do the same.

The research seemed timely, in my opinion, as a result of the Provincial Health Officer's report. The report (British Columbia Provincial Health Officer, 1996) suggests that the numbers of hysterectomies within the Northern Interior Health Region were high as compared to most of the other health regions within the province and should therefore be examined. It is also timely according to Dan (1994) who states that "the recent visibility for women's health issues is no accident, but is based on the growing recognition that research and practice in medical and health care needs generally have been based on male perspectives, which have allowed needs and concerns of women to be neglected" (p.ix). Such is the case on the topic of hysterectomy. Therefore I have chosen to examine hysterectomy decision-making in the north, starting with and including my own experience, as a way to draw attention to a specific lived experience. As well, my inquiry into the decision-making experiences of hysterectomy has been undertaken with the hope and desire to share the experiences and voices of other women, to educate myself, other health care providers and women about this experience and to contribute in a small way to the production of knowledge about women's lives.

## DATA COLLECTION: THE SETTING

This study was conducted within the boundaries of the Northern Interior Health Region (Appendix A). The health region covers the central-eastern portion of the province of British Columbia and stretches from the small community of Granisle to the west, MacKenzie to the north, east to the Alberta border encompassing the communities of Valemount and McBride and at the southern most tip, the small community of Hixon. The major urban centre of the region is the city of Prince George, with a population of approximately 78,000. The other communities are small, more remote and rural. The overall population of the health region is 128,597, with males numbering 66,316 and females 62,281 (British Columbia Division of Vital Statistics, 1996).

The communities of the Northern Interior Health Region are linked primarily by road and rail lines that run through the natural pathways formed in the valleys and forests that make up the geography of the area. The largest major centre east of Prince George is the city of Edmonton, Alberta, which takes approximately eight hours to drive. The largest major centre in British Columbia is Vancouver, an approximate ten hour drive south of Prince George, much of it through the mountainous terrain. Air travel to Vancouver is about one hour. However, transportation is often adversely affected by the geography and weather conditions of the area (Prince George Regional Hospital External Review, 1993). The economy of the area is based on forestry, mining, transportation, tourism and agriculture (Ministry of Health & Ministry Responsible for Seniors, 1993).

The city of Prince George is home to the largest acute care facility in the area, namely the Prince George Regional Hospital. It is the regional referral hospital for the patients of the

Northern Interior Health Region, as well as for patients from the Cariboo and Peace River Health regions due to its geographic location and variety of specialists, including gynaecologists, surgical specialists in women's health. Referrals to access the services of these specialists must come from family doctors. An anomaly sometimes seen in the referral pattern to specialists in Prince George comes from the communities to the east, McBride and Valemount, known as the Robson Valley. Because these communities are approximately a three hour drive from either Prince George or Kamloops (which houses another regional referral hospital) women have the option of seeing specialists in either centre. It would appear that the decision to go to either centre likely relates to preference of the person and/or waiting times to see particular specialists. In this study, the two women from the Robson Valley had their surgery performed in Kamloops, rather than in Prince George.

## SELECTION AND RECRUITMENT

My initial proposal with respect to this study was to interview only women who lived in the city of Prince George due to resource constraints. However, since I was funded by the B C Centre of Excellence for Women's Health, the study was expanded to include women from all the communities throughout the Northern Interior Health Region.

The next step in the process was to determine specifically the women to be interviewed. Because phenomenological inquiry seeks depth and richness of experience rather than breadth, smaller numbers of participants are generally involved (Oiler-Boyd, 1993; van Manen, 1990). As Luborsky and Rubinstein (1995) suggest "there is no formula or criterion to use" (p. 105). Rather the answer to size emerges within the framework of the study; its aims and goals, along with the practical and economic resources available. The method suggests that even though one participant would be sufficient to provide insight into a phenomenon, it is generally believed that more participants will add to and provide greater insight to the essence of the experience. However, there is a point when the information being provided does not offer any new insights or understandings to the experience and therefore the researcher becomes aware that there is no more need for further participants. I had designated a minimum of seven interviews in order to include all of the significantly sized communities in the region. In the end I interviewed eleven women and found by the fifth interview that similar themes were emerging.

Concurrently, while considering the numbers of interviewees, I needed to ensure that the women selected would have the experience I sought to describe. Therefore purposive sampling, (Reardon-Castle, 1987; Luborsky & Rubinstein, 1995) a method in which the researcher selects participants based on specific criteria, was used. The specific criteria I established for the study included women who: (1) had an elective hysterectomy; (2) were between the ages of nineteen and forty-five years of age, although preference was given to women between the ages of thirty-five and forty-five as this corresponds to the age range in which the highest numbers of hysterectomies are performed (British Columbia Provincial Health Officer, 1995; Ross, 1996); and (3) the hysterectomy was performed within the last three to four years in the city of Prince George. This time frame was established so that the experiences and perceptions would be recollected more immediately and fully. However, as indicated in the previous section, I soon found that women from the Robson Valley were more likely to have their hysterectomies performed in Kamloops and on that basis would have been excluded from this study. It was not my intent to exclude those women as I recognised that what I was really trying to uncover was the decision-making experience, not the surgical experience. Thus I decided that for the communities of the Robson Valley, I would accept women who only met the time frame portion of the third criteria

## THE GO AHEAD

On June 2, 1997, I received approval from the University of Northern British Columbia Research and Ethics Committee to proceed with the research. I then prepared a letter to present to agencies (Appendix B) and an advertisement (Appendix C) outlining the criteria, and invited women to contact me. The advertisement was placed in several locations around the city where women worked, received services or were likely to congregate, such as the hospital, the library, the Northern Interior Health Unit, the Northern Native Health Centre and the grocery stores. After approximately ten days of receiving no responses, I contacted the local newspaper, *The Citizen*, to place the information in the "Around Town" section, in the hope of attracting interest that way. The morning the announcement appeared in the newspaper I received five phone calls from women living in Prince George. In total, I received twenty-two calls over seven days, all from women in Prince George. Women who did not meet the initial criteria were thanked for their interest in participating in this study. I explained to those who met the initial criteria that I would need to limit the number of women from Prince George to be interviewed, so I took their names and telephone numbers and advised them that I would re-contact them with a final decision. To make the final selection, I reviewed each woman's condition or stated reason for the elective hysterectomy. I chose to include women who represented the following conditions for which hysterectomies are performed; abnormal bleeding, endometriosis, fibroids, stress urinary incontinence and uterine prolapse. The date they called, their interest in sharing their experience, and their availability to be interviewed within two weeks became the final selection criteria. Five women from Prince George were recruited in this fashion.

As I had not received any response from women in the surrounding Northern Interior Health Region area, I proceeded to take out a paid advertisement (Appendix D) in the local *"Free Press"* newspapers in each of the communities within the Northern Interior Health Region. As a result of the advertisement, ten women called me. I found myself again needing to be a little more flexible with the age factor, as the women who called from specific communities did not meet that criteria, but met the other two. After a certain period of time to allow for women to call, again, I decided to include the decision-making experiences of these women, rather than exclude them. Thus, one woman from each of the communities of MacKenzie, McBride, Valemount, Vanderhoof and two from the community of Fraser Lake were selected. Unfortunately, I received no calls about the research from women representing any of the other smaller communities.

Times and places for the interviews were determined by each woman because I wanted them to have as much control of the process as possible. I believed firstly, that they needed to be in a place in which they felt comfortable and safe to share their experience. Secondly, I wanted to show respect for the busyness of their lives, since I was asking them to give up some of their valuable time to help me accomplish this study. Seven of the interviews took place in the women's home, two took place in my home, and two occurred in women's workplaces.

Reflecting on the process of recruitment and selection, I recall some very anxious and upset moments when no women responded to the advertisements that I thought were so strategically well placed. I immediately began to have doubts about whether or not this was a topic of interest to anybody except me, so you can imagine my joy and relief when following the small newspaper announcements, women called, and wanted to take part in such a study. I learned the importance of having “back-up” strategies with which to attract participants.

I also found this process a challenge intellectually and emotionally in terms of having to say no to women who did not meet my specific criteria, as they all had their own stories to tell and I found myself drawn to each of them. One particular woman, whose hysterectomy had been performed ten years ago, challenged me about the time frame criteria, as she said that having a hysterectomy is not something that you forget. However in the end she accepted my rationale and wished me luck with the study. Another woman, age 65, told me it was about time that someone was doing research about hysterectomies, as it seemed to her that there were just too many being done. She then told me a little about her experience, about taking hormones, and about her breast cancer, and suggested that my next study should be about that connection. All of the conversations reinforced for me that women are interested in health research in general, and in the topic of hysterectomy, in particular.

## CHARACTERISTICS OF THE WOMEN

The women in this study included ten Caucasian and one First Nations woman. They ranged in age from thirty-five to fifty-two years at the time of the interviews. At the time of having their hysterectomies, they ranged in age from thirty-three years to fifty years. All had a Grade 12 education, several had college diplomas or some university education and a number had specific on the job training. Three of the women were full-time homemakers, while the other eight were employed outside of the home, either in a full-time or part-time capacity.

At the time of the interview and at the time of having their hysterectomy, eight of the women were married, one was widowed, one was separated and the other divorced. All of the women had children. In terms of their hysterectomies, four women had had vaginal surgery and seven had abdominal surgery. Three had both ovaries removed while the others retained at least one ovary. Four of the women decided to have hysterectomies due to fibroids, two had endometriosis, one had uterine prolapse, while the others had diagnoses of heavy or abnormal bleeding.

## ETHICAL CONSIDERATIONS

Guidelines established by the University of Northern British Columbia for ethical conduct were used throughout this study. Each woman who called to inquire about participating was advised about the confidentiality of the study. The women selected for interviewing received a formal Letter of Information (Appendix E) explaining the purpose of the study prior to the interview. Each of these women was then asked to read, review and sign the Letter of Informed Consent (Appendix F) before beginning the interview. All of the women were advised that their participation was voluntary and that they could withdraw from the study at any time. None of the women chose to do so. To further protect the confidentiality of the women, they were advised that only their first names would be used at any time throughout the thesis report or in any presentation, unless they had any objections to that or preferred that I use a pseudonym for them. Two women asked that I use pseudonyms to identify them.

For purposes of my own record keeping and to preserve confidentiality, after each interview the tapes were coded with the woman's first name only and the date of the interview. All transcripts and corresponding analysis were identified this way as well. All of the data collected was stored in a locked cabinet in my home office.

Prior to and throughout the study, I was sensitive, both personally and professionally, to the possibility that the sharing of a personal experience might elicit emotional distress for some of these women. In anticipation of that possibility, I decided to carry the names and numbers of several counselling agencies in my briefcase so that I could respond to the participant's needs. I was conscious of the fact that I was not engaged with these women in the capacity of a social worker, but that of a researcher. However, as a professional social worker I was confident that I would use my best professional assessment and judgement before offering a counsellor, so as not to offend or appear intrusive to the woman. Fortunately, I did not need to offer this type of service to any of the women.

## INTERVIEWS

One of the ways to gain understanding about women's experience is to ask them to describe it. This is done by interviewing, a process which offers researchers access to people's thoughts, ideas, and memories in their own words rather than in the words of the researcher (Reinharz, 1992). In terms of concrete practice, as stated previously, the setting up of each interview was done to respect the comfort, confidentiality and time of each of the women. Each interview began with a discussion of the purpose of the research, a general overview of how the interview would proceed and issues of confidentiality. I then reviewed the letter of informed consent (Appendix F) with each woman and procured her signature. The women were free to withdraw from the study at any time or to have the tape recorder turned off. I also gathered demographic information from each woman (Appendix G). Finally I sought each woman's permission to take notes, particularly of any word, phrase or comment that I felt I might need to clarify. All of the interviews were audio-taped and lasted anywhere from one to two and one half hours. I transcribed seven of the tapes and the other four were completed by a transcriber. The interview transcripts produced a total of two hundred and seventy-one pages of data.

The interview process itself began with the request, "tell me about your experience of deciding to have a hysterectomy." What I received was a rich collection of personal stories highlighting women's physical suffering, their challenge with the medical system, and their relief or disappointment following surgery. I heard this by paying particular attention to each woman's words, her choice of expression and what connections or other experiences this question elicited. Throughout the interview I used open-ended questions (Appendix H) and probes to draw out the descriptions and perceptions of the experience. I tried to allow the women to express themselves as fully and completely as possible. As van Manen (1990) suggests, it was often not necessary to ask a lot of questions. I felt that the pauses and silences created the atmosphere for the women to gather their thoughts and further their perceptions. I also tried to create a climate of respect and non-judgemental acceptance that allowed the women to share intimate feelings and experiences. I did this by encouraging each woman to tell her story at her own pace and comfort level. I did not pry into personal matters, I simply asked the woman to tell to tell me more and accepted if she chose not to elaborate.

Initially, I followed an approach similar to that described by Gregg (1994). During the interviews I focused on the women's experiences and shared very little of my own. I kept to the conventions of my training with the use of "mmm, uhuh , yes" and nods to encourage the women. However after the second interview, I recognised the dilemma that Webb (1984) discusses in her interviews with women about their hysterectomies. I also found that the women were eager to engage in a conversational exchange about their experiences, had questions to ask and were genuinely interested in hearing and comparing their experiences with mine. This caused me to reflect on whether saying little about my own experience was the "right" route, as I had shared with all of the women who asked and who were selected to participate, that my interest in conducting this research was from personal experience. Therefore, while still acknowledging that my focus was on their experiences, I preceded each subsequent interview by being more explicit in my intent for the interview. I advised the women of my wish to listen to their experiences and that I would offer my own experiences if they appeared to be relevant and helpful to further their perceptions. I found that this allowed for free exchange and did not distance me from them. As Gregg (1994) suggests, this approach reflects the tenets of feminist research and social work values of respect and self-determination[2]. It also allowed me to gain further understanding and meaning of this experience in women's lives. I found that women posed questions during the interviews, a notion supported by Gregg (1994), Oakley (1981) and Webb (1984). If it was a question that I felt I could answer, I did or made references to books and articles that I had read. If I was asked for advice or my personal opinions, I generally

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2 An ethical principle which recognises the rights and need of clients to be free to make their own choices and decisions (Baker, 1991).

demurred. There were times throughout the interviews where I skilfully had to balance the role of researcher and social worker. Some of the information shared and the emotions revealed by the women were very personal and raw. Two of the women shared their feelings of sadness and anger at the loss of their sexual desire and felt that the gynaecologist should have explained more about this issue before they decided to have the hysterectomy. For one of these women who was particularly struggling with issues of sexuality, I gave her articles that I had collected and encouraged her to continue her discussion with her family doctor. Another woman began crying as she reflected that her decision meant that she could no longer have any more children. She explained that the hysterectomy was still the right decision for her, but because she had never talked to anyone before about this decision, she hadn't realised how much this aspect had meant to her. I wanted to offer "therapeutic" intervention, but I refrained, as I intuitively knew that this was not necessary. However I did reach out to touch her hand and offered a tissue. My response had been appropriate for at the end of the interview this woman hugged and thanked me for this process as it had allowed her for the first time since her hysterectomy, the opportunity to talk about and reflect on her experience.

At the conclusion of each interview, usually while sitting in my car, I would fill out my Field Note Guide (Appendix I) to capture the interview process, as well as my thoughts, feelings and impressions. This proved to be a useful reference throughout the analysis and writing stages. It allowed me to recapture the context of the interview. It helped me to recall the non-verbal and specific verbal comments or phrases of each of the women. And, it revealed my train of thought and experience following each interview.

The interviews took place over a period of three months, June to August. By the time they were all concluded I found myself physically exhausted, but intellectually excited. I knew that I had learned a great deal from these women and felt privileged that they had shared so much about their experiences with me. I could also appreciate van Manen's (1990) statement more fully: "We gather other people's experiences because they allow us to become more experienced ourselves" (p. 62). Now, I was moving into the most demanding phases of all, analysing and reporting on the experience.

## DATA ANAYLSIS

Marshall and Rossman (1995) state, "data analysis is the process of bringing order, structure and meaning to the mass of collected data" (p. 111). As they further suggest, "the process is not linear, but is usually time-consuming, ambiguous, creative and fascinating all at the same time" (p. 111). Throughout my research, I was always in the process of collecting the data and simultaneously analysing it. During each interview for example, while I was listening to the story, I was also actively involved in watching for the verbal and nonverbal communication of the woman and analysing its meaning for common themes. I listened for common language and repetitive words. For example, a phrase which occurred frequently throughout the interviews, describing the experience of talking with the doctor about having a hysterectomy was "it was just so matter of fact". When this phrase was used, I would ask the woman to elaborate further on it; what did it mean in light of their decision-making experience? After several interviews, noting that each woman had talked about the gynaecologist not even raising the issue of the possible emotional impact of hysterectomy on her life, I brought that notion into the conversation with the remainder of the women. Thus, I was constantly engaged in attending to the phenomena, "looking and listening", "keeping my eyes open" (Speigelberg, 1994, p. 682).

Colaizzi (1978) offers seven procedural steps to analyse the data. However, he cautions that these procedures should be viewed flexibly and freely by the researcher and can be modified in whatever way seems appropriate depending on the phenomena under study (Colaizzi, 1978, p. 59). The steps are as follows:

1. Read all the subject's descriptions, conventionally termed *protocols*, in order to acquire a feeling for them, a making sense of them.
2. Return to each protocol and extract from them phrases or sentences that directly pertain to the investigated phenomenon: this is known as *extracting significant statements.*
3. Try to spell out the meaning of each significant statement, known as *formulating meanings.*
4. Repeat the above for each protocol and organise the aggregate formulated meanings into *clusters of themes*. Refer these clusters of themes back to the original protocols in order to *validate* them.
5. The results of everything so far are integrated into an *exhaustive description* of the investigated topic.
6. An effort is made to *formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental*

*structure as possible.*

7. A final step occurs when the exhaustive description is returned to each subject for validation as to whether the description compares to their experience and /or what has been omitted. Any relevant new data must then be worked in the final product of the research (pp. 59-62).

Following these procedures, I began reading the transcripts, one after the other, to familiarise myself with the information contained in each, as well as listening to the individual story. As I did so, I found myself hearing the voices of the women and reflecting on their words and the interview itself. After the first round of reading, I re-read the transcripts, this time to listen for common words, phrases or sentences. Once I had done this, I went back again to each transcript and with a marker pen highlighted each sentence or phrase which I felt pertained directly to the decision-making experience. The significant statements for each protocol were then extracted on a separate piece of paper, numbered and identified by interview date as belonging to a specific woman. The process of extracting these statements is at the discretion and perspective of the researcher, however, I continued to keep in mind the original question being asked and the need to bracket any of my own presuppositions about what would make up this experience.

After I completed step two, I moved into formulating meanings from the statements. As Colazzi (1978) suggests, this step cannot be precisely delineated because the act of engaging in it requires creative insight to leap from what the women have said to what they mean (p. 59). He advises:

> …the researcher must go beyond what is given in the original data and at the same

> time, stay with it. He must not formulate meanings which have no connection with the data, as would be the case if I had formulated the preceding original quote as, "Subject's tendency to identify with book's characters suggests weak ego-boundaries" or "Subject's previous conditioning fosters the illusion of a number of inner men operating within himself." For these formulations would impose conceptual theories upon the data, and would not allow the data to speak for itself: it would not let that which shows itself be seen from itself in the very way it shows itself from itself. (p. 59)

Therefore, for each of the significant statements I had extracted, I took another piece of paper and formulated a meaning from the sentence or phrase (Appendix J). For example, from this piece of interview: "My first impulse was no way, I mean I'm only like 37 years old or 36, you're not going to do this to me, so it was kind of funny in the end, but oh, I was devastated and I thought no way, you don't have to do that. I mean you've heard, right, how these doctors just prescribe that women have them and they never ever had to have them done." I formulated this meaning: "she experienced a strong reaction to his [the doctor's] statement, as she perceived that she was too young to have a hysterectomy done." This part of the process was very time consuming, exhausting and ambiguous. By this I mean that because there are potentially endless interpretations to any of these statements, I found myself writing and re-writing what I sensed the woman was expressing through her choice of words. I continually asked myself, "was I getting this right, did it capture the experience, or was I getting too caught up in my own experience?" Finally, I had to tell myself to let go of the need to make a perfect interpretation, but to let the words speak for themselves and go with what I sensed was being said, the first time I read the excerpt. In other words this was the form of bracketing, of not allowing any preconceived notions or judgements to get in the way. Finally, themes began to emerge; that is words or phrases that seemed to give order and control to this process were conceptualised and written. Themes provide a focus and a way of capturing the phenomenon that one is trying to understand (van Manen, 1990). Van Manen (1990) suggests "that phenomenological themes may be understood as the structures of the experience" (p. 79).

After I completed the process of naming all of the themes of the decision-making experience, I went back through each of the formulated meanings and put the number of the meaning and the corresponding interview date under a theme which I felt best described it. I continued to do this until all of the formulated meanings had been assigned to a theme name. This too was an exhausting process, as just when I thought that the meaning fit one particular theme, I would re-read it and decide to put it under another theme or create a new theme. This process continued for some time and finally I stopped, reflected, and concluded that there was no right or wrong placement of the meanings. I realised that this is the process of creative insight and only I, and finally the women, had to decide if the themes described the essence and structure of the decision-making experience. As the procedure suggested, I went back through each original transcript to assure myself that I had not missed any expressions and that I had uncovered all of the themes apparent to me.

Within each theme, I reviewed the formulated statements and put together an exhaustive description. Essentially, the description was a brief synthesis of the theme followed by actual quotes from the women to illustrate the meaning of the theme. As I was doing this writing and re-writing, the metaphor which came to mind for me was that of putting together a puzzle. As I looked at each piece (theme), I tried to visualise how and where it would fit into the whole (essence) and eventually make up the picture (description) of the "lived" experience. Each piece was examined and re-examined until I derived eight essential themes with which to describe the decision-making experiences of women who have undergone elective hysterectomies in the

Northern Interior Health Region. These themes included: setting the stage, experiences of the body, involvement with doctors, alternatives and choices, knowledge is key, figuring it out, reflections of the north, and outcomes. However, the overall theme which connected all of these together is "You need to do what's right for you". The process fit with van Manen's (1990) assertion that: "Writing fixes thought on paper. It externalizes what in some sense is internal: it distances us from our immediate lived involvements with the things of our world. As we stare at the paper, and stare at what we have written, our objectified thinking now stares back at us." (p. 125).

Having completed this writing, the next process was to send each woman a copy of the description. I also sent each woman a copy of the transcript of her interview so that she could make reference to her experience while reading the description. I invited all of the women to review the material and to contact me with any additional thoughts, comments and critiques of the written description. One of the women wrote me a note, advising that from her perspective, all of the elements had been captured. She also found that reading the quotes of other women helped her to understand that she was not alone in her experience and that other women had had similar experiences. Another woman called me offering some suggestions to language, but essentially that the themes validated her overall experience. I contacted another woman because I felt the need to assure myself that the written word had captured the experience. She also validated the material. I left telephone messages for three more of the women, however I did not hear back from them. It is difficult to know how to interpret the silence. Perhaps because several months had passed between the interviews and receiving the written description, they did not wish to engage themselves any further. Or perhaps the description did capture their experience and they did not feel the need to have to say so. Nevertheless, those women who did respond provided their approval and validation of the experience.

## EVALUATION CRITERIA

According to Marshall and Rossman (1995) "all research must respond to canons that stand as criteria against which the trustworthiness of the project can be evaluated" (p. 143). Trustworthiness encompasses the ideas of internal and external validity, reliability and objectivity used in quantitative research. Conceptually, these terms refer to the ability to accept that the research was appropriately conducted and worth believing (Linenberger, 1996). In order to ensure that this qualitative research met the test of trustworthiness of describing the decision-making experiences of the women who have had an elective hysterectomy, four essential criteria for evaluation were addressed (Lincoln & Guba, cited in Morse & Field, 1996). These include truth value or credibility, applicability or fittingness, consistency or auditability and neutrality or confirmability.

Truth value or credibility is subject-oriented and not defined in advance by the researcher (Morse & Field, 1996). Qualitative research recognises that there are multiple realities or descriptions of human experience and, as the researcher, it was my task to try to elicit those realities through the in-depth interviews and finally through the written description of the experience. Credibility means that I have listened to the experiences of all eleven women and have found similar stories, word expressions and phrases. It also means that I have discovered differences in experience and perception of the decision-making experience which demonstrates that no woman's life is exactly like any other woman's life. These variations have contributed to the richness and value of the findings. Finally, those who have experience with this phenomenon, namely the women, have provided credibility through the verification of the description.

Applicability or fittingness is used to determine first, whether the findings can fit into contexts outside of the study situation and secondly, whether a similar audience views the findings as meaningful and applicable in terms of their own experiences. The aim of this research is not to generalize the findings to other contexts, rather to seek depth regarding these specific phenomena and to describe the "lived" experience. Therefore, selected expressions, phrases and sentences derived from the verbatim transcripts are used throughout the presentation of the findings to provide thick description of the decision-making experience of the women. Comments and feedback from the women themselves indicated that they found reading the experiences of the other women provided them with insight. Other's descriptions validated their own experience, especially for those women who had never really spoken about their hysterectomy experience to another person.

Consistency or auditability refers to whether the findings would be consistent if the inquiry were replicated with the same subjects or in a similar context (Morse & Field, 1996). Qualitative research emphasises the uniqueness of the human situation, so that variation in experience rather than identical repetition is to be expected (Morse & Field, 1996). It is essential therefore in order to meet the criteria of consistency, that an audit trail be developed and described. Rodgers and Cowles (1993) state:

> There is widespread agreement among qualitative researchers regarding the importance of maintaining accurate and comprehensive notes related to the contextual background of data, the impetus and rationale for all methodological decisions, the evolution of the

findings and the researcher's particular orientation to the data (p. 219).

From the beginning of the research, I kept notes about my thoughts, feelings, experiences and any major conversations with others about the topic of hysterectomy or the research. I kept brief notes of my conversations with the women who called about participating in the research. As previously mentioned, I used a Field Note Guide to keep track of the interviews and to relate any further thoughts or analysis. Later I was able to refer to my own musings, such as "Is this an issue of power, or of gender?" or "listen to the lack of respect and not feeling heard" as a way to begin to reframe the information and experiences. If I came across an article in the newspaper or magazine, I cut it out and kept it in my files for reference. As well, I conferred with my thesis supervisor with respect to my data analysis process and sought advice on the themes that I had generated. Throughout the writing of this thesis I have made references to myself; my experiences, my biases and my orientation in order to keep the consistency of the research in the forefront of my own and the reader's mind.

The final evaluation criterion is confirmability which relates to the traditional concept of objectivity. In qualitative research the question to be continually asked is, "does the data help confirm the findings?" Van Manen (1990) suggests that objectivity and subjectivity are not mutually exclusive categories, rather that "objectivity means that the researcher remains true to the object and that subjectivity means that one needs to be as perceptive, insightful and discerning as one can be in order to show or disclose the object in its full richness and in its greatest depth" (p. 20). The writing and re-writing of the text until the essential themes and "essences" were revealed and accepted by the women as a description of the decision-making experience meets this criterion. As well, the confirmation of the women ensures that a feminist perspective has been achieved and that "understanding the experience of women from their point of view corrects a major bias of nonfeminist participant observation that trivializes female activities and thoughts, or interprets them from the standpoint of the men in the society or the male researcher" (Reinharz, 1992, p. 52).

In conclusion, Lincoln and Guba (1985) offer a final caveat regarding trustworthiness. They suggest that "a naturalistic (qualitative) inquiry operates as an open system, thus, no amount of checking, auditing or triangulation can compel one to accept its trustworthiness, at best the process can persuade" (Linenberger, 1996, p. 46). However, it is my hope that the reading of the descriptive findings of this research endeavour will persuade health care providers and women having had or contemplating this surgery, that these women's stories offer an important glimpse into how women experience a health care issue.

Throughout this chapter, I have detailed the design and process of the study. In summary, I explored the decision-making experience from a feminist phenomenological perspective. The study took place within the boundaries of the Northern Interior Health Region of British Columbia. Purposive sampling was used to select the eleven women. I audio-taped the interviews and then transcribed them. The data were analysed using a method developed by Colaizzi (1978) in which significant statements were highlighted and meanings formulated. Themes were then derived and an exhaustive description written. The themes and descriptions were returned to the women for any additional comment and validation.

Chapter Four presents each theme and offers my description and analysis of the "lived" decision-making experience.

# CHAPTER FOUR

## PRESENTATION OF THE DECISION MAKING EXPERIENCE

### INTRODUCTION

The purpose of this chapter is to present the findings of the "lived" decision-making experience of elective hysterectomy in the lives of eleven women from the Northern Interior Health Region of British Columbia. The use of phenomenological inquiry coupled with a feminist approach uncovered the "essence" of the experience of deciding and focused the meaning and context of this experience on women's lives. The findings of this research are presented through the narratives of northern women and as stated in the previous chapter, I have chosen to use the first names of the women in order to personalise the voices and experiences. I have attempted throughout the descriptive themes to make connections to the existing literature, but also have tried to reflect on the unique experiences of living within the North. What I hope will emerge for the reader throughout this chapter are the individual voices of the eleven women, yet more importantly, their collective experience and wisdom as they shared their hysterectomy stories with me.

The description of the decision-making experience of women in the Northern Interior Health Region who have undergone an elective hysterectomy evolved as the women were asked the question: "Tell me about your experience of deciding to have your hysterectomy". As each woman was interviewed a piece of the puzzle was provided and by the end of the eleven interviews, pieces of all shapes and sizes had been collected. As I read and re-read the material I felt like a detective, sifting through each transcript, reviewing each line carefully in the hope that it would uncover further clues or descriptions of this experience. What follows is the uncovering of the pieces, an analysis of the experience that puts the pieces into a picture and provides a descriptive perspective of the decision-making experience of these women. The framework of the puzzle or the emerging central theme describing the essence of the decision-making experience was **"You need to do what's right for you".** All of the women were very clear about this. They stressed that this decision must be the woman's alone, as it is her body, and her life that will be most significantly affected. However, the experience of decision making involved relationships, connections of past and present information and experience, and interpretations of these experiences both from a cognitive and an emotional level. It is these descriptive themes that make up the connecting pieces of the puzzle. Thus the connecting pieces or descriptive themes included: setting the stage, experiences of the body, involvement with doctors, alternatives and choices, knowledge is key, figuring it out, reflections of the north and outcomes. Each of these themes will be detailed and a glimpse into these women's experiences will be gained. The reader is reminded that this study does not concern itself specifically with the process in which women make the decision. Rather it is the experience itself; how it emerges for women, their thoughts, their emotions, their concerns and how these components make up the whole of their experience.

## SETTING THE STAGE

When I asked women to tell me about their experiences of decision making, it was important for them to start their stories at the beginning and to proceed in a chronological manner, describing the events which shaped the experience and the decision. In other words what the women were providing was a context from which to frame their experience. The context was multi-layered. The beginning for most of them was a description of their physical condition that prompted them to start looking for information, advice and support about how to improve their health. What the women described was not a single event or moment in their life in which they suddenly just decided to have the surgery, rather it was a collection of events and circumstances, reflections and feelings that lead to the decision. This finding echoes that of Chasse (1991) in "that respecting the context of a phenomenon involves allowing the informants to tell the stories and share the experiences that they believe are relevant" (p.89). Chasse was interested in the process of recovery following a hysterectomy, and found however, that the women could not discuss their recovery without discussing all the events which surrounded and lead up to the decision to have the surgery. Women from the Northern Interior Health Region responded similarly and set the stage through these comments. Susan's story started like this:

> All my life I've had problems with my period, I can never say I had a normal time. Like it's always been really heavy or really light or whatever, but they said it would clear up when I had kids. It didn't. And it's funny when I had my tubes tied after my daughter, I remember saying to the gynaecologist at the time, am I going to have to have a hysterectomy in the next ten years?

Judy's experience began this way:

> I couldn't tell you the different types of birth control pills I've been on, the different types of hormones that I've taken and nothing has worked and the hysterectomy was like the last resort.

Sally said this:

> Well my experience is I was having problems with heavier flow and I went to see my doctor and she wanted me to see the specialist in Prince George.

Julie's story went like this:

> I think that I was around thirty-eight or thirty-nine. I started having a lot of problems with fibrocystic ovaries and they would burst or do whatever they do, so we tried some hormone therapy with that and that seemed unsuccessful really and then when I was forty-two, I was diagnosed with fibroids on my uterus and that diagnosis came because I was having so much pain during my period.

And Fran said this:

> Well the decision part of it itself wasn't all that difficult because I was in so much pain all the time anyway and there was just so much bleeding and I was weak and so when the doctor decided to send me to a specialist, it was very well, fine then.

As noted, the stories generally began with descriptions of physical symptoms, however soon the women were making connections about how their symptoms related to their relationships with a partner, family or work. This provided another layer to the context. Mary gave this account:

> Actually, I spoke to my family physician about two years before I had the hysterectomy done because I was having pain with intercourse and I didn't feel that things were right.

Donna offered this:

> My son said to me one day "What's the matter with you? You sleep all the time." I said no I don't, but he goes, you do and I thought, I do. I have an afternoon sleep almost every day when I'm not working.

Amanda said this:

> It started with my periods getting really heavy, they were lasting two or three weeks and I was starting to pass lots of clots. It was affecting me at work and I thought that maybe this [a hysterectomy] would be the answer.

In terms of setting the stage, a number of the women spoke of finding it necessary to consider the impact the surgery would have on all aspects of their lives. In this context, it referred to how busy women are in their lives and that decision making around this surgery needs to accommodate their family, work and economic situation.

Julie expressed it this way:

> When I first started having problems with all this female stuff, actually my GP at forty-two, said I think you're going to need a hysterectomy, do you want me to go ahead and get things in place. And I said what makes you think I could take off work for six weeks to recuperate. (laughs)

Judy had a similar experience:

> Well he tossed the hysterectomy at me around that time, but I didn't think much about it at the time. I was so busy at that time that I, you know, there was no way that I could take the time off for a hysterectomy.

And Linda offered these thoughts:

> I think the biggest thing is just to take the time out for something like this because it's a major part, not only are you in hospital for a week, but you have a couple of weeks afterwards where you're really not up and running around and doing things and it's almost like you lose three months productive time and after that you're still only working at 50 percent capacity.

These comments reflect the notion that women's health and women's lives are inseparable and that health care professionals need to be more attuned and sensitive to the social and economic issues which influence women's lives. For some women, financial constraints may play a major influencing factor in their experience of decision making.

As well, for some of the women, the experiences of other female members of their families were taken into account in describing the context of their own decision-making experience. These other experiences provided an historical and relational component to the experience. Susan commented this way:

> I started thinking that I might need a hysterectomy because my mom had a hysterectomy at thirty-four, my grandma had a hysterectomy in her late thirties. It's something that

> runs in our family and I just started thinking along that route that I might have to have that.

Susan also shared her concern about the threat of cancer in her family history as setting the stage for her decision making experience. She expressed this:

> And always in the back of my mind, I'm sitting there thinking, well mom had problems, grandma had cancer, maybe they're missing something.

Julie shared this thought about her family history:

> My mother had a total abdominal with both ovaries when she was thirty-eight and both of my sisters who are younger than I...one was thirty-nine and one was forty. Yea, not real healthy uteruses in our family.

Eva commented on how "things" have changed since her mother's experience:

> Like my mother had had one, but you know, that was years and years ago and there wasn't much thought that went into that then. She just went and saw the doctor and he went this what you have to do and that was it. They just did it like that, quite different than my experience.

For each of these women, being aware of family history and knowing the stories of their mothers and other female relatives was important. It seemed to assist them in providing a reference point for their own experience.

A final layer of context in the decision-making experience was locale or living in the North. Only two women made explicit comments about the North as being a part of their decision-making experience. Shirley offered this:

> I think the big thing about the small community is you don't have access to a lot of information that you would have in a bigger city or centre.

And Linda said:

> I don't think living in the North made any difference to me, other than wanting to get a second opinion because that means travel.

However, implicit in the comments of the other women were experiences of difficulties in finding good information, limitations to accessing second opinions and unsatisfactory or limited treatment options which were attributed to living within the Northern Interior Health Region. This will be further explored under the theme of "reflections of the North".

Thus, the beginning theme of the decision-making experience, "setting the stage", was a very logical place for women to start to describe their experience. What they were doing was locating their experience within the social context of hysterectomy. Hysterectomy is a phenomenon constructed from physiological, social and psychological sources. While many of us tend to think and talk about hysterectomy in terms of its bodily experience, what the women seemed to be describing was that the decision-making experience extends beyond the physical. Decision making reflects women's perceptions and interpretations of information. Decision making begins with reflections from personal sources, from past and present circumstances and from where they live in this world. It is a reflection of social construction. As Lorber (1997) states, "it involves all the patterns of social life – interlocking social roles, power and conflict, social statuses, networks of family and friends, bureaucracies and organizations, social control, ideas of moral worth, aspects of work and occupations, definitions of reality and the production of knowledge." (p. 4). The women in this study "set the stage" of describing their decision making by establishing an overview of the physical, social and emotional experiences that go into it.

The next theme drawn from the interviews was descriptions of the physical conditions that women experience and how that fits into the decision-making experience. The women described this theme in the next section.

## EXPERIENCES OF THE BODY

A significant portion of the decision-making experience focused on the women's experiences of their body. The decision to undergo a hysterectomy began with descriptions of the onset of symptoms. It was through experiencing these symptoms that the women began to consider that something was wrong with their bodies and by necessity they sought consultation with their doctors. All of the women were very attuned to the discomforts and changes of their physical conditions. Eva described her body experience this way:

> So when I started getting the pains, …I thought I had a bladder infection. I started to know this 'cause I couldn't go to the bathroom 'cause everything had just swollen up and so I, and then I started to notice a pattern, it was every month [when] I should be getting a period, right. So I thought this was really weird.

Susan was equally aware that her body was not functioning as she felt it should:

> I was sick a lot. I had headaches, backaches, that kind of thing, so I checked with my doctor to see if that was normal and he said give it a couple of years and let it settle down, you've just had three kids all at once, give it some time. Then I would stop having my periods for a few months, then I would have it again and I was always getting sick and I just felt like there's something wrong here, so they sent me to a gynaecologist.

Mary described her body experience in terms of its impact on her sexual relationship:

> For me the decision to have a hysterectomy was partially based upon the changes I was undergoing physiologically. I was uncomfortable bleeding more than I should have been and it was interfering with my relations intimately with my husband. Because of a uterus that was beginning to prolapse and things were in the wrong place, it had become almost painful and that puts a high degree of stress on a relationship.

For Sally, the bodily experience was pretty straight forward: "My experience is I was having problems with heavier flows and I went to see my doctor."

Many described the months, the years of discomfort and pain that they had experienced and endured along the path of their decision making. Shirley's experience started like this:

> I'd always had pain with menstruation, but it just got so that I was bleeding all the time and the pain was worse and cramps and things like that.

Julie said this:

> When I was forty-two I was diagnosed with fibroids on my uterus and that diagnosis came because I was having so much pain during my periods. I was still able to work, but I felt like I was walking literally bent right over and it was just trying to get through my day, I was in so much pain.

Fran's experience started like this:

> Well my doctor had a concern probably eight or nine years ago. But then again I'd done a lot of reading about menopause, all that sort of stuff, so what I was experiencing, like the pain and the heavy periods was just put down to a part of that and I don't know, I guess just one day I got fed up and said that's it, I'm 50 years old and I can't take this any more.

Judy offered this:

> After five years of on/off bleeding, you know, one month it could be a whole month and the next time it could be two weeks or get one week off in a month and after you go through that for a couple of years, you want an end to it."

And finally Linda said:

> I am feeling better and have more energy now, so I'm sure that I'm not as anaemic as I was, at least I'm not passing out any more (laughs) which is a good thing.

Women vividly described the impact the experiences of the body had on their personal, family and work lives. Much of it was laced with emotional overtones. As Donna said:

> I'm sick and tired of bleeding to death and I practically wore a diaper last month ...it's just disgusting and uncomfortable and I'm starting to bleed thirteen, fourteen days a month, for six months it's been going on and I said I just can't stand this.

Susan shared this experience:

> I started distancing myself from my husband because he didn't understand and he's a very kind person and everything, but he didn't understand what I was going through. I

> said there's no way that I can handle this, I'm so upset with my family, you know, and not just at the time of my period, but before and after, 'cause it hangs on so much of the time and it was really affecting my life. Every decision that I made as far as trips or anything like that always centred around that time.

Eva seemed to sum up what a number of the women expressed:

> I think back now and I don't even …I can remember how tired I used to be. I used to come home from work and do nothing. For two years I did nothing in the house. Like I used to nap here and you don't notice it, like it just kind of creeps up on you and you don't really realize how sick you are until you finally start feeling better. He [the doctor] tried putting me on hormones and the pain was so bad I was having to miss work and stuff, so I said to him, no, I didn't want to try any more things.

A few of the women talked about a variety of measures that women go through to help themselves cope with the physical discomfort. Strategies for coping with the conditions varied. Amanda shared this:

> He [the doctor] said I could have a D&C and that might clear it up, but I'd had one before, I was about twenty-three [when] I started having a problem then and I thought no, because the problems reoccurred again and during that several year period it just got worse and I just decided I think I need something else. He didn't want me to [have a hysterectomy] because I was so young, but I was kind of annoyed because he didn't have to live, you know, with having to take an extra change of clothes with you everywhere you went, never knowing when you were going to have an accident and always in pain.

Donna expressed similar sentiments:

> I'd just start feeling better and the bleeding would start again and very, very heavy. I could be just walking down the street and just be flooded and have to run to a place to change clothes. I always took clothes with me for the last year because you never know.

Julie laughingly stated this:

> I'd come home from work and I'd say [to my husband] "you're on your own tonight" and I'd curl up with a blanket and the heating pad.

Some of the women described how their bodies didn't respond to anything that they tried and how after a while that impacted on how they felt about their situation. These women expressed feelings of hopelessness and being out of control. Donna found this bodily experience to be the most difficult time of her life and the idea of having a hysterectomy was her one salvation.

She shared this:

> I had done everything. I had tried taking the pill. I had tried different kinds of things to wear, to you know, you name it. I had tried herbal things to correct this female problem. There was nothing that would work and I finally felt very hopeless about it. I thought it [a hysterectomy] was the only thing that might put my life into perspective because with all the bleeding and all the ups and downs I was starting to wonder, you know, God am I going to be able to cope…and I'm just getting worse and worse and I had this feeling that I was getting worse. The bleeding was starting to be a day longer every month and I had this sense of impending doom, like I had to get rid of this.

Susan also shared that the experience of her body was wearing her down and sometimes she just didn't know how much longer she could cope.

> I wouldn't say anything, but I was just getting, I was just getting really depressed and really down and I just felt like, I just couldn't handle it.

All of the above descriptions of the "experiences of the body" support the first three phases which Chasse (1991) described as "experiencing a disruption". The women in Chasse's study and this study described similar symptoms, indicated similar concerns about how their symptoms were interfering with their daily lives and tried self-help or coping measures to deal with their body. Ultimately, all of these descriptions of the experiences of their bodies informed the women that they must turn to their doctors for further consultation. What the women were looking for was relief from their pain and ways to improve the quality of their lives. This supports Harris (1993) finding that a woman's physical status was the personal characteristic that most frequently guided her in the decision-making process. The experiences of the women also seem to support Kaplan's (1994) contention that research focusing on functional outcomes rather than biomedical concerns would benefit women in the decision making process. However, the underlying assumption would seem to perpetuate the use of hysterectomy rather than researching and advancing alternative measures to surgery. Research that focuses on quality of life through alternate means and outcomes would serve to provide balance for women in decision making.

Through the experiences of their bodies, the women turned to their doctors for advice, support and treatment. The next section will explore the theme of women's involvement with doctors.

## INVOLVEMENT WITH DOCTORS

The experience of decision making cannot be separated from encounters with the medical profession, as physicians are the gateway to conventional treatment alternatives and ultimately to the surgery of hysterectomy. These encounters and the decision-making experiences are coloured by the communication, the information and the relationships that the women experienced with the doctors. It is with this part of the experience that the women had the most varied experiences and reactions. It is also here where a number of the controversies about the necessity of hysterectomy become apparent.

The experiences of their bodies lead the women to have contact with doctors. The initial visits were to family doctors or GP's (general practitioners) to begin the process of trying to get help and relief for their symptoms. This corresponds to the process described in Chasse (1991) as "evaluating the illness experience" and "negotiating the medical management of the condition." A number of the women in this study described feeling a great deal of support from their family doctors throughout the process. Donna described her encounter with her family doctor like this:

> [He said] I can't give you answers but I'm getting you in to see someone as fast as I can that does have answers, and so I thought that that was really awesome. I really felt a lot of respect for him and so I have decided to keep him for my doctor. [Also] he's very up on things, like he called me in between specialist's visits because he wanted to see how I was doing and if I understood everything.

Eva shared this:

> I had a doctor who gave me many choices and we tried many things and then it got to the point where I didn't want to try anything else.

For those women, feeling that they had been listened to and heard by their family doctor was appreciated and allowed them to feel more comfortable and confident with their referral to the specialist, the gynaecologist. However, a number of women described not feeling heard or listened to about what was happening to their bodies and how it was interfering with their life. In fact, they had to go to all sorts of ends to be taken seriously. These women experienced frustration with the way they were treated by their doctors. This concern is echoed in the British Columbia's Women's Hospital and Health Centre Society (1995) consultation report. Many of the women who took part in the consultation indicated that they were frustrated with the lack of attention to their concerns and often left the doctor's office with questions unanswered. Women in the study by Chasse (1991) also expressed frustration when the physician failed to address or acknowledge their concerns. Many of the women in this study felt that same way. Susan said this:

> It's frustrating because when you go in there and I didn't know too much about what was happening and I read more as time went on, but I sort of took them at their word, you know, this would go away or this would get better or the old clichés, you know, once you have kids your periods will straighten out and you'll be fine. And I sort of went

> along with that and it didn't happen."

She went on to say:

> "he [the doctor] could see, I would break down crying in his office because I was so frustrated, that's the only word I could think of and I just, he could see that I was really upset and it had been going on for so long and I would explain to him what had happened.

Mary expressed it this way:

> So I got angry and I went back and confronted my doctor and told him what was happening again and this time he looked at me and he heard me, I wasn't shouting or anything like that, but I was a whole lot more assertive.

Some of the women described feeling that because the experiences of their bodies were not openly visible or apparent, that their family doctors did not take them seriously and did not want to make referrals for them to the specialists. Shirley described it like this:

> I always felt like they were putting me off, you know, there's nothing we can see…so. A lot of it, I think has to do with if it's not a visible illness as well. They go, well you're handling everything all right, what's your problem?

Some of the women said that the experience of going to the doctor can be an intimidating one at the best of times, so not feeling that you have been heard or attended to adds insult to injury. Mary put it this way:

> When you go into the physician, at least for me as a woman, it's often intimidating. I sometimes have to write down what it is I want to say to him, otherwise I forget or I make light of it and sometimes, I just, you know, you get answers where the physician doesn't even look you in the eye, he's like, he's too busy, he's got so many other people to talk to that you don't feel that he's actually listening to you as an individual.

Julie offered this insight:

> I think it's so important to have a doctor who you feel is honouring what you're reporting. There's nothing more devastating to your self-esteem as a person or as a woman than to have someone say "Oh really?" a tone of voice, I mean, it's not particularly the words, it's the looks, it's the tone of voice and you know, if that's what

> you get, then fire him like you would an electrician who wasn't listening to where you wanted the plug-ins put.

Many of the women reflected that their doctors did not appear to appreciate the significance and concern which they had regarding this matter. In the literature about hysterectomy this response is described as doctor's style (West, 1994) and refers to the attitudes and beliefs which doctors convey about what is in the best interests of their female patients and how they approach changes in knowledge and treatments. A number of women described the rather cavalier, routine tone in which the doctors talked about their medical problems. Mary shared this:

> There wasn't a lot of emotional support there. He acted concerned and oh yes, we do want to help you feel better, but it was more matter of fact kind of thing. Your body's doing this and these are the options you have and like, it was like the bills have to be paid, you want to keep your telephone, you pay them now (laughs).

Eva's experience was like this:

> I had the feeling it was just another woman with another problem and in the end, that I ended up having to be in such severe pain that they had to do it quickly because I couldn't go through another month with it.

And finally Shirley's comment seemed to sum it up: "Well, it's a 'woman's thing' (laughs). It's just something that you have to put up with."

These sentiments are reflected as well by Lockett (1995) under the heading "receiving impersonal health care: Ho hum hysterectomy". All of the women with whom I spoke wanted the experiences of their bodies to be taken seriously and acknowledged that having to consider surgery was not just a routine, run-of-the-mill event for them. Most commented on the fact that surgery is not just something that you decide to do lightly, given the risks with anaesthetic or bleeding, or death. However the phrase used over and over again to describe their experience with talking to the doctors about the surgery of hysterectomy was "it was just so matter of fact." Linda put it this way:

> Well it seemed to me that they spoke of it so casually and I guess in my mind's eye this was major surgery ...I had had a tubal ligation, I had no interest in having more children but I wasn't forty yet and they're saying, well, just have a hysterectomy, something like well go and buy a dress. And this is my body, this is fairly invasive surgery, this effects the rest of my life and there is a marriage and it will have an impact on that. And you're given this decision and I kept thinking, "is there no other alternative, is there no other way? Why aren't there choices, why isn't there more information available?" It just seemed so casual and it's hard to put into words, but it obviously didn't matter to them, that was the solution, just do it.

Sally echoed those comments:

> Yeah, like it was very matter of fact. Like so and so from Vanderhoof had one and so and so from Fraser Lake and another one from Endako and oh, there was two from Burns Lake and you know, like it's very common. That's what I got from him.

Women themselves do not consider hysterectomy to be a "matter of fact" surgery rather it is something that needs to be carefully considered and evaluated. In the experience of these women then, appointments with the gynaecologist took on an added dimension because this is the doctor who has the power to recommend performing the surgery or not. This is the doctor whom you must convince that your pain, your discomfort and overall quality of life is affected by the symptoms of your condition and that, in your opinion warrants a hysterectomy. For most of the women, the experience in the gynaecologist's office was described as professional. They appreciated the listening and concern accorded to them. Mary offered this:

> So when I went to the gynaecologist my first impression of this particular individual was very positive. This man actually appeared to be listening, he looked you straight in the eye, he had a wonderful way of doing some reflective listening which was something my doctor hadn't done and so it really put me at ease.

Donna observed this:

> He has a very excellent patient relationship. He's just, you can tell that his mind is totally focused on his work. He's totally interested in what he's telling you. He's interested in your questions, you don't have to feel stupid if you have a stupid question.

A number of the women reported being surprised and grateful that the descriptions of what had been happening to them were taken seriously and not discounted. This confirms that women want to have validation from health care professionals regarding the experiences and knowledge of their bodies and life events (British Columbia's Women's Hospital and Health Centre Society , 1995). Susan commented:

> I walked out of his office and I felt like the world had been lifted off my shoulders. It was such a good feeling. I felt like finally someone was listening to me, finally someone believed me that, you know, I have this problem and they're going to do something about it.

Donna said this:

> I was just so grateful to be getting it. It was like yes, they're going to do this for me for the opposite reasons probably for why I want it done, but I don't care and I've never been unhappy with my decision.

Several women described the relationship which they had developed with their doctors, especially the gynaecologist, as a factor in their decision-making. If that relationship had been a positive one, it made them feel comfortable and that deciding to have a hysterectomy was the right decision for them. Julie described her experience:

> It would have been just like talking to another woman who had gone through the procedure. Like I just felt really cared about and that he had covered all the bases.

Judy said this:

> He just put me at ease. I knew exactly what he was going to be doing and how he was going to go about doing it. So it was very relaxing for me and I went home and I could explain all this to my husband and my children because they couldn't understand why I

> had to have this done. I'm glad I had the gynaecologist I did and all the help that was around me.

And Linda explained this:

> I think it was the combination of things and maybe a lot of it was that it was coming from another woman and that it was not flippant, well just have the surgery. It was sincere and was well thought out and she was not prepared to do the surgery unless she felt it was necessary. And for me it was then I had the confidence to go ahead and it was just up to me.

However, like their experiences with family doctors, some of the women experienced frustration at the treatment they received. It was their perception that the gynaecologist was just too busy to offer much more than the option of surgery itself. Fran expressed this:

> Well, it was very factual. Okay, he's obviously very good at his job and extremely busy, but he took his 30 seconds to present the options and then it was like, make a choice and so I made my choice and it's really hard to explain...it's like I was given a checklist, check one off. Actually, I was feeling a little pressured because I know that this is a very busy person.

Sally experienced this:

> I just felt like I was a number, bang, bang. He was like, well this is what has to be done, let's get you in there and get this done and over with.

Women had varying experiences of questioning the gynaecologist about having a hysterectomy. As Lorber (1997) suggests "when patients go to see doctors, physicians ask the questions and patients give the answers" (p. 40). Some women described feeling very comfortable in asking any question they wished no matter how trivial it seemed. Judy had this experience:

> And if I had any questions, he would stop and answer them to the best of his ability and in a way that you could understand it. It wasn't all doctor talk, so I felt very comfortable with him.

Others were less comfortable and even expressed that they felt intimidated about asking questions that might appear to be stupid. Fran stated this:

> If I would have said to him, would a D&C work, he might laugh me out of the office, so naturally I'm not going to ask those questions.

And Amanda offered this:

> There are lots of stupid questions, like um, how am I going to be feeling afterwards, am I going to be normal, how's my sex drive going to be? You know, things that you're just too embarrassed to ask, but that's why that person is there. He should be your best friend that you're talking to. But he was the type of doctor you really had to ask the right question in order to get the right answer, you know, you really had to drill him and if you didn't know what to ask, you didn't get the answer.

Sally offered this comment in relation to her perception of being from the North:

> In the North, in small towns, you see, a lot of us are raised, and I don't know if you come from a small town, [but] you get the small town attitude. You're raised here that the doctors, they're up here (hand gestures) and next there's someone else and you're not to make waves or ruffle their feathers...

What these women were describing was the struggle that many patients encounter in the medical setting to make themselves heard. Attitudes, behaviours and communication styles, both of the patient and doctor influence the medical encounter. Carlson and Skochelak (1998) suggest that communication between doctors and women patients can be explained by typical gender differences between how men and women are socialized in ways of interacting. They state that "men and women physicians are raised with the same societal norms as patients and would likely use conversational styles similar to their group" (p. 35). However, as Lorber (1997) argues, it is the doctor or other health care professional who carries the most authority, power and knowledge into this relationship, therefore it is incumbent upon them to change their practice style to ensure the patient is heard.

Through their experiences with the gynaecologist, most of the women felt that they had been informed sufficiently about the risks and the benefits of the surgery to their physical health and could then make a decision. However, few of the women described having a conversation about the possible emotional impacts or outcomes of hysterectomy with the gynaecologist. Again the women recounted the gynaecologists as being extremely good at detailing the technical aspects of the surgery, but little or no attention was paid to emotional outcomes, either positive or negative. As this aspect was not raised by the doctors, a number of women then did not think to ask about it either. A few of the women indicated that they couldn't find much written about it either, so it must not be worth talking about. According to Strausz (1993) this is likely typical behaviour of gynaecologists, as most are not particularly adept at addressing or providing emotional support to their patients. Susan provided these thoughts:

> You know, I would have liked to have been sort of prepared 'cause I didn't expect it, eh. I didn't expect to be so emotionally upset. I didn't think it would affect me that way because I honestly felt like this was a good thing and it would solve my problems, so I didn't even think about that. In some ways I did because I tried to read up on it and see how women felt, but because I couldn't find anything, I didn't really think too much about it. You just find what you can and go from there.

Fran emphasised this:

> Not at all, I mean it never came up for a second. An emotional aspect? (laughs) We're not supposed to have emotions I guess, I don't know…and the amount of reading I've done about it, I haven't really seen anything about it either, you know. So when it happened, I was shocked, like what's going on here.

And finally Sally stated it like this: "He did not mention any emotional impact and believe me, it's been a roller coaster."

However one of the women who did receive information and discussed the emotional impact with her gynaecologist was very pleased and summed it up this way. Judy said this:

> I don't know if he did it with all his patients or just the ones from out of town, but he did and I found it very helpful. And I don't think many doctors or like your family doctor or a gynaecologist ever think about that, the emotional aspect. They're just thinking, well you have your surgery. It takes a caring doctor to see the whole aspect of the surgery.

The lack of mention or discussion by doctors about the emotional aspect of this surgery is a serious omission. Women are not seen as whole persons, rather they continue to be the sum of their parts. It reinforces the notion that hysterectomy is just a surgical procedure that has only physical significance to women and nothing to do with their psychosocial well-being. Ignoring this major aspect of the possible surgical repercussions does not provide women with all of the information that they need to make a decision which will be right for them.

One of the women experienced firsthand the controversy when clinical indicators for hysterectomy are not clear. Donna said this:

> He [the gynaecologist] said he figured a hysterectomy would be the best choice considering the amount of bleeding, so it seems like a lack of knowledge between the doctor [GP] and the specialist, almost because the doctor's telling you, you don't have much to go on and the specialist is telling you that you have plenty. So it's a bit of a difference there and I thought that's kind of odd, isn't it, that one doctor thinks you don't have enough and the other thinks you have plenty.

She expressed dismay at being caught in the middle of the fact that her two doctors, family and gynaecologist, had such differing opinions about whether or not a hysterectomy should be performed. Decision making is more difficult to sort through because women are not sure which doctor to believe or trust and points out that women do rely on their doctors for direction and advice in these matters. Women who did not have a clear indication of the diagnosis understandably expressed concern about making the right decision.

Another controversy in the discussion of hysterectomy relates to the value or significance that doctors attach to the uterus in their discussions with women. The value most often described by all of the women in their discussion with the gynaecologist was that of reproduction. Shirley recalls her discussion like this:

> Oh, you don't want any more kids, okay fine, out it comes. That was the big [thing] for him, it seemed as long as I didn't want any more kids, that was the only drawback he had for the operation, that was it.

Sally said this:

> [He said] 'I guess it's for the baby factory' and after that you don't need it anymore …there's no string attached, once it's finished what it's there for, let's get rid of it.

Only one woman gave a description of her experience which seemed to take the whole person into account. Julie shared this:

> He asked me what I believed. He asked me if I believed that if I didn't have my uterus or ovaries that that would change me as a woman in any way. And I thought that that was very perceptive of him and I think if I were a younger woman it might have, I don't think so, I don't think that's where I've been with it..

A number of the women wondered if the gender of the doctor would have made a difference in their discussion and experience. The gender of the majority of family doctors and gynaecologists in the Northern Interior Health Region is male. Eva pondered:

> But you know, I had haemorrhaged and lost so much blood and it takes awhile for them to take it seriously. If I would have had a choice, I would have a female gynaecologist, if I could have.

Fran offered these thoughts:

> Well when I stop and think of it, like I meant, I'm past the age of having babies and all that stuff, but I mean, surgery's an important thing in your life and when I stop and think of it, Holy God, it was over and done before you know [it]. And like I say, I probably would have had to go the same route anyway, but I think a woman doctor would have been more understanding perhaps (laughs). I do. I mean especially they understand the

> female body to start with and now I'm not saying that all men are like this, but I find many male doctors I've dealt with, that there's certain cures for certain things, so let's get at it lady, let's not sit around and whine. So that's what I feel like.

However Linda commented that it didn't matter to her whether the doctor was male or female, so long as he or she acted professionally. She was the only woman who had the experience of seeing a female gynaecologist. These are reflections of her experience:

> I asked for a referral to a gynaecologist and I was extremely fortunate, I got a female gynaecologist, who made me feel very comfortable. ... I think because she had the experience because that's what she dealt with and she was able to explain things that probably would have made no impact on a male physician, things were said that just would not have been said between a male and female, where between two females there was not that uncomfortableness or I won't offer that unless the question is asked and a lot of people, myself included, when you're in a doctor's office or any professional type building, I think you are somewhat ill at ease anyhow and you do not think of all the things that you would like to ask. And I think a lot of it was just comfort level, knowing that there was someone who understood what this meant and could answer questions very candidly, very, not in medical jargonness, but in very comfortable terms that you had no inhibitions in saying, but what about or any questions ...probably the manner in which she spoke about it and the analogies that she used, ... just those things, she conveyed such an understanding about the surgery, the actual physical surgery, the how your body will be left and the way things would play out afterwards, in expect this, expect this, it was just, I then had the confidence to say okay.

But this description suggests that a link between the doctor's gender and Linda's comfort level.

Finally, in terms of the controversies surrounding hysterectomy, one woman expressed frustration with a system that appears to pay doctors more to do surgery to remove vital organs rather than surgery that could prevent it. Shirley had her hysterectomy because of endometriosis, but still suffers from remnants of it today. She later found out about a clinic in the United States that deals exclusively with endometriosis and said this:

> Basically there's no need to take out the ovaries and no need to take out the uterus if it's done right. You have to get it all out and that's just it. His [doctor from the US clinic]

> surgeries take anywhere from four to seven hours, so they're just not doing it here. One, the hospital time, two they don't get paid, they get paid per surgery, not per hour, so they just run you through. The gynaecologist down here, he actually wrote to MSP (B C Medical Services Plan) saying he believed that I needed to have this done because now my vagina and bowel are together, scarred together because of the endometriosis, so it has to be a lengthy operation. Twenty thousand dollars to do in the States, so obviously, I don't have the money. And no they wouldn't do it [here], so knowing that the only reason that I can't to this day get full relief is dollars and cents, it just blows me away.

Shirley's comments support the argument that certainly not all gynaecologists have the training or expertise to perform alternative surgeries to hysterectomy. However, it also speaks to the fact that governments, as the primary funding sources of health care, do not keep current on treatments that would be of benefit to women's overall health.

The involvement with doctors played a significant part in the decision-making experience and offered interesting and informative descriptions. However many of the comments suggested to me that decision making in the North is often not a shared experience, but indeed, as suggested by Travis (1988), one fraught with issues related to communication, gender differences, power and authority. In several cases the descriptions of the women perpetuated the examples of the medical encounter in which "the physician's perspective is the 'voice of medicine'; the patient talks with the 'voice of the lifeworld'" (Lorber, 1997, p. 40) and in the end the voice of medicine usually prevails. Thus women's descriptions within a social context are often unacknowledged, leaving only the body to be singled out for diagnosis and treatment. Lorber (1997) suggests the reason for this is that doctors are trained in the biomedical model which looks and tests for pathology. As a result of that orientation, Lorber (1997) states "that although patients' accounts of their illnesses could provide valuable supplemental data to these objective findings, physicians tend to discount them as subjective and therefore unreliable" (p. 40). Therefore it was not surprising that the women described experiences of not being fully heard, further indicating that women and doctors still have far to go in understanding and promoting the shared meaning of women's health.

Lorber (1997) also points out that gender does make a difference in the medical encounter in two ways: " women and men patients are treated differently, and women and men physicians treat women patients differently" (p. 44). While I cannot comment on how male patients are treated, the descriptions given by the women in this study suggest that many of these women had to struggle to make themselves heard and understood. Many had to endure significant pain and discomfort and some had to resort to rather demeaning measures like wearing adult incontinent briefs, before they could convince the doctors that their symptoms were valid and interfering with the quality of their daily lives. Women expect to be treated as reasonable, intelligent human beings, however the reality is often different. In terms of the hysterectomy decision-making experience, I think Julie's remarks capture the issue:

> And when I envision men going through the same thing, I just laugh. I don't think there's a man living that would just bleed from his penis for two weeks out of every month and put up with that! So I just said that's it and I picked up the phone.

The next theme introduced the experiences of considering alternatives and choices of an elective hysterectomy.

## ALTERNATIVES AND CHOICES

It is necessary to be provided with alternatives and choices in order to make an informed decision. As stated in Chapter Two, an informed consent means that a woman has been provided with current information on her existing condition, with the various strategies or treatment alternatives and finally with the corresponding risks and benefits associated with each. Woman should then be able to evaluate alternatives and make choices based on individual values, preferences and circumstances. In describing this experience to me, many of the women indicated that having a sense of control over the decision making about one's body was the most significant aspect surrounding the theme, alternatives and choices. It was described as owning and taking responsibility for your own health care because no one else was going to do it for you. Linda said it this way:

> I would just really encourage them [women] to be in more control of the decisions that effect them so seriously and not to be passed over or rushed out the door and I think doctors find that too easy to do to us.

Julie was more emphatic:

> It's your responsibility to research it out. You cannot expect a physician to give you all the alternatives. If you have a problem, you research it out. Everyone is a normal thinking human being ...you go to the library, look up menopause and start doing research. I think it's personal responsibility and nobody's gonna take care of you, you've got to figure it out. I think sharing information is so valuable and talking to other women.

Thus having a sense of control meant that they could participate fully in the exploration of alternatives. However, a number of women did not perceive that they had any choices or alternatives because the pain and discomfort of their bodies could no longer be tolerated and their doctors could not offer any more suggestions. Hence their opportunity for choice was eroded by their physical condition. Mary expressed it this way:

> And in the period of time when he told me it was my own choice that I should give him a call when I was ready, I actually, ...the problems increased to the degree where I actually lost, I lost that choice, it would have to be done.

Similarly in studies by Chasse (1991) and Lockett (1995) women felt that they had no choice in the matter because their conditions failed to respond to medications or minor surgeries. Nonetheless, the decision making was not any easier.

A number of the women described what seemed to be a fine line between the woman's decision-making role and that of the doctors. It appeared that women were influenced as much by the words, as by the communication style of the doctor. Shirley offered her perceptions and experience:

> He [the gynaecologist] basically said that that's what his option would be, to have a hysterectomy, that I had, I can't remember the name of it, excess bleeding or whatever, but he didn't mention endometreoisis at all until after the operation, so it was basically, yea, that's the solution, right. There wasn't too much decision making going on by that time, taking all those pain killers and the frustration of dealing with everything, it was okay, well the doctor's God, this is what has to be done.

Mary said this:

> He checked me over and then he said it seemed this is really the way to go because at this point you don't have to do it, but in a couple of years you're going to need it because there's something happening here and we don't know what, but you're going to need it and it would be easier for you to do it now. And I said, yea, did this mean it's my choice now and go ahead and do it and I'll feel more in control or wait until I don't have a choice and it's done to me, right, and that was an option I really didn't like. I wanted to feel like I was partially in control.

Fran's experience was somewhat similar:

> But he basically said to me, well you can choose to do something or you can choose to do nothing. It's not about nature taking its course and so when I said I really think that I want to get something done about this, then afterwards I thought, oh, what have I done,.. am I making the right decision?

And Amanda added this:

> We [women] did decide to have the surgery, but the doctor's the one who says yes or no really. He's the one who's stating "you should get this done, I recommend you get this done", recommending being, like he said it's my choice [but] I have no alternatives left

> because I've used everything. This is the end of the rope for you, a hysterectomy.

Donna faced a different situation. She was presented with information that she might have pre-cancer cells which really terrified her, so she immediately consented to the hysterectomy. However, the actual diagnosis following the hysterectomy turned out to be endometrosis. This supports Haas (1992) argument that the various symptoms are often complex, sometimes making a definitive diagnosis difficult. However it does suggest that women must be vigilant and not necessarily accept the first diagnosis, but ask for second opinions before consenting to a hysterectomy. Donna offered this:

> If I had to do it again, I'd probably get a second opinion before I'd make that rash of a decision.

What appears to be presented throughout these comments are feelings of powerlessness and lack of control over your own circumstance or destiny. So often women feel that it is too difficult or hopeless to challenge the medical system that is dominated by the power and authority of doctors, so they just acquiesce. In terms of hysterectomy decision-making, it means a fine line between having to choose to live with pain and discomfort and choosing to have surgery that may or may not have benefits.

Several women felt that the gynaecologist had already made up his mind to perform the surgery even before the discussion began. Some were happy about that, others were not. Susan observed this:

> It was funny; I was thinking when I was sitting across from him, like he seemed a bit, almost nervous or something and I realised after he was asking me questions and stuff, but I knew that he had made up his mind already. He had the letter from my family doctor and I just knew, just the way he talked. He said there is one other procedure you could use, but because of the amount of pain that I had with my periods, he didn't feel that it would be an option for me, but he said it was entirely up to me of course.

Sally felt her age was a factor:

> Well, like I said, I was 49 and I know lots of people who haven't had one, but it appeared to me this guy's mind was made up before I went in there. But how did he know before he went in there if my ovaries had to come out. So he knew what he was doing, he knew before he was even doing an internal, he knew that he was going to do it and that was that.

In terms of second opinions all of the women spoke of knowing it was their right to ask for one, but few of the women actually sought them out. Some of the descriptions for not seeking second opinions ranged from women feeling comfortable with the manner in which the information had been presented and the doctor presenting it, to also being comfortable and confident in their own appraisal as it pertained to their individual situation. Thus they did not feel the need for a second opinion. Eva said this:

> I just wanted to get it done and I knew he had a fairly good name in Prince George, you know, a lot of people have said positive things about him and you do look at that...So I didn't think about going to another doctor.

Susan gave this account:

> I was prepared when I went in there. I had studied up, I had read up on hysterectomies, you know, and I went in there and I told him that. I said even before I came to this office, I made sure that I knew all my options. I had already studied up, I knew all about it, so I didn't ask him a lot of questions 'cause I didn't feel like I needed to.

And Julie added this:

> He did tell me that I could change my mind at any time, that if I didn't feel comfortable that we could cancel and I could come back and talk with him. I don't think he told me I could have a second opinion, I knew I could, I know my rights, but I was very comfortable with him and basically what he had said.

On the other hand, travel costs were mentioned most often as the element that prevented women form seeking a second opinion and this will be commented on further under the theme"reflections of the north".

Another reason described for not seeking a second opinion was a perception that the community of gynaecologists in the North is so small and close-knit, that the women felt that the doctors would back each other up or stick together, so what difference would a second opinion mean anyway. Shirley's experience speaks to this. The first gynaecologist advised her that she should have her ovaries removed, so she said she'd wanted a second opinion and this is what happened:

> Again I went back to my family doctor and I expressed my concerns so he said well, I think you should go and get a second opinion and so he suggested Dr. X. I came down to see Dr. X for a second opinion and I brought down some of my literature and why I felt this [not wanting her ovaries removed] and he said well Dr. Y [the first] gynaecologist] feels it's necessary, then that's the way it should be. So off I went for the hysterectomy.

Sally experienced this:

> And I asked him, could I get a second opinion and he said, oh yes, there's another gynaecologist across the hall. But they worked together, so I didn't feel that that was quite fair. Like, I would have liked to talk to somebody else about it, but my family doctor had sent me to this specialist in the first place. So I figured that I should be able to see another specialist, but as far as I'm concerned, there was none available.

Fran offered similar thoughts:

> Well this is Prince George, who would I have gotten a second opinion from? There's maybe one other, I'm not sure. That's a real problem because I had my doctor's opinion, then I had the specialist's and maybe I was just too damned desperate to get this thing taken care of, just because of all the agony you know. It sounds kind of wimpy, but it was a lot of pain for a lot of years.

Thus for these women, their expectation of seeking a second opinion was curtailed by their geographic location. However, this quote from Julie seems to sum up the experience for most of the women:

> I didn't feel like I needed another opinion at all, I was sick and tired of the pain I was in. I thought we had tried everything and I wasn't willing to try anything else. Quite

frankly, I'd had it and I just didn't want to mess with it anymore.

Thus being presented with alternatives and having choices is an important element in any decision-making experience. It represented a process by which the women could begin to evaluate what would be right for them. Some of the women described being very sure about their decision after having weighed the alternatives and choices. Others did not seem to experience that sense of personal choice or involvement. Harris (1993) made reference to this in her study as power, one of the characteristics necessary in order to make a decision. She described power as being an internal and external source of authority and control. Internal power meant a woman took on the authority to make the decision. External power was described as other authority figures, most often doctors, involved in the decision-making process, thus taking control of the decision. Shared power would represent decision making in a collaborative manner. In this study women provided various descriptions of alternatives and choices, which supported the notion that power, both internal and external is significant in the experience of decision making. If the woman felt and believed that the alternatives and choices were available to her, she described the experience of deciding as being easier to digest. If alternatives and choices were beyond her reach, geographically, economically and physically, the sense of control and power was compromised and the experience described as more difficult to deal with.

The next theme introduced the importance of knowledge and information in the decision-making experience and depicted how this is necessary while simultaneously sorting through the alternatives and choices.

## KNOWLEDGE IS KEY

For each of the women participants, gaining knowledge about hysterectomy played an important part in the decision-making experience. Knowledge comes to women in different ways and they use it based on their own needs and experiences. However, where and from whom women sought this information was diverse, as most women wanted information beyond what their doctors had provided to them.

Women described a variety of ways and means of getting and assessing information, other than from their doctors. Most often the women described seeking out the advice and experience of other women who had had this surgery. This seemed to be a way for women to compare notes, to get feedback and receive support (Chasse, 1991). Julie said this:

> Actually I talked to other women who'd had hysterectomies, who had had similar symptoms that I was having and everyone of them said, I'd always do it again, that they had had good results. I think with the women I asked, well one of them said to me, why are you putting up with that for crying out loud, like the best thing I ever did was have a hysterectomy and she was ten years older than I was, and I thought, hum, that's something to think about.

Susan also talked with a couple of friends:

> I have a close friend here that had a hysterectomy. She had it when she was twenty or twenty-one. It was for medical reasons that she had to and she was really good, she said you can ask me anything, I'll tell you about it. Also my brother's girlfriend had a hysterectomy last summer, so she was really helpful, I was able to talk to her and she was very open with me and told me how she felt and everything.

Even though talking with other women was viewed as a preferred choice for information gathering, women are sensitive to the fact that this is a rather individualized experience and they do not wish to appear that they are being snoopy or invasive with their questions. Mary reflected this way:

> Well, I think I was really distressed before I had to make this decision, but it was just a neighbour girl and we got to talking, you know, we might have been talking about kids and are you going to have any more, no, no, I've had a hysterectomy or whatever. I knew she'd had one so I asked her, I got brave and I asked her how do you feel about this, not I knew that she'd had it and she didn't seem to have any problems, [rather] I said how do you feel about it. This is really, it's the kind of question that could be invasive.

Susan was equally sensitive as she reflected back on what she had said to other women before her own surgery:

> People had said to me, like friends who had had hysterectomies and stuff and I remember asking them, do you feel like less of a woman and I realise now that that was a terrible thing to say to someone who has had a hysterectomy.

Therefore approaching the subject of hysterectomy and talking about it with other women is not always straightforward or easy. A couple of the women commented that they really didn't know anybody whom they felt they could talk to, hence they felt somewhat isolated and alone. It was as if this topic was rather silent and that somehow having to have a hysterectomy would mean you were a failure or that you couldn't cope very well. Shirley expressed it this way:

> It's this secret woman's thing. It's back to the days when you're in the corner, you're in a different room when you have your periods, you're not allowed out and I think it's still inbred in us that you just don't talk about it at all. Yea, it's almost like you should be ashamed you've had a hysterectomy, that you couldn't handle being a woman, I guess and basically you couldn't handle it and everybody thinks it's the easy way out. Well no, it's not exactly the easy way out.

And Fran said this:

> You know one of my cousins said to me, wow, way to go Fran, now you'll never have another period, like this is a great way of ending it, isn't it? And I felt like slapping her because I mean I was scared. You know I had never really had surgery, I mean I'd had a tubal about 25 years ago, but other than that nothing. So I wasn't really looking at it that way, as ah, I'll never have another period again so let's just go and get a hysterectomy. It's just not that easy.

Mary and Susan commented that being able to talk with women their own age would have been helpful. Mary said this:

> Well after four children, I knew, you know, all about the birth and pregnancy process, but at my age I don't have many peers that, you know, or women that I know intimately who have gone through something like this, so there was nobody to talk to and I just began to feel really isolated.

Susan echoed Mary's remarks after she had viewed a video about hysterectomy:

> I don't know, I was crying through the tape, so maybe I missed part of it, but it didn't seem like it addressed emotions a lot, like they were talking about how great they felt, how terrible they felt before they went in and how great they felt after, so I was looking forward to that, but I was thinking there to myself, I wish there was someone who was my age or sort of, you're all having a hysterectomy and losing your organs, so you're all the same in that respect, but I didn't feel that it was quite what I was going through.

Women in studies by Lockett (1995) and Chasse (1991) also reflected the comments regarding isolation and having a similar age group to talk to. However one woman shared a different opinion about the notion of isolation. Linda said this:

> I don't even like the word isolation because I think each one of us is individual and it is very individual and just because we don't sit around the table talking about hysterectomies nor do we sit around the table and talk about menstruation or monthly cycles, it's individual for every one of us and although we can find some common ground, it's still going to be different. I think it's in getting your own confidence up. That is, is this the right thing for me to do and it comes to different women in different ways. Some of it is more by talking to other women than to talk to another doctor and perhaps it would be nice to have something like the cancer agency has, somebody who you can call and talk to you about things like that and maybe it would be nice to have some sort of support group available.

Many of the women supported Linda's comments that it might have been helpful to have an opportunity to be part of a hysterectomy support group, not unlike the support groups for women who have had mastectomies. However there is no such support group for women undergoing hysterectomies in the north. On the other hand, a few of the women who stated that they would not have been comfortable going to a group mentioned that they would have liked an opportunity to discuss their hysterectomy with a trained female counsellor specialising in women's health care. Women themselves were offering suggestions about various ways to pursue knowledge.

Several women described their experiences with the nurse in the gynaecologist's office as the most helpful and supportive information source of all. They experienced it this way because the nurse was a woman and gave her undivided time and attention to the matter. Fran offered this:

> It was afterwards that I realized that he [the gynaecologist] hadn't sat down and really talked to me. The talking to me was done by his nurse. Thank goodness, I mean, she was an awesome lady.

Donna experienced this:

> I had a little session with the nurse to make sure, you knew, what you were doing and I'm sure that's why they do it, to make sure you understand. She told me what a hysterectomy was, what I could expect from the hysterectomy itself, what I could expect afterwards and she was also there to answer questions after the hysterectomy, which I did phone her and talked a couple of times afterwards. But his nurse was a lot of help, she was very informed and I liked it because I didn't feel like, like he said I could phone, but I knew that people don't phone doctors and so I said to her, is it okay if I don't understand something and she said it's okay to even come in and she'd make time to talk to me. But they want to make sure before the operation that you know what you are doing.

And Susan added this:

> It helped me more to talk with the nurse because she was very straight forward, but also very kind and she was supportive, very supportive.

Women in the smaller communities made references to public health nurses as resources, whereas women in Prince George did not. One woman referred to the counsellors at the local crisis centre. Judy said this:

> I talked to other women and we have a crisis centre and the counsellors there have all the information for you. You can talk to the public health nurse. I used the counsellor, well I used them both. I talked to the public health nurse and she explained a little bit more about the pain aspect I think than anyone else, but it was informative. They do have a lot of information if you, like I say, if you want to use it.

Sally expressed that written material is also important.

> I really think everybody should get a handout or a pamphlet that they could sit down and read exactly what could and could not happen, what changes to expect and different things. And if doctors are not going to go into that part of it, then train their nurses to take you in and discuss the whole thing with you.

What these women were describing was that women seem to want and appreciate having a person with knowledge and information to talk with and perhaps develop a relationship with, which can be drawn on during their decision making. Ward and Heidrich (1989) also conclude that "people" sources of information are more important than written or videotape material. However, what the women in this study were also describing was that the notion of gender is important. Women generally feel more comfortable talking to other women, especially about issues related to their bodies and to their general sense of health and well-being.

Some women referred to medical books they had at home, while others went to the public library. Two of the women accessed the Internet. Shirley and Eva both experienced it as a helpful, informative tool in the process of gathering information and gaining knowledge. However, as with any information source, they cautioned that women must be diligent in sorting through the facts and using other sources to verify the information.

The ability to seek out and sort through information sources other than what the doctor had recommended made women feel more confident and informed. Susan describes it this way:

> I wanted to make sure that I knew as much as possible about what was happening to me and even as I'm going along, I thought different things like maybe I'm going through

> early menopause and I would read up on that. But you know, because it was my body, I wanted to make sure that everything was done that could possibly be done and maybe, it's, I don't know what the right word is, but I wanted to make sure that he knew too. I don't know if it's distrust or whatever, maybe it is, because it had been happening for so long and I wanted to make sure that I knew all the options, everything around it, from his point of view, from my point of view, as much as I could, I'm just that kind of person.

Another component of information described by several women as lacking was the discussion of sexual function and well-being. Most felt that this topic should have been brought up by the doctor, but if he didn't, it often wasn't discussed. These remarks are echoed in Carlson and Skochelak (1998) who stated that in a survey of female patients of primary care doctors more than eighty percent wanted their doctor to take the initiative in discussion of sexual issues and forty percent would not discuss sexual issues without doctor initiative. Mary shared this:

> And even though I was embarrassed about asking certain kinds of questions, um, I did say to him that I had concerns about…things weren't going great as far as intimacy was concerned, but I could cope most of the time and I didn't want an operation to make things worse. But here I am sitting in front of a person that I don't know and I believe that he has the authority and he's got the answers and I'm asking him, "will this effect my sexuality, will it decrease the way I feel afterwards?" and he said he didn't believe that there would be a change, so I felt slightly reassured.

Fran said this:

> Well here's where I think us gals need a lot of help with this stuff, because they're taking out a part of you that, that is part of who you are sexually too and your uterus reacts to a lot of things and I've done a lot of reading about this since, but of course I didn't ask then because I didn't know. Now I know.

Linda was the only woman who seemed to feel that she had a satisfactory discussion with her doctor about sex and sexuality. She said this about her experience

> And she explained to me how it would effect our sexual relationship, that it would be awhile before you could indulge once again, but that after that, it should not have any effect whatsoever. In fact she said, what will probably happen is that when the anemia is reduced, you'll have more energy and will probably feel more inclined (laughs).

The whole issue of sex and sexuality seemed problematic. Some women wanted to seek knowledge about this issue, but few of the women described actually having done so. Thus, some of these women did not have all of the information in order to make an informed decision. It also seemed to suggest again, that hysterectomy is portrayed by doctors as purely a medical condition, with little elaboration or acknowledgement of psychosocial issues.

The gathering of information about hysterectomy from a variety of sources provided most of the women with the additional knowledge that they were looking for in order to make a decision. The experience of gaining this knowledge was different for all of the women. However all seemed to support the assertion that knowledge gained from other women's experience is seen to be some of the most valuable and useful sources.

The next section describes women's experiences of sorting through what is important to them in order to make a decision.

## FIGURING IT OUT

Decision making is a process of considering all of the information that one can and blending it with one's beliefs, values and preferences. It involves the use of cognitive skills, as well as emotions. In this theme of "figuring it out", the decision-making experience was described by the women within the context of relationships and several different factors were considered essential to coming to a final resolution. The various factors are interrelated and integral to the decision-making experience and the women spoke of them as significant depending on their individual situation or circumstances. The factor most frequently described as crucial in the decision-making experience was whether or not the woman had children or had completed having her children. Thus women's biological role was deemed an important factor for these women. Donna expressed it this way:

> I'm so grateful this didn't happen to me when I was nineteen or twenty when I didn't have my kids. That would have been a decision from hell then.

Judy commented: "I mean we'd already got our three children, so to me it was no decision." And Eva shared this:

> I've had my kids, it didn't bother me. I mean the way I figured it, it wouldn't make any difference whether it was there or not. I mean if I didn't have any children or wanted to have more, you know, it would have been different.

However, Susan and Mary, who had both completed their families and consciously expressed that the condition of their uterus was interfering with the quality of their lives, still expressed feelings of sadness and loss at the realization that they could no longer give birth. Susan said:

> It was the same thing again, this was it you know, I'll never have kids again in my life (soft crying). It might sound silly 'cause I had my tubes tied already, but you know, it's a door closed.

Mary shared this:

> I realized after having this hysterectomy, the thing that I had given up most was not necessarily that I wanted more children, but that I had the possibility of having more children and that gift of creativity, as an artist, for me is really important. I understand that as part of the creative process of being a woman and being able to fulfil that is a really wonderful thing.

Thus the role of reproduction for women who have had children and obviously for any woman considering having a child, is a major factor in this decision-making experience.

Age was also described as an issue that was taken into consideration. While a number of the women stated "I'm past the age of having babies" as part of their own mental criteria in the decision-making experience, they did not want the doctor to use that as a factor. The women in this study wanted to decide themselves at what age and time was best for them to have a hysterectomy. Eva said:

> Actually the very first time when I was brought into the hospital, in the emergency ward, this GP saw me and he just went "hysterectomy" right away, that's what you need, that'll fix you right up. And my first impulse was no way, I mean, I'm only 37 years old or 36, you're not going to do this to me. So it was kind of funny in the end. But I was devastated. I thought, no way, you don't have to do that. I mean, you've heard how these doctors just prescribe that women have them and they never ever had to have them done.

Julie commented:

> And I saw a gynaecologist in Prince George, who I found very caring, a very good listener, he was compassionate and he said basically you need a hysterectomy, you've tried all these things, you know in a younger woman we might try just taking out the fibroids, but unless you want to have more children, which I absolutely did not (laughs), I was forty-five, and at that point I said how much longer do you think we'll be doing this and he said , oh probably five more years before they start shrinking up and at that point I hesitated for a bit and said no, I'll try to wait this out and see, but finally, a couple of years later, I said no that's enough.

Amanda related her story:

> So I went to my GP and he suggested no, don't get it done because you're too young. He said wait and I was about thirty-one then, so he said wait and I waited another year and it was getting worse. [Then] he said I could have a D&C and that might clear it up. I'd had one before, I was about twenty-three, I started having a problem then and I thought no, because the problems reoccurred again and during that several year period, it just got worse and I just decided no, I think I need something else. [But] he still didn't want me to because I was so young.

The comments by these women are supported by Harris (1993) and Lockett (1995). Harris made reference to age as one of the personal attributes that women considered in their decision making, while Lockett referred to age as part of the process in shaping the hysterectomy experience.

Another factor described in the decision-making experience was the value or significance of the uterus. For most of the women the uterus was seen as an organ that was significantly interfering with their life and would now have to sacrificed. Julie put it this way:

> I looked at my body as a gift and my uterus had given me three beautiful children and all that…[but] it was causing me pain, so it was time to go.

Shirley said this about her experience:

> The uterus for me never made that much difference. Like I say, it wasn't that much of a change for me. It was just, the relief was worth the trade-off. The ovaries would have been different, I would have been really upset, I am upset that he took them out now.

And Eva shared this:

> I guess that maybe you're supposed to be emotionally attached to your uterus, not to me. All it was was a problem. I didn't care, it wasn't working properly anymore.

For a couple of women the importance or significance of the uterus did not occur to them until it was gone. Fran reflected this way:

> You know what I've decided, that a loss is a loss. I mean, it's [the uterus] a part of you whether it was working properly or not. And I know that that's addressed, but I think just through some of the reading I've done on women who've had a mastectomy, the loss of a breast and the grieving process and stuff like that, so why would it be so much different to have this body part taken out? Well maybe you wouldn't go through it with your appendix, but something like your uterus that has been very vital to,… I mean that's part of what makes you a woman, right, and if you were to lose a breast or an arm, like wouldn't you go through this grieving process?

And Mary shared this:

> It's surprising that, you know, those parts of you that you never even see or consider important to you, have such a, for me at least, a huge emotional impact. I've referred to myself as a female eunuch on one occasion to a female friend and she looked at me and was so shocked. Like, well that's the way it is.

Thus the value of the uterus and its loss remains a controversial component in the discussion of hysterectomy. It is clearly an issue for further qualitative and quantitative research.

Women described the relationship with their partner as a significant factor in the decision making experience. Several described talking to their husbands about whether or not to have a hysterectomy and its possible outcomes. Some of the women stated that their partners had been concerned for some time about their wives' health and well-being, therefore they were pleased that something was going to be done. Julie said this:

> My husband was part of the decision, but you know, he was saying five years before that, honey isn't there anything they can do? ...But it wasn't like I was down all the time, I just had no energy and that and he was aware of that, he knew the mood swings and all that. He was quite supportive of the surgery.

Fran gave this account:

> I was really ill, I mean there was no two ways about it. Like he [her husband] was getting scared because I was just really not well. And okay, I mean talking to him, like he was in full agreement, he wanted me to get this done. He just wanted me to get better, not so that we'd have this raging sex life or anything (laughs), but I mean he just wanted me to get better [because] he told me afterwards that he was starting to get scared too because he said I was such a terrible colour, you know, I would come home from work, I was just so tired I would just drop. So I was a lot of fun to be with (laughs).

What most of the women were looking for from their partners was understanding and support in order to make the decision-making experience easier. Susan described it like this:

> My husband said you do what you feel is right, you know, you're the one who's going through it, so you decide what's right for you and I thought, great, I'm glad that he would support me in whatever I did.

And Shirley shared this:

> Ray is excellent, he's a real support. He reads the books that I read. And we've pretty much sat down and talked about these things before we do them and we both came to this decision pretty much together. It's not the same as having someone who's gone through it, but it's as good as it can be, put it that way.

Only Mary described her partner as cautious in his support:

> The only person I had to talk to was my husband and he wasn't necessarily in favour of the hysterectomy because there was another added component. I have high blood pressure problem and I didn't want to go into surgery, it was really a frightening prospect for me and that's why I didn't want to have surgery. So he [husband] was like, he didn't want me to have to do this, but if that's what needed to be done, he was going to support me.

The descriptions indicated the value women place on having a partner who is open, who will share concerns and who will offer support around this decision. Interestingly though, none of the women described inviting or taking their husbands with them to appointments with the gynaecologist.

For all of the women, improving the quality of their lives, in other words, living without the pain and discomfort they had been experiencing was of paramount importance. The findings of Carlson, Miller and Fowler (1994), Henderson (1995), Kinnick and Leners (1995) also conclude that the elimination of pain and discomfort was an essential component in hysterectomy decision-making. Amanda described it this way:

> After being sick during those couple of months, that was the deciding factor then. I thought this is enough, I want to be pain-free.

And Shirley simply said:

> To me, it really wasn't so much the big operation word, as it was, yes, I'm going to get relief!

But finally in terms of "figuring it out", all of the women concluded that ultimately the decision had to be theirs and theirs alone. Judy stated this:

> No, it's not an easy decision for some people, but I know that ultimately it should be the woman's decision. It's the woman's body, and I mean, she's the one that has to go through everything, not the male. And once it's done, you feel good.

Linda said it this way:

> You have to feel that this is the right choice, whether it's having a child or having a hysterectomy or having a mastectomy. If you're not sure, then you're not ready. Be comfortable, be really comfortable with it and I would say that about almost anything.

In coming to a decision, all of the women gathered the information that they could; weighed the various alternatives and choices; used the knowledge and experiences of other women; sought support, advice and guidance from partners and their doctors and ultimately determined what would be best for them. Harris (1993) referred to this as resolve, the characteristic which people use to bring something to a conclusion, thus ending the process and making a decision. Most of the women seemed to describe relational, contextual and pure physical factors as components of their resolve. Perhaps in the end, the women intuitively knew that no matter what else was offered, it would only seem temporary at best and what they were striving for was closure to physical pain and suffering and looking forward to an improved quality of life. Decision making for women is an experience with many layers and multiple players requiring strength, persistence and determination.

The next theme focuses on the experience of living in the North as it pertained to decision making.

## REFLECTIONS OF THE NORTH

Living within a specific location or context, such as the Northern Interior Health Region, suggested that some of the perceptions and experiences would be framed by those boundaries. The women in this study indeed described their experiences based on where they lived and how they perceived their health encounters. To begin, a number of the women indicated that living in a northern community meant that one's access to health care resources was dependent upon the size of the community. The women who lived outside of the community of Prince George described limited access to medical specialists and to the information sources they perceived women in the urban area had. Shirley said this:

> I think the big thing about the small community is you don't have access to a lot of information that you would have in a bigger city or centre. Even the support groups that they have, the information that's out there, the pamphlets and stuff like that. You really don't have a lot of that information in a northern community.

Linda commented on her perception of the north versus the south.

> I also believe that in the South there are perhaps a few more resources. There is more networking. There are more people available to discuss these things. There are more alternative medications where here we don't have access to some of those services because there is not sufficient population here to support them. I think that when you look at the bigger centres and there are more people available and you're a little closer together and it's those little intangibles that makes the difference.

However, even the women who lived in Prince George, the urban centre, did not always feel that they had good access to resources and second opinions. Eva was the only woman in the study who described seeking out alternate treatments and getting a second opinion by being referred to what she called, "Vancouver's Women's Hospital", which in fact is British Columbia's Women's Hospital. I found this a salient remark as it does speak to the fact that although British Columbia's Women's Hospital and Health Centre is a provincial resource, women in the north do not actually perceive it as such. Issues of distance, geography and financial constraints, create barriers and thus its resources and expertise are not accessible to all women. Nonetheless, Eva who did go for an appointment, shared these observations:

> Yeah I wouldn't say there's very many places here to get information on it. I mean you rely on your doctor a lot. I went to the library here, but there's not very much there and well there's no women's centre here. I mean the one in Vancouver, they had a library

> there [and] anytime I had to wait in between or whatever, there were books on everything. People could just pull it out and read all kinds of stuff on, like, what's the typical situation we're in, the bleeding and stuff and just different things, what could be causing it and you could read up on it.

Women from the smaller communities, however, were resourceful and used whatever services were there to the best of their abilities. As noted in the previous section, public health nurses, crisis counsellors and the libraries were seen as valuable information sources.

One of the women commented that in the North the turnover rates for family doctors in the small communities are high and thus continuity of relationships is impaired. This has an effect on women because women value having a relationship with a doctor who knows and understands their situation. In the case of hysterectomy it is more comfortable talking with and asking questions of a doctor whom you know and trust. Shirley said this:

> I mean you lose them [doctors] quite a bit. We do have a high turnover which is another thing in the North too. We usually have young doctors coming to get their experience and get out, so you don't have a good steady relationship with a doctor. As a matter of fact again in a smaller community you don't have a lot of choice about your doctors.

However Linda commented that sometimes when new doctors come into a community they bring fresh ideas and information. She offered this perspective:

> And I think we were fortunate here in that we had a locum come … and again it was a woman doctor and I think for women, for me and I'm assuming that other women think the same way, that in talking to another woman, that somehow it's more credible, the information becomes more real. And she did an information session at the local high school where she talked about women's issues: safe sex, hysterectomy, hormone replacement therapy, a whole gamut of things, sexually transmitted diseases and just so many things like that, that obviously the women in this community had not had the opportunity [to discuss].

Eva reflected in more general terms about women's health care in the North:

> So are we as women then not being served very well? I would say so because of where we live. I believe that. I mean especially when I saw what the treatment was like in

> Vancouver with the couple of trips I made there. It was definitely, the care was way better than what it is here.

Travel was the most common theme that all of the women remarked on regardless of whether they lived in the urban centre or the outlying communities. For women in the outlying communities, travel for medical care is a part of life. Judy said this:

> I'm used to it because my son had arthritis, so I used to have to, at three months, six months and a year, he had to have a check-up through a rheumatologist. So I was used to the long trips, but it can be time consuming, sometimes the roads aren't that good and it was always a scary trip especially in the winter. And then of course the money factor, there's always an extra expense.

Julie offered this:

> So the only thing was the trips back and forth worrying about the winter conditions because it does get nasty in February. But other than that, my GP is in Prince George and I've chosen that because in this small community and working as closely as I do with physicians, especially when I was having female problems, I wanted my privacy and so I was lucky enough to find a physician in Prince George. So I'm used to the roads, it's part of my life and I don't think too much about it except if it's –40, I call and cancel!

For the women from Prince George, travel generally meant going to Vancouver. Eva considered herself very lucky that the company she worked for offered health benefits which included coverage of travel expenses. As stated earlier she in fact went to Vancouver to try a treatment alternative before making her decision to have a hysterectomy. She continued:

> So what he [Prince George gynaecologist] suggested I have was endometrial ablation, So I went to Vancouver to have it done because they didn't do it here. I had to get myself there, but because I work for a company, they paid for all that, anything that you're referred to, so my airfare was paid. And they paid for both trips because there was a trip to go down there for them to look at me and that was just for a couple of hours, so that was just one day and then I came back. And then the doctor in Vancouver let me know that I was an acceptable candidate and they gave me a couple of different days that I could go for the surgery and then again the company I work for paid to send me down and also my husband to come with me 'cause I had to be escorted, right. So that was nice.

However most of the other women did not have such coverage, therefore having to pay out of their own pocket would have created a hardship. This limited their ability to seek out a second opinion. Sally's experience speaks to this:

> I was told I could fly to Vancouver if I wanted to see somebody, but I couldn't afford to go to Vancouver, so I said, fine, book it and that's that.

However, Linda felt very strongly that women in the north must challenge themselves around the fact that financial issues with respect to travel should not preclude women from making good health care decisions for themselves. She emphasized this:

> But this is the rest of your life, you have to do this. You may have to travel. You know, I started out in Valemount, then I went to Jasper. I then went to Kamloops and if I'd had to go to Salmon Arm or somewhere else, I would have done it until it felt right because it was important. And if you can go out and spend $50,000 on a car, certainly you can spend a couple of days deciding the rest of your life.

While the emphasis on travel is very much a part of living in the north, most women in the north do not have the time or the financial resources to make the many trips that some medical treatments often require. Thus living in the north limits the range of alternatives and choices to care.

For women living within the Northern Interior Health Region access to health care services and good information is a challenge. However financial supports and resources aimed specifically at women's health would go a long way toward ensuring equality in decision making with women in the larger southern centres. This issue was also raised during the community consultation process conducted by British Columbia's Women's Hospital and Health Centre Society (1995). Removing the barriers to women's health care and ensuring equity of access with our counterparts in the South will require a major shift in health care funding policy.

## OUTCOMES

To draw my description of the decision-making experience to a close, I asked the women to reflect on how having had a hysterectomy had affected their lives and what advice, if any, they would offer to other women in the North who were trying to decide. Most of the women described being satisfied with the hysterectomy because they were feeling better both physically and emotionally which support the findings of Carlson, Miller and Fowler (1994), Henderson (1995), and Kinnick and Leners (1995). Julie said this:

> And I've not been sorry one day of my life and I had more energy one week after my surgery than I've had for years.

Judy concurred:

> Physically I knew that I'd made the right decision. It was just the idea, like the doctor told me, that once I had a hysterectomy my body would slowly build up from being so run down and loosing so much blood that I would be able to do things that I was always so tired physically and emotionally, I just wanted to sleep. So in that respect, I knew I'd made the right decision.

And Susan was also emphatic:

> I feel great and I feel emotionally great, the whole part of it. My whole life has improved since I had it, not just the physical part, but everything.

Some of the women wished that they had decided to have the surgery years ago. Eva said this:

> Yeah, like I say, I don't really regret it. I regret maybe having tried so many different things, like I wish at the beginning I would have gone and had it done and I would have had another at least three years of enjoyable life, but I didn't so. ..

Julie stated this:

> If I had to do it over again I would have done it sooner and I think I still would have been one hundred percent. And I think the last two years was just an exercise in not giving up. Somehow we still feel like we're a failure 'cause we can't cope, then I just switched my

> language from I can't cope with this to I choose not to be coping with this one more day of my life and just choosing to switch your language helps.

Judy added this:

> I almost wish that I'd had my hysterectomy earlier. Sounds crass, but then I wouldn't have had to go through, like I wouldn't have had to be put through all those different stages, the birth control, the hormones and if this doesn't work we'll try this and if that doesn't work we'll do that. I almost wish that they would have done that when I was thirty-five and then I wouldn't have had all that worry.

But for a few of the women there were still ambivalent feelings about the hysterectomy. All three indicated that if they had to do it again, they would not have had the hysterectomy. These women all experienced various side effects from the surgery and that the hysterectomy had not met their expectations of feeling recovered and whole again. Amanda described it this way:

> I'm not the same person, that's for sure. There is a definite loss there, it's a closeness you lose with your spouse. I would say now, I'd say no, I would never have had a hysterectomy, but I'm kind of glad I did sort of. I know that I got all these other problems, but those are put away and you deal with it. It's a life-altering experience.

Mary had this to say:

> If I had not had an intimate relationship that I was meant to maintain, you know, feel good about the intimate part of a relationship, I would not have done it. I wouldn't have. There wouldn't have been any reason because as long as I could handle the bleeding and the heaviness and the other things that happen when your uterus prolapses, I could have dealt with that.

And Shirley shared these feelings:

> It was the day after surgery and I was pretty much out of it, but even then I was really upset. I just had this real sense of 'I should never have done this'. I shouldn't have done this and this real sort of doom came over me like, type of thing and even to this day, I know in my heart, I should never have went ahead and did it. I should have found another way or went to see another doctor or done something more.

These descriptions are painful reminders that the decision-making experience is a complex one with no right or wrong attached to it. As in any health care decision making, there will always be variations based on individual experience. There will always be the element of the unknown that each individual will have to assess for herself and evaluate the potential consequences. Chasse (1991) and Linenberger (1996) both found that women in their studies who indicated a lack of input into the surgery decision experienced more difficulty with recovery after the hysterectomy than other women.

As the interviews came to a conclusion, it seemed important to ask each of the women based on her experience, what advise or suggestions she might give to women who were in the process of making a decision to have a hysterectomy. All of the women were thoughtful and cautious in their responses. They all took the position that it is an individual matter and that each woman would have to assess her own situation and ultimately have "to do what's right for her". Fran started this way:

> I'm not even sure that I would want to give her any advice. I think that I would want to say, okay, would you be interested in hearing some of my experiences about what it's like afterwards, you know, because I would never presume to say to anybody, well you should or you shouldn't do something, because I don't know. I mean the doctor doesn't always know best, but obviously it's a decision that's to be made. …But I would want to be able to talk with her about some of the emotional stuff that she might be experiencing afterwards and that it's okay to be having these emotions, but it's really important for me to let her know I'm available for her to talk to if she's feeling kind of down and not as sexy as she used to.

Mary said this:

> I would say because of my experience 'why are you doing this? Are you doing this for yourself or for someone else? Is it really necessary? Have you explored all the alternative ways of feeling? Do you, if you are of childbearing age, do you really understand what this means to not have children, to never have the possibility of having children. This is not the same as having your tubes tied.

Donna offered this:

> It would depend on her age and what she was like and whether she had to have her ovaries removed. Obviously I wouldn't encourage anybody that had to do that 'cause I don't know what I'm talking about, but as far as this surgery, it was so simple and so easy and I would recommend it to anybody going through what I was.

Amanda said this:

> I would say first off, do everything possible to not have it, keep all your reproductive stuff. Read everything, everything you can get your hands on and ask every stupid question that pops into your head, 'cause it may sound stupid to you, but it is that question that you forgot to ask that he [the doctor] needs to hear and to answer.

Sally emphasized this:

> I would say to her whatever you do make sure you get two opinions. Find out for sure if there's no other possible way and research it. Do as much research as possible for yourself, don't take someone else's opinion as the gospel, you do your homework too.

All of these women described knowledge, support, seeking second opinions, talking to other women, determining your own situation and taking your time as the keys to the decision-making experience. Indeed in the end most of the women expressed that deciding to have a hysterectomy had been the right decision for them. Donna expressed it in these words:

> I felt very comfortable with my decision...I felt very sure and very comfortable. I didn't even look back and think, oh, I don't want to do this. I just felt like I was doing the right thing and I'd never miss those parts.

Linda said this:

> I've had three people say yes, this is the right thing to do, it's not going to be that bad, maybe this is the right thing to do and certainly I have no regrets for having it done.

And finally Susan explained this:

> No, overall it was a good experience, it really was. I have no regrets. It's actually kind of nice 'cause I haven't talked to anybody, I haven't sat down and put the whole story together in one session with somebody, so it's actually kind of nice. And I put things into perspective anyway, but it sort of seems like, like seeing the whole picture set out before

you and it makes me realize again that I made the right decision.

Thus the puzzle has been completed and the themes of the "lived" decision-making experience of undergoing an elective hysterectomy have been described. I deemed the essence of the experience as "You need to do what's right for you" because what each of these eleven women experienced and described was the best decision they could make, given the contextual and social factors of their lives. The decision-making experience was challenging, for some wrenching and, for others more manageable. As with my own experience, I was not trying to second guess their reasons nor make judgements on their decision to have a hysterectomy, as that would have been presumptuous and unfair. Rather the analysis revealed that the "lived" decision-making experience of hysterectomy was constrained and often problematic by virtue of living in the north. It was constrained by issues of gender and doctor-patient communication. Women in the north have a limited choice of family doctors and specialists, and this is further limited by the fact that the vast majority of doctors in the north are men. While most of the women appreciated the technical expertise of the doctors, many remarked that it was the conversations with women; public health nurses, crisis counsellors, family members and friends that made them comfortable in seeking out information to help them make a decision that would be right for them.

However, the decision-making experience was problematic because not all women in the north have access to alternative sources of information nor to technologies which in some cases may have prevented a woman from loosing her uterus. Second opinions were also problematic, firstly, because some of the women did not perceive the specialists in the north as practising independently and secondly, because many women in the study did not have the time nor the financial resources to travel to the Lower Mainland. This barrier indicated that women in the north experienced limited information and knowledge by which to make an informed decision. In other words, the women made the best decisions they could, given their resources.

The analysis also highlighted the fact that not all women received an holistic perspective of the outcome of the surgery, such as information about emotional and sexual issues. Once again women made their decisions without being truly informed. Thus the essence of the experience speaks to the resolve of these northern women to get on with their lives. However, it points out that there is much work to be done with various health care providers and policy makers about understanding women's experiences of health care decision making in the north and the need for further consultation and partnerships in ensuring quality care for women.

In the final chapter I offer concluding remarks, conclusions, and implications for practice, policy and further research.

# CHAPTER FIVE

## CONCLUDING REMARKS

Hysterectomy is a surgery which countless numbers of women in Canada undergo each year. However, women's experiences of decision making regarding this surgery are not well documented or understood. As a result, there is little awareness among women and health care providers about how women perceive this experience. Therefore, the primary purpose of this study was to explore and describe the "lived" decision-making experiences of women who have undergone an elective hysterectomy within a specific geographic context in British Columbia in order to gain an increased understanding of this phenomenon. The impetus behind the study came from my own personal experience of hysterectomy, but also from the knowledge that the Northern Interior Health Region of British Columbia had the second highest rate of hysterectomy per 100,000 women in the province. These numbers illustrate the fact that a considerable number of women were undergoing this surgery however, the experience of deciding to have this surgery was not known. Hence, this research rendered the first opportunity for women and health care providers in the North to examine the issue of hysterectomy decision making from personal, lived perspectives rather than from abstract, clinical frameworks.

I used phenomenology combined with a feminist perspective as the frameworks to approach and conduct the study. These frameworks were chosen because they reflected my preference to conduct research that was women focused and revealed the "lived" perceptions of this health care decision-making experience. As well, both frameworks recognised the uniqueness of the individual experience, yet strove to discover the commonalties or "essences" of experience which connect us to one another. Data were collected from within the boundaries of the Northern Interior Health Region. Purposive sampling was used to select the women. Interviews were conducted in person using open-ended questions to gather the experiences. All of the interviews were audio-taped, then transcribed either by myself or by a transcriber. The transcripts were analysed using Colaizzi's (1978) phenomenological methodology. Significant statements were identified from the descriptions of experience, meanings were formulated, and clustered into themes, then a description of the phenomena was written to identify the essence or fundamental structure of the experience. The transcripts and a description were returned to each woman for further input and validation. Thus the essential structure or "essence" of the decision-making experience of eleven women who underwent an elective hysterectomy within the Northern Interior Health Region of British Columbia was described as "You need to do what's right for you". The supporting themes of the experience were described as follows: setting the stage, experiences of the body, involvement with doctors, alternatives and choices, knowledge is key, figuring it out, reflections of the north and outcomes.

## DISCUSSION

Women from the Northern Interior Health Region provided a view of the decision-making experience of hysterectomy that suggests that women do want to be involved in decision making which affects their overall health and well-being. The basic premise of my thesis has been that in order to form partnerships in women's health care, there must be understanding and dialogue about women's experiences. This study reveals women's experience of barriers and difficulties in decision making. It shows that women often experience not having all of the information and knowledge available to them in order to make a truly informed decision. In most instances women make decisions for practical and logistical reasons. This study discovered that relationships and connections with family, significant women, and doctors were imperative to making a decision that was felt to be right to the individual. The decision-making experience of hysterectomy is a process whereby a woman seeks information and knowledge from others, but ultimately must integrate that knowledge and information into the context and circumstances of her own every day life.

This study discovered the relational barriers that women experience. Firstly, women did not feel heard or respected as “knowers” of their own bodily experiences or situations from the doctors who were central to this phenomenon. Secondly, a number of women did not believe that their partners or significant others in their family or support network were supportive of the decision they were making. Both of these experiences made decision making more difficult and challenging. Another barrier from a contextual perspective revealed that decision making was difficult due to geographic location. Living in the North meant that access to second opinions, other treatment options, or information in general, was infrequently offered or unavailable because of communication differences between the women and doctors, doctors lack of skills or training, and restricted financial resources of the women. Issues of family and work responsibility also factored into this context.

While this study offered the aforementioned discoveries, I too discovered insights and information as part of the process of conducting the research. I learned that women do want to talk about issues related to their health and health care generally. Indeed, as evidenced from the numbers of calls and conversations that I had with women about the topic of hysterectomy, I am lead to conclude that this topic sparked a sense of importance and interest to women in this region. It suggests to me that qualitative research combined with quantitative research about hysterectomy will provide a balanced, holistic perspective of the issue and enhance the decision making experience. Another insight was that the volume and richness of the data on this issue is an indication of the wealth of information and knowledge women have and wish to share about their experiences and lives. As this is some of the first research within the North that systematically asked women to reveal their experiences, it will be imperative not to lose that momentum, but to encourage and involve women in being vocal about the need to promote women's health issues regarding policy and practice through funded research. This is a call to challenge myself and other readers of this document to keep women's voices front and centre.

I am also convinced that women within the Northern Interior Health Region are looking for ways to partner with health care providers in order to make health care decisions that will be informed and right for them. While some of the data revealed experiences and language that were less than flattering about the medical profession, I believe that the data should be viewed as an opportunity for women and doctors in the North to have a constructive dialogue. This research begins to elucidate the lived experiences of women and offers all health care providers some insights into how women perceive their health care. Thus discussions with women must include how women expect to be treated and what will facilitate partnerships in health care. Women and women's health advocates should expect to take a lead role in this process.

And finally I learned that I was not alone in some of my personal experiences of decision making. Many of my own concerns, worries and anxieties were echoed by these women. Similarly, living in the North was the back-drop, cloaking the experience. While I am genuinely concerned about the number of women undergoing hysterectomies in this region, I am now more informed about the context and relationship in which women experience this decision. Through this process, I have become more "experienced". It has reinforced my personal and professional perspectives of valuing women's experience. It has reinforced my own practice stance of listening to women's experiences and assisting them in finding ways that will be comfortable for them to challenge assumptions of the medical system about women's health and lives. And I am hopeful that this research will serve as a platform to build more fully on the issue of hysterectomy in the North, but also to enter into dialogue about women's health, health care and decision making. As such, my intent is to disseminate the findings of this research to women throughout the Northern Interior Health Region, by offering to speak and present the material to them, to attend any women's health forums in the area and to offer a copy of the research to the Prince George Public Library, as public libraries are places where many women seek additional information. A copy of my research will also go to the BC Centre of Excellence for Women's Health. As well, I will make myself available to speak to other health care providers, doctors, community health nurses, social workers and counsellors about the findings.

## IMPLICATIONS OF THE STUDY

Findings from this research have implications for practice, policy and further research. Health care providers, including medical social workers, need to understand the decision-making experiences of hysterectomy in order to better meet the needs and services of women.

Implications for social work practice include:

1. Assisting in the development of education materials or forums about the issue of

hysterectomy in relation to the psychosocial aspects of the surgery for women and doctors. Materials might include pamphlets, web sites, or newsletters. Forums might include support groups, women's discussion groups or conferences.

2. Because women value the support of their partners, medical social workers are in an excellent position to offer their skills to women, their partners and doctors in facilitating discussion on any concerns, misunderstandings or misinformation about all aspects of a hysterectomy, but particularly the psychosocial aspects. It would obviously be important, if not imperative that these discussions take place prior to a woman deciding to have a hysterectomy, therefore medical social workers must ensure that doctors are aware that this service may be accessed.

3. Medical social workers possess the skills and training to counsel and assist women with problem-solving and decision making, therefore they should make these skills available to women in their communities who may want to access this resource.

4. Medical social workers should explore ways of collaborating and partnering with other health care providers, such as community health nurses within the Northern Interior Health Region, in order to provide an holistic perspective and service for women.

5. Medical social workers working in conjunction with women and women's health advocates, need to determine strategies which address a woman's right to a doctor-patient relationship of mutual respect, trust and equality.

6. Medical social workers must continue to educate and advocate to doctors and other health care providers that women's experiences of their bodies are valid and the social context in which they live is significant to understanding the whole person.

Implications for policy include:

1. Medical social workers, acting as advocates of women's health, should assist women in presenting information and evidence to the Ministry of Health which addresses the issue of travel costs for women, specifically for women's health issues, of which hysterectomy is just one of them. While there is a provincial program in place called the Travel Assistance Plan (TAP), it only covers thirty percent of actual transportation costs and no accommodation or meals. This does not address the realities of most women's financial circumstances.

2. Medical social workers need to partner with women in their communities to consider developing women's health centres and /or to advocate for travelling clinics specialising in women's gynaecologic health and care. The model for these would be the mammography screening vans that travel to the smaller communities of British Columbia.

Implications for further research include:

1. To explore, examine and compare the decision-making experiences of women who decided not to have a hysterectomy. What was that experience like and how was it different from the women in this study?

2. To explore the experiences of women who do not have children in order to offer the diversity of women's experiences around the issue of hysterectomy.

3. To explore the experiences of hysterectomy further with First Nations women as this study captured only one woman's experience. First Nation's women are a significant group of women within the Northern Interior Health Region, therefore knowledge and insights into their experiences would compliment this research.

4. To explore the needs and concerns of women within specific age ranges, thirty to thirty five, thirty-five to forty and forty to forty-five in order to develop resources and services.

5. To further explore the issues of relationship, power and gender of health care providers in the decision-making experience of women.

## CONCLUSIONS OF THE STUDY

Clearly, the decision-making experience of hysterectomy for women who live within the Northern Interior Health Region of British Columbia was a challenging, complex and multi-layered phenomenon. Because the phenomenon itself has never been researched within northern British Columbia, the lived experiences of women from this area have not been voiced or heard before. The research frameworks that I chose were intended to facilitate an understanding of women's perceptions and descriptions of their experiences, but not intended to generalise the findings beyond the women interviewed. The study findings are limited by not being able to include the experiences of women that represent all of the small, northern or First Nations communities within the boundaries of the Northern Interior Health Region. The study is also limited by not representing women from other ethnic or cultural backgrounds. However, the conclusions drawn from the findings may provide insight into the phenomenon and can serve as a guide or reference for other women, their families, their doctors and other health care providers. Once again, the focus of this research was to explore and describe the "lived" decision-making experience of elective hysterectomy within the Northern Interior Health Region of British Columbia. In addition, I wished to answer the question: What can be learned or concluded from this experience? I concluded that the women in this study view the decision-making phenomenon within a relational (partners, family, doctors) and contextual (geography, finances, lifestyle) framework. I concluded that women in this study want to be treated with respect, acknowledged and validated for their experiences by the doctors they encounter in this process, but many felt that was not the case. As well, I concluded that women want to be fully informed about hysterectomy from an holistic perspective, meaning the physical, sexual, psychosocial and emotional aspects. Lastly, I concluded that the women in this study made the decision to have a hysterectomy to get relief from pain and suffering, as they appeared to be unable to alleviate their symptoms any other way.

In addition to learning about the experiences of hysterectomy decision-making, I also concluded that women in this study were eager to become involved in research regarding women's health and health care issues in order that other women can be more informed and knowledgeable about their health and well-being. And finally, I concluded with the belief that women in this study are experts of their own experiences and therefore can provide information that is insightful and beneficial in communicating and understanding the person as a whole.

In summary this study has provided an initial glimpse into one aspect of women's health experience and into the everyday "lived" experience of residing in the north. The decision-making experience of hysterectomy is one of personal choice and balance. Yet the issues which surround it, communication, relationships and partnerships with health care providers, must continue to be debated and researched. The dialogue generated by women ensures that different approaches and perspectives on women's health care are voiced and that women continue to take charge of their decision making in a fully informed manner.

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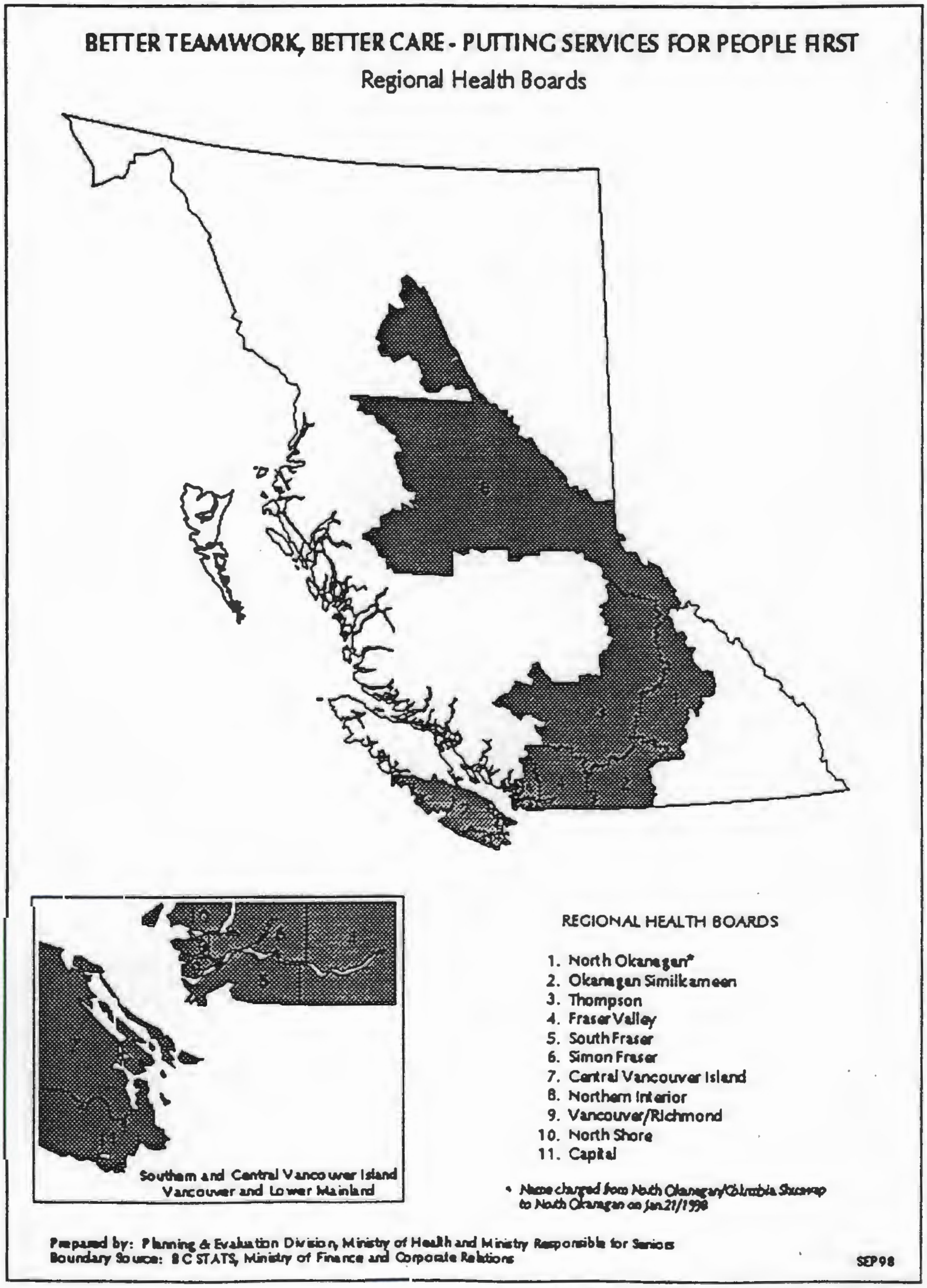
# APPENDIX A NORTHERN INTERIOR HEALTH REGION



BETTER TEAMWORK, BETTER CARE - PUTTING SERVICES FOR PEOPLE FIRST
Regional Health Boards

* Name changed from North Okanagan/Columbia Shuswap to North Okanagan on Jan.21/1998

Prepared by: Planning & Evaluation Division, Ministry of Health and Ministry Responsible for Seniors
Boundary Source: BC STATS, Ministry of Finance and Corporate Relations

SEP98

# APPENDIX B LETTER TO AGENCIES OR OFFICES

Dear _______________________:

The purpose of this letter is to request permission from your agency to post an advertisement regarding my research study.

My name is Pat Jordan and I am a supervised graduate student in the Social Work Program at UNBC. My research study is on the decision making experiences of women who have undergone elective hysterectomies in the Northern Interior Health Region. The purpose if the study is to explore and describe this phenomena with an aim to gain greater insight into northern women's experience.

I am now in the process of recruiting women to participate in this study. Therefore, the posting of this advertisement in your agency in a place where women would have access to it, would be appreciated. I will contact you in one week's time as to your response. The advertisement is enclosed.

This research topic has been approved by the UNBC Research and Ethics Committee. Should you need further information please contact me through my pager at 561-6487 or through my academic supervisor, Professor Barbara Herringer at 960-6643.

Sincerely yours:

# APPENDIX C ADVERTISEMENT FOR PARTICIPANTS

## HAVE YOU HAD A HYSTERECTOMY?

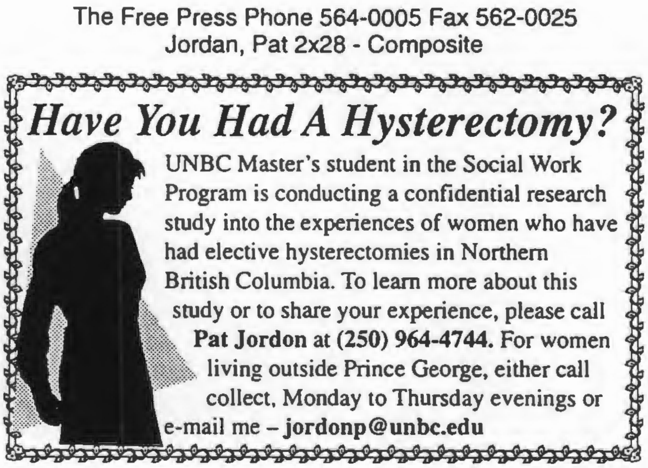
**How did you decide? What was it like to decide?**

**What factors were most important in that decision making experience?**

**If you are between the ages of 19 to 45 years, have had an elective hysterectomy within the last three to four years in Prince George and are interested in participating in a confidential research study, I am interested in hearing from you.**

**My name is Pat Jordan and I am a Graduate student enrolled in the Master of Social Work Program at UNBC. I am interested in talking to women about their decision making experiences of hysterectomy as this is the topic of my thesis study. If you are interested in learning more about this study or in participating, please feel free to call me at 964-4744. Leave a message and I will get back to you with more details. Your identity and confidentiality is assured.**

# APPENDIX D PAID ADVERTISEMENT FOR PARTICIPANTS



The Free Press Phone 564-0005 Fax 562-0025
Jordan, Pat 2x28 - Composite

## *Have You Had A Hysterectomy?*

UNBC Master's student in the Social Work Program is conducting a confidential research study into the experiences of women who have had elective hysterectomies in Northern British Columbia. To learn more about this study or to share your experience, please call **Pat Jordon at (250) 964-4744.** For women living outside Prince George, either call collect, Monday to Thursday evenings or e-mail me – **jordonp@unbc.edu**

# APPENDIX E LETTER OF INFORMATION TO PARTICIPANTS

Dear Participant:

My name is Pat Jordan. I am a registered social worker enrolled in the Master of Social Work Program at UNBC.

As a result of my work as a social worker in the health care field and from my own personal experience, I have become interested in the topic of hysterectomy as a woman's health care issue. I am especially interested in the experiences of women making the decision to have this elective surgery. Therefore, the purpose of my research study is to explore and describe the decision making experience of women who have undergone an elective hysterectomy in Prince George. My aim is to gain an understanding of northern women's experience of this surgery and to reflect that experience into words that other women contemplating this decision may find useful. The sharing of your own experience will help meet this aim.

What your involvement would consist of is the time for two, possibly three interviews. The first interview will be an introduction to the research and ensuring that all the criteria have been met. If you agree to participate, a letter of informed consent will be signed. The second interview will allow me to tape record your thoughts and perceptions about this experience. You will be free to decline to answer any of the questions during the interview or to ask that the tape recorder be turned off. After I have finished transcribing and analysing the information, I will send a copy of the description to you for your comments. Your comments will assist me in ensuring that I have captured your experience.

Confidentiality is assured. No names or any identifying information will appear on the transcripts or in the final thesis report. You are under no obligation to participate in this study and you are free to withdraw at ant time.

Should you wish to contact me at any time about the research or any further discussion about this topic, feel free to call me 964-4744. I look forward to our involvement together.

Sincerely:

## APPENDIX F LETTER OF INFORMED CONSENT

Research Title: Decisions, decisions: A study of the decision making experiences of women who have undergone an elective hysterectomy
Researcher: Pat Jordan, Graduate Student, University of Northern British Columbia
Telephone: 964-4744; E-mail address: jordon@unbc.edu

I, ________________________________, do hereby consent to voluntarily participating in this research regarding my decision making experience of having a hysterectomy. I agree to participate based on the following conditions:

1. Pat Jordan has my permission to tape record and/or take notes of the interviews,
   however I can ask to have the tape recorder turned off or ask that no notes be taken and that I can stop the interview at any time.
2. Pat Jordan may use the information from these interviews in her thesis report, presentations and publications. This information may include lengthy quotations taken from the interviews. However, no information that could personally identify me can be used.
3. The interview tapes, transcripts, consent forms, notes and any other personal information will be kept by Pat Jordan in a secure, locked file cabinet. The only other persons who have my permission to listen to the tapes will be Pat Jordan's thesis advisors and a professional typist who may transcribe the tapes. At the completion of the study, the tapes will be erased and the paper material will be shredded.
4. I will be given an opportunity to review or be read the description of the decision
   Making experience once it has been completed. I will be invited to make comments to ensure clarity or provide new insights.
5. I can contact Pat Jordan at any time should I have questions, concerns or second
   thoughts about my participation in this research. I understand that I may withdraw from the study at any time.

The participant and researcher have discussed each of the conditions and agree to proceed with the interview(s).

Signature of the Participant Date

Signature of the Researcher Date

## APPENDIX G PARTICIPANT DEMOGRAPHICS

1. **Present Age:**
2. **Occupation:**
3. **Level of Education:**
4. **Marital Status:**
5. **Age at the Time of Hysterectomy:**
6. **Reason/ Diagnosis for Hysterectomy:**
7. **Type of Hysterectomy Performed:**
8. **Marital Status at Time of Surgery**
9. **Location Where Surgery Performed**
10. **Children:**

## APPENDIX H INTERVIEW GUIDE

1. Tell me about your experience of deciding to have your hysterectomy.
   Probes:
   Describe your experience when the doctor first recommended you have a hysterectomy
   What were some of your thoughts and feelings?
   Describe the kinds of supports and/or resources that you used.
   What was helpful? What was not?
   Was a second opinion a part of your experience?
   Describe your experience of what having this surgery would mean to you as a woman

2. Describe what stands out for you most in this experience?
   Probes:
   Who and/ or what seemed most influential?
   Describe any fears, hesitations, anxieties, concerns
   Describe any conclusions, confirmations, etc., that you came to

3. Describe for me how you knew when you had made the decision that was right for you.

## APPENDIX I FIELD NOTE GUIDE

Participant Name: Interview Date:

Start Time; End Time:
Pre-interview goals:

Location of Interview:

People Present:

Description of Environment:

Non-verbal Behaviour: (tone of voice, posture, facial expressions, eye movement, body movement, hand gestures)

Content of Interview: (use of key words, topics, focus, exact words or phrases which stand out)

Researcher's Impressions:

Analysis (questions, hunches, trends in data, emerging themes):

Technological problems:

# APPENDIX J DATA ANALYSIS

## Selected Examples of Significant Statements of the Decision-Making Experience and Corresponding Formulated Meanings:

| Significant Statements | Formulated Meanings |
|---|---|
| 1. For me the decision to have a hysterectomy was partially based upon the changes I was undergoing physiologically. I was uncomfortable with bleeding more than I should have been and it was interfering with my relations intimately with my husband. | Decisions are based on physical as well as social, relational factors |
| 2. I'd always had pain with my menstruation, but it just got so that I was bleeding all the time and the pain was worse and cramps and things like That and it took me three doctors before I got sent to a gynaecologist. | She experienced a lot of pain and discomfort from her condition while in her search to see a gynaecologist. |
| 3. It started with my periods getting really heavy, they were lasting two or three weeks and I was starting to pass lots of clots and it was effecting me at work And I thought that maybe this would be the best answer. | Her physical symptoms were getting worse, effecting her work life, so she thought a hysterectomy would be the answer. |
| 4. I started thinking that I might need to have a hysterectomy because my mom had a hysterectomy at thirty-four, my grandma had a hysterectomy in her late thirties, it's something that runs in our family and I just started thinking along that route that I might have to have that. | She reflected on her family history of hysterectomy and thought it might happen to her |

## Examples of a Theme Cluster with their Formulated Meanings:

Women felt that the experiences and concerns of their bodies were not being taken seriously and that having a hysterectomy was a common place treatment.

1. She was shocked at the casualness of the discussion of the surgery which she believed to be a major invasive procedure. (interview #8, meaning #12).
2. She was astounded that the gynaecologist spoke of the surgery so matter-of-factly. (interview #10, meaning #96).
3. She felt betrayed and judged by the doctor's lack of concern and ability to know her as an individual person and Expression that the surgery was so routine. (interview #6, meaning # 25).
4. The gynaecologist made the surgery sound fairly routine, so she decided that it would end her problems. (interview #5, meaning, #15).
5. The doctor doesn't understand the meaning of this surgery to a woman's life. ( interview #3, meaning #33).