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WOMEN WITH BREAST CANCER AND THEIR LIVING IN AND THROUGH DISCOURSES: A FEMINIST POSTMODERN STUDY

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We accept this dissertation as conforming to the required standard

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ABSTRACT: WOMEN WITH BREAST CANCER AND THEIR LIVING IN AND THROUGH DISCOURSES: A FEMINIST POSTMODERN STUDY

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This feminist postmodern praxis oriented research investigates the journey and discourses of women living with breast cancer. This study explores the ways in which discourses and health care practices are implicated in relations of power, and how these discourses and practices inter-relate and inform each other. Alternative possibilities for creating new discourses and practices for women living with breast cancer are also examined in the study.

Seventeen women in various stages of being diagnosed and treated for breast cancer participated in two years of individual interviews, group discussions, and informal conversations with the researcher. Participants also read and responded to the emerging construction of the dissertation and contributed pieces of original writing that they had created over the course of their journey with breast cancer.

This research uncovers and illuminates the ways in which participants interpret biomedical discourse and position themselves in biomedical and other discourses. It also fosters an understanding about the ways in which women's discourses, sense of agency, power, and identity are impacted as they traverse their journey with breast cancer. In fore-grounding women's discourses, the differences between a woman's personal illness story and her journey with breast cancer and the biomedical emphases on the disease diagnosis and treatment trajectory are highlighted. An examination of women's discourses also illuminates the various ways that women may be positioned by biomedical discourse, position themselves and others, and as well, resist and reposition themselves in relationships. These understandings direct our attention to the strengths and capacities of women and the manner in which they exercise personal and collective agency.

This research is unique in it's emphases on illuminating women's discourses about living with breast cancer and on the professional, social, historical and institutional discourses that shape experiences for women. Highlighting a woman's journey with breast cancer, her own discourses, exercise of agency and development of transformative knowledge provides health care professionals with an insider's view. Knowledge of health care practices and relationships in the care of women with breast cancer are useful in envisioning ways of practicing to support and strengthen women's construction of a cogent illness journey and ability to participate in their care in meaningful ways.

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CHAPTER ONE
SETTING THE STAGE FOR THE RESEARCH

How Big Is the Problem?

> Imagine yourself picking up the newspaper one Saturday morning to find a front page headline screaming, "747 crashes. All 415 passengers killed. Onlookers shocked and horrified". Unrolling your paper over morning coffee four weeks later, you read another huge headline. "Second 747 crashes. No survivors. Families and witnesses stunned". Now imagine that this same headline appears every month for a whole year. One month it appears twice. (Caldwell, 1994, p. 263)

This is the statistical reality of breast cancer. As Judy Caldwell says, with plane crashes things would never get this far. Planes would be grounded, inquiries would be held and problems identified. The above quote is dramatic and it presents statistical facts about breast cancer in a way that captures attention. More usual, however, is the following presentation of the facts. In Canada, in 1999, an estimated 19,200 new cases of breast cancer will be diagnosed, and an estimated 5,500 women will die from the disease (National Cancer Institute of Canada, 1999). The most frequently diagnosed cancer for women will continue to be breast cancer, with the incidence continuing to rise, although deaths from lung cancer in women over fifty will exceed deaths from breast cancer for the first time ever. Breast cancer continues to be the leading cause of death among women between the ages of thirty-five and fifty-five. Twenty-two percent of all breast cancers occur in women below the age of fifty.

Breast cancer will account for a loss of 94,000 potential years of life among women, while prostate cancer accounts for 33,000 potential years of life lost for men. The more common the cancer, and the earlier it leads to death, the higher the premature mortality it causes, thus reflecting the relatively young age at which women die from breast cancer (National Cancer Institute of Canada, 1999). Canada and the United States have one of the highest breast cancer rates in the world. In fact, breast cancer is increasing world wide with the exception of Israel (Whelan, Parker & Hasuyer, 1990; National Cancer Institute of Canada, 1999).

In my early exploration of breast cancer, I learned about the statistics, the disease itself, the research agendas being pursued, and the corporate and charitable interests that are involved. I also learned that mortality from breast cancer has remained virtually unchanged for the past twenty years (National Cancer Institute of Canada, 1999). I began to feel dismayed at how uncritically I had bought into the myth perpetuated by the cancer charities, the media, and the medical community that the war on breast cancer was being won. I also began to feel dismayed by own complacency with regard to so-called progress in the diagnosis and treatment of breast cancer.

As a longtime nurse, I had been traditionally educated in a biomedical model of care. It was the practice area of childbirth and midwifery that first made me aware of how pervasive the biomedical model was in my thinking and how little I had questioned it until I had been nursing for many years. As I began to question childbirth practices, and to think and act outside of biomedical discourse, I became much more aware of the way in which a biomedical model positions women in childbirth as passive participants in their health care. I also became aware that our western medical model of childbirth was only one way, and that it had been constructed in ways that served particular interests over others.

During my doctoral course work I found myself moving away from midwifery and childbirth as areas of research interest and more towards mid-life women's health and the disease of breast cancer. When I read Sharon Batt's book, *Patient No More* (1994), I was inspired into further study of breast cancer, and feminist and postmodern theory. During this time, my work with Bachelor of Science in Nursing students was illuminating many issues faced by women with breast cancer, and I was becoming passionate about this topic. I wanted to explore how women live with breast cancer and became active in my position as a nurse educator and volunteer with the Cancer Society, participating in a variety of projects designed to question and, in some ways, challenge taken-for-granted medical and nursing practices.

As a woman and a nurse, I hold fundamental beliefs around honoring women's voices and experiences of health and illness; yet in my reading of nursing and medical literature about breast cancer women's voices were starkly absent. I turned to women's personal stories of living with breast cancer in popular literature and began to understand the life experiences and issues for women with breast cancer in a different way. The more I read, the more I also recognized the differences within and among women's voices. I began to raise questions for myself. Why are women's voices so absent from professional literature? Where does knowledge about breast cancer come from? Who generates it? What counts? I wanted to understand more about the relationship between a woman's experience of breast cancer – her subjectivity – and how that experience relates to formal knowledge about breast cancer, illness care practices, and the power relations that socially construct the breast cancer experience (Weedon, 1987).

My Journey

Over the past four years I have immersed myself in nursing practice and research with women living with breast cancer, and I have learned much about the homogenized and fragmented system of care available to these women. My work with the Cancer Society, the Cancer Center for the Southern Interior, local hospitals, support groups for women living with cancer, and nurses working with women experiencing cancer has provided me with an appreciation of the complexity and diversity of women's experience. I attended both the First World Conference on Breast Cancer, held in Kingston, Ontario, in July 1997, and the Second World Conference, held in Ottawa in 1999. Participants came from all parts of the world, from diverse circumstances, and were embedded in different phases of their journey with breast cancer. What many had in common, however, was a profound anger – directed primarily towards research agendas and treatment protocols that continue to view breast cancer as only an acute disease. Many questions and issues for debate surfaced in the conference presentations and discussions. Why is there so little research emphasis on environmental pollutants? Why is so little known about the cause(s) and course(s) of breast cancer? Why is the research and treatment emphasis still on chemotherapy and radiation therapy rather than on less harmful treatment modalities? Why is breast cancer increasing in incidence, and why is mortality relatively unchanged despite twenty-five years of research?

During both formal and informal sessions, many women expressed the belief that finding their own voice was a turning point in their journey with breast cancer and that having voice enabled them to move on from an initial place of overwhelming fear and uncertainty. Many expressed their joy at being with women and in finding a collective voice. The passion, commitment, and personal struggles were moving, and the strength of these women was awesome.

Situating the Research

Biomedical Discourse

When one looks at the professional literature about breast cancer, it is evident that the voice most heard is that of medicine, supported by the cancer establishment, the media, and in part, the nursing profession. This is a remarkably cohesive discourse dominated by powerful medical and institutional interests. Biomedical discourse holds a privileged position over other ways of knowing and in this social historical time, the power to define truth about health and illness. Additionally, biomedical discourse and the professional and institutional proponents of the discourse, exert strong political influence, thereby ensuring the dissemination of biomedical discourse as the truth. This has the consequence of silencing other discourses from health care for women with breast cancer.

The dominance of biomedical discourse, and the consequent power of the medical profession, relies in part on its ability to lay claim to truth and to being a body of professional knowledge grounded in objective reliable science (Turner, 1995). The voices of predominantly white, upper class physicians and research scientists dominate this discourse. Nursing may be seen as supporting dominant discourse, at least some of the time. Biomedical discourse is grounded in a world-view that sees objective "science as independent of particular social and moral values and interests...and language as a transparent tool for expressing facts" (Weedon, 1987, p. 131). This world-view is exclusionary in the way that biomedical discourses measures all other discourses against the cannons of objective science and is focused on disease in contrast to illness.

Alternative perspectives are seen as invalid or not scientific if they don't measure up to the rules of verifiable science.

As I read this body of literature I became increasingly aware of how a claim to one particular version of reality can result in power-over relations. Claiming truth status for biomedical discourse effectively confers power to holders of that knowledge and a marginalized position for holders of other ways of knowing about breast cancer. I believe that when women's voices are not available in the framing of discourse they are positioned as object --a body with disease -- rather than as subject --a woman experiencing both the disease and illness of breast cancer.

Following Weedon (1987, 1999), Powers (1996), and Rudge and Cheek (1994), I believe that biomedical discourse has been able to maintain its supremacy through intricate webs of actual and ideological power. I think of ideology as fore-grounding some things to the exclusion of others and valuing systems that are complicit with dominance (Allen, 1997). Cohesive and mutually rewarding relationships are forged among medicine and powerful policy-setting and funding agencies. These relationships have resulted in the presentation to the public of one particular truth about breast cancer. As Weedon (1987) notes, we know and see what our language permits. The language used in talking about, for example, breast cancer does not label a real world or truth, but rather is a story that is socially and historically constructed through discourse. In the case of breast cancer, the story is constructed as war.

My own understandings about breast cancer have been illuminated and deepened by an examination of the manner in which a war metaphor informs much of biomedical discourse. Metaphors have a way of becoming invisible, beyond our conscious awareness and therefore able to influence the way we think about cancer. I believe that war language and imagery have been useful in maintaining the dominance of biomedical discourse and ideology, and in perpetuating a monopoly over breast cancer research and treatment practices.

Discourse, Language and Metaphor

Hawkins' (1984) comparison of autobiographical descriptions of illness is illustrative of how illness experiences are shaped by discourses and images given meaning through metaphorical constructs. Ryan, writing in his journal about his experience with cancer, uses the images and language of warfare. Hawkins' critique of the war metaphor so prevalent in our society's consciousness of illness raises an important question. What would health care look like if disease were not conceptualized as war?

> His doctors are reminiscent of the various generals of World War II about which he writes in his histories, each a skilled tactician...his cancer is of course the enemy, his therapies function as weaponry, and the many helpful friends are like the courageous civilians of the Resistance. Ryan himself, figures...not only as the battlefield upon which rage these forces of the disease and the therapy, but also as the commander-in-chief in consultation with the other generals...and in the end, he figures as one of the many brave and courageous soldiers who die fighting (Hawkins, 1984, p. 242).

The war metaphor is crystallized in the language used to describe cancer. Cancer strikes or attacks, it invades or spreads within us. We must mobilize the body's defenses, defeat or kill cancer with the toughest of therapies, and, finally, we expect our research scientists to discover the latest magic bullet to disarm the enemy (Sontag, 1978; Carins, 1985; Beardsley, 1994; Montgomery, 1993).

War defines a set of images that pervade our consciousness about cancer at both individual and societal levels. These images, in turn, define the scientific edifice of knowledge that is sanctioned about cancer. Just as punishment and divine retribution were the images of the middle ages, war is the image of the twentieth century (Montgomery, 1993). The images of cancer perpetuated and sustained through this discourse serve to create a battleground on which the war against cancer is to be fought (Clark, 1992; Lupton, 1994; Delvecchio, Good, Good, Schaffer & Lind, 1990). Cancer is portrayed as an evil predator, an insidious enemy invading from within one's own traitorous body. A concerted campaign is required to fight this war of epidemic proportions. Like Ryan in the Hawkins description, the patient is expected to be a good and loyal soldier – brave, stoic, and willing to fight to the end. She is also expected to provide a docile body on which the war can be waged.

When Richard Nixon declared war on cancer in 1971, the images and language prevalent in biomedical discourse became embedded in the psyche of the western world. There was justification for enormous spending; the media took hold of the images and routinely reported on the advances in the war. The links among medicine, pharmaceutical companies, and the cancer establishment were strengthened in an all-out effort to win the war. Questioning of this view of cancer is only beginning now -- some twenty-five years later. The war metaphor has been adopted and globalized so effectively that the very bones of the construction become invisible to us (Street, 1995).

Use of metaphor causes us to understand and express one kind of thing in terms of another (Lakoff & Johnson, 1980). We can not underestimate the effect that metaphor can have on our construction of reality, and on how we view the world. In the case of cancer, metaphor has had a powerful effect in shaping consciousness about the disease for the public and for the nursing and medical professions. As Lakoff and Johnson state:

> Metaphor may create realities for us, especially social realities. A metaphor may thus be a guide for further action. Such actions will, of course, fit the metaphor. This will, in turn, reinforce the power of the metaphor to make experience coherent. In this sense, metaphor can be self-fulfilling prophecies (Lakoff and Johnson, 1980, p. 156).

A war metaphor focuses our attention on the acute emergency of diagnosis and treatment and makes invisible the subjective experience of being in the war, whether as a survivor or not. War language terrorizes women and shapes health care professionals in ways that ensure a hierarchical relationship where passivity and compliance are valued. Within biomedical discourse, and through the war metaphor, women's subjectivities are shaped, just as knowledge and practices are shaped. The power, pervasiveness, and privileging of this discourse situate women as *other,* whose voices and experiences are not acknowledged (Mathieson, 1994; Wear, 1993). In fact, women are positioned as docile bodies on which to wage war (Foucault, 1972, 1973, 1975), and as voiceless in the discourse (Davies, 1992; 1993).

Oppositional Discourses

Oppositional discourses about breast cancer stand outside of mainstream thought. These discourses may be seen as marginalized and in direct conflict with dominant discourse. The voices heard within these discourses are usually not considered part of the speaking community with regard to influencing knowledge development or the practices associated with the diagnosis and treatment of breast cancer. Oppositional discourses challenge the hegemony and boundaries of existing and dominant modes of thought (Harlene, 1994).

There are at least three different marginalized discourses evident in the literature on breast cancer. One is the discourse of alternative/complementary therapies. Within this discourse are multiple and divergent voices having at least one thing in common: a search for more natural and less invasive forms of treatment for cancer. A second discourse is comprised of the phenomenological voices of women living with breast cancer. This discourse provides us with an account of women's own consciousness and subjectivity related to their illness experience. A third oppositional discourse is provided by feminists/activists. Feminist discourse is open about its political interest in challenging the power/knowledge interests of the dominant discourse. The nursing literature is an interesting blend of dominant and oppositional discourses, with the biomedical predominating and feminist activist discourses being almost completely absent.

At this particular historical moment dominant and oppositional discourses are competing for meaning with biomedical discourse being in a position of power over other discourses. The exclusion of women from the knowledge base of biomedical discourse "brings into question that which has passed for wisdom" and alerts me to the exclusivity of biomedical discourse and the invisibility of women's discourses about breast cancer (Lather, 1984, p.54).

Intent and Overall Aim of the Study

The overall aim of this study is to explore the construction of the breast cancer experience for women, illuminate more clearly how women interpret biomedical discourse, take up and position themselves within various discourses, and how their sense of agency, power, and identity are impacted. In this study, women with breast cancer and the researcher are positioned as political agents in a collaborative process of reflection and action aimed at transforming our own understandings about living with breast cancer and the nursing and medical practices associated with the care of women with breast cancer.

The purpose just described clearly reveals my positioning ontologically and epistemologically in critical science (Allen, 1986; 1992; Lather, 1991; Denzin & Lincoln, 1994; Campbell & Bunting, 1991). I am explicitly oriented to research as praxis, which clarifies the critical and emancipatory roots of a "research paradigm openly committed to critiquing the status quo and building a more just society" (Lather, 1991, p. 172). Following Lather, I use the term emancipatory knowledge to describe a way of knowing that "increases awareness of the contradictions distorted or hidden by everyday understandings, and in doing so...directs attention to the possibilities for social transformation" (Lather, 1991, p. 52). At the center of praxis research is the goal of reciprocal shaping of theory and practice.

Conclusion

Having located myself in relation to my interest in breast cancer and in critical science, I next discuss the relevant literature. Chapter Two reviews literature related to breast cancer from biomedical, alternative/complementary, phenomenological, and feminist orientations. In Chapter Three, I locate myself theoretically in feminist postmodern praxis-oriented research methodology and describe the actual process of the study. A portrait of the study participants as a group and individually is presented in Chapter Four. Chapters Five and Six describe the research findings by providing the reader with a construction of women's own discourses about their journey and living with breast cancer. In Chapter Seven, utilizing a feminist postmodern lens, I develop my own discourse about the manner in which biomedical discourse positions women with breast cancer and the ways in which women's own discourses provide sites of resistance and potential for agency. In the final chapter of the dissertation, I reflect back on the outcomes of the research, the research process as experienced by both myself and participants and some of the ways this research was authenticated. I then reflect forward and respond to two questions. The first, how do we develop critical insights into particular discourses as we simultaneously live in and are constructed by them? The second question I address in Chapter Eight, how do we turn critical insights into emancipatory actions? I conclude the chapter with a discussion of the development of transformative knowledge and praxis research.

CHAPTER TWO

THE LITERATURE: SURVEYING THE TERRAIN

Situating Myself

The literature about breast cancer is vast. I realized early on in my study that the professional health care literature (nursing and medical) is a limited source of information about breast cancer. It therefore became important to me to read widely, in some depth, and from a multidisciplinary perspective. It also became apparent that I needed to go outside of mainstream professional literature and peruse literature not found in the traditional academic journals. My search for this non-academic body of work has been fruitful and rewarding. My own understandings, insights, and emotions have been profoundly affected. I would sometimes finish an academic research article with the question, so what does this mean for the woman with breast cancer? Or with the question, so what does this mean for nurses interested in caring for women with breast cancer? I found myself drawn more deeply into non-academic literature. Upon completion of a personal narrative, a poem, or a story about self-healing, I would find myself moved by the strength and courage of the woman I was reading about. I would also find myself angry at how sterile my own body of professional literature was about this disease and illness. So, although there are multiple and varied discourses available, only one, the biomedical, seemed accessible via the professional literature.

I have chosen to review the literature related to a woman's experience of living with breast cancer under the general rubric of discourse. As Foucault (1972; 1973; 1975) explains, the power of a discourse lies in its ability to shape meanings, subjectivities, and actions. Language is the vehicle of discourse in which meanings about breast cancer, for example, are created. This knowledge is not value-free, but carries authority by virtue of the power given to the discourse by society. Discourse is constituted by ideologies which have power to shape consciousness and generate beliefs, practices, truths, and taken-for-granted ways of looking at something (Dickson, 1990). Thus the language used to talk about breast cancer creates meanings health care professionals and women themselves take on. These meanings then shape our understandings, beliefs, and practices in diagnosing and treating breast cancer. It is our job as a community to notice what stories are told and what stories are disregarded (Gray, 1996).

Biomedical Discourse

The story of being treated for breast cancer within biomedical discourse is a story of authority and power exerted over women by medical experts. Commanding time lines and set protocols and institutional practices foster a war like sense of haste, fear, and powerlessness on the part of women being diagnosed and treated for breast cancer. The voices heard are those of medical specialists: surgeons, oncologists, and radiologists. They wield enormous power in dictating diagnostic and staging protocols, surgical options (breast conserving or breast destroying surgery), and follow-up treatment. The protocols and options have varied only slightly over time.

The initial diagnostic and treatment phases of breast cancer are a place where many alternative voices exist, yet it is also a place where biomedical discourse has the power to silence and marginalize adherents of oppositional discourses. The power and authority given to, and demanded by, cancer specialists, and the support of this view of the world provided by the cancer establishment, act in strong ways to shape the consciousness of women, nurses, doctors, and society.

Initial and Adjuvant Treatment

In the recent past, biomedical discourse described breast cancer as a local disease that invaded muscle and axilla before spreading via the lymph system to distant parts of the body. This belief provided the rationale for treatment using the Halsted radical mastectomy, during which the breast, chest wall muscles, lymph glands, and underlying fat tissue were removed (Batt, 1994; Love, 1995; Montini & Ruzek, 1989). This was a severely mutilating kind of surgery that frequently left women with a sunken chest, lymphedema, and immobility on the affected side. This drastic form of surgery was framed as necessary in order to get every possible cancer cell.

The Halsted radical mastectomy was the operation of choice in both Canada and the United States until the mid-1970s, despite falling out of favor in Europe much earlier

(Batt, 1994; Moss, 1996). The prevailing belief that breast cancer was a local disease and that it spread via the lymph system led to several other practices. A sense of urgency was felt, so surgeons rushed women into surgery with what was called the one-step process. Women with suspicious lumps were operated on for removal of a piece of breast tissue, the tissue was examined for cancer cells under frozen section, and, if the tissue was believed to contain cancer cells, the surgeon proceeded with the radical mastectomy. Women have Rose Kushner (1986), a breast cancer activist, to thank for raising and challenging the ethical and psychological issues of a practice that was taken for granted within biomedical discourse.

While radical surgery did slowly give way to less drastic forms of surgery, feminist voices have questioned the slowness with which this occurred (Batt, 1994). Even today, with the efficacy of breast-conserving surgery having been demonstrated, vast differences in surgical procedures are commonplace (Margolese, 1994). The power of biomedical discourse and war-like imagery sensitize women to the need for haste and getting rid of it as quickly as possible (MacPhee, 1994). Breast cancer is now considered a systemic disease, and most breast cancers are believed to have been growing for anywhere from two to ten years before they can be detected by any of our currently available, traditional means (Olivotto, Gelman & Kuusk, 1995; Love, 1995; Batt, 1994).

Despite a general belief that breast cancer is a multi-causal and systemic disease that is present long before it can be detected, treatment practices continue to reflect a biomedical discourse that highlights the treatment of breast cancer as a technical problem, amenable to particular rules. The routine and unquestioned use of staging surgery, whereby lymph nodes are removed during the breast surgery itself, provides an example of one such practice. Lymph nodes are removed for examination, with the purpose of offering some prediction for survival and guidelines for further treatment (Olivotto et al, 1995; Clark, 1996; CMAJ, 1998). These clinical guidelines determine whether further treatment is advised. Particular treatment regimes are based on the designation of the stage of breast cancer. Stage one, for example, is defined by a tumor less than two centimeters in size and negative for cancer cells in the tested lymph nodes. Stage three is defined by an advanced local tumor fixed to the chest wall, with positive lymph nodes.

Survival rates are also fixed to stage: a five-year survival rate of between 80 and 95% for stage one, and a survival rate of 30 to 60% for stage three breast cancer. Love (1995) criticizes the use of the staging system as not fitting well with what is currently known about breast cancer. Both the staging system and the TNM (tumor, node metastasis) systems ignore the behavior of the tumor itself and the current belief that the lymph nodes are probably not the main route of spread. As Love (1995) reminds us, lymph node evaluation does not give us foolproof facts. In about 30% of cases, women with positive lymph nodes will not have microscopic cells elsewhere. With negative lymph nodes, 20 to 30% of women will have microscopic spread. Positive lymph nodes provide probability information only, a piece of information that women are frequently unaware of.

Staging systems do provide a conceptual way to categorize each case of breast cancer so that different kinds of treatment can be compared across patients with similarly staged breast cancers. This can be useful from a medical clinician or research scientist's point of view. In biomedical discourse, the extent of breast cancer is defined and circumscribed by staging criteria that are then used in dictating treatment protocols (CMAJ, 1998). This belief in the accuracy and necessity for staging is based on what we currently know about the course and spread of breast cancer. Women's experience of pain and swelling, and the questionable utility of removing an important portion of the lymph system, have gone unquestioned until recently (Soffa, 1994; Humble, 1995; Granda, 1994).

There is little dissonance among discourses about the necessity for surgery itself. In fact, most acknowledge that breast surgery is the one known method that sometimes cures breast cancer (Olivotto, et al, 1995; Love, 1995). Women do, however, highlight the illusionary notion of choice regarding type of surgery. The rapidity with which women are thrust into the system, the personal opinion of the surgeon, and his or her power in the interaction profoundly influence the ability of the woman with breast cancer to participate in the decisions made (Luker, Beaver, Leinster, Owens, Degner & Sloan, 1995; McFall, Warnecke, Kalusny, Aitken & Ford, 1994; Margolese, 1994; Schain, 1990; Souminen, 1992). What this means is that women may be in the midst of, or finished, follow-up treatment before they can begin to reflect or question the path they have embarked on (Batt, 1994; Wittman, 1993; Hoy, 1995; Hooper, 1995). Completion of initial treatment may give a woman the time and space to contemplate the enormity of what has just gone on in her life and is often the place in a woman's journey with breast cancer when she will begin to write about her experience.

Biomedical discourse presents adjuvant therapy (treatment given in addition to surgery) as preventive, with the rationale that microscopic cancer cells may remain following surgery (Olivotto et al, 1995; Anorulis, 1997). Whether or not adjuvant therapy is recommended will depend on staging and a statistical prognosis. Biomedical discourse positions chemotherapy and radiation therapy as scientifically validated treatments for cancer and often talks about the new recommendations that are constantly being developed and updated to keep pace with new understanding of breast cancer (Olivotto et al, 1995).

There are four general situations where radiation is recommended for women with breast cancer: after a lumpectomy; after a partial or radical mastectomy; as treatment for locally advanced cancer; or for systemic relief when the cancer has spread (Olivotto et al, 1995). Radiation has become usual treatment following surgery, and it is presented as innocuous, with minor symptoms of skin irritation, fatigue, and the possibility of a sore throat and pneumonitis if lymph nodes are also treated. Assurances are given that although the throat and lungs will be in the path of the radiation, there is no risk involved. Of course, radiation can be given to a part of the body only once, meaning that women who are treated with radiation and then later have advanced disease requiring radiation for palliative treatment may not be eligible.

Chemotherapy, as an adjuvant therapy, is usually recommended when the woman presents with advanced local disease, a tumor size five centimeters or larger, suspicious feeling lymph nodes, or a tumor attached to the chest wall. Additionally, chemotherapy is recommended if the cancer has already spread, or "if there is a risk of cancer recurring in other parts of the body" (Olivotto et al, 1995, p. 148). Like radiation, chemotherapy is used quite frequently in the initial treatment of breast cancer, and even more commonly in the recurrence phase. The side effects that accompany the administration of chemotherapy are explained by Olivotto et al in this way.

> Chemotherapy has had a bad name due to the severe side effects women used to experience years ago when these drugs were first being developed. Because of these problems, many new drugs have since been found that control or eliminate many of these side effects. ...Fear also stems from patients not having a clear idea WHY chemotherapy is being given (Olivotto et al, 1995, p 149).

Biomedical discourse minimizes the toxic effects of chemotherapy and seldom makes an authentic place for women's own accounts of what receiving adjuvant treatment is really like (Youngblood, Williams, Eyles, Waring & Runyon, 1994; Graydon, Bubela, Irvine & Vincent, 1993; Lev, 1992). It is in being with women undergoing chemotherapy, or reading women's own stories, that a more realistic picture of their lived experience emerges. It is interesting and illuminating to note that when doctors were surveyed about undergoing chemotherapy themselves, or recommending that their family members do, three quarters said they would not (Moss, 1995). They cited both the ineffectiveness of chemotherapy and unacceptable levels of toxicity as reasons.

Living in Limbo

During the treatment and living with hope-of-cure phase of the breast cancer journey, women are expected to maintain a good veteran role. An image is presented of the woman with breast cancer and her doctors fighting a courageous battle until one of two things happens: a remission of the cancer occurs and the woman becomes a survivor; or the woman dies and becomes a causality of the war. Inherent in the good veteran role is the obligation to remain cheerful, optimistic, and trusting about medical and nursing treatment. Looking normal and taking on the battle with cancer as a challenge are examples of ways the cancer establishment and the media participate in generating and perpetuating biomedical discourse.

The Reach to Recovery program was originally started by the Cancer Society as a support program for women undergoing mastectomy, and can be seen as part of the looking-normal metaphor. The program soon developed policies and practices that clearly indicated support for dominant discourse and reflected values of compliance, silence about the ravages of treatment, and support for medical practices (Lorde, 1980). Specifically, a woman required a referral from her surgeon before being visited by a volunteer. The volunteers recruited for the program (breast cancer survivors) were required to adhere to a prescribed set of rules, which included, for example: the necessity of providing a testimonial to the skill of the surgeon, information on ways to temporarily fill a bra, and support for medically prescribed treatment. Off-limits for discussion were the woman's experience with her doctor, her thoughts and feelings about having breast cancer, and other treatments she might be considering (Batt, 1994). Additionally, volunteers were required to wear a prosthesis and bust fitting clothes. If a woman's cancer returned she could be removed from the program (Soffa, 1994). It is interesting to note how the Reach to Recovery program, initially an attempt by women with breast cancer to support newly diagnosed women, became co-opted by the medical profession and the traditional medical perspective put forward by the Cancer Society.

The media have also played a strong role in perpetuating images of cancer, which can be seen as part of the metaphor, "cancer as opportunity". Batt (1994, p. 27) recalls seeing a television documentary, entitled, *Destined to Live*, that profiled well-known American women with breast cancer. All spoke of their fear and horror on hearing their diagnosis of breast cancer. The program then went on to describe how they had conquered their fear. The overall message was about the personal growth that each woman had experienced as a consequence of having had breast cancer, punctuated by such pithy statements as, "I've never felt better in my life" and "Breast cancer was the best thing that ever happened to me". Nowhere in the program were the ravages of treatment or the uncertainty of prognosis acknowledged; nor were the women dead from breast cancer mentioned or mourned.

As illustrated above, biomedical discourse is quite silent about what living with breast cancer is really like. In addition to the images portrayed, i.e., getting back to normal and taking up the challenge, breast cancer is depicted as an acute disease. Initial categorization of the extent of the disease leads to particular treatment regimes. Once treatment is completed the initial emergency is over and the woman enters a time of surveillance. She is expected to conform to designated surveillance protocols (scans, blood tests, examinations) and to practice vigilance by reporting any untoward signs to her doctor (Krause, 1993).

Surveillance protocols take place in the acute care system. A woman with breast cancer is expected to attend the acute care agency, submit to the tests, and then go home to wait for results, which will be conveyed to her through her doctor some time later. If test results show a recurrence of disease, the woman will again enter the acute care system, undergo whatever treatment her physicians advise, and then exit the system again.

At some point in this medical trajectory issues of quality of life may surface. Quality of life in relation to living with cancer and receiving cancer treatment has become an area of research interest for many health care professionals. In the brief section below, I merely highlight some of the directions this research is currently taking.

Within biomedical discourse, quality of life is often addressed from two perspectives. The first, quality of life related to long term survival, is defined as five years or more, disease-free (Fredette, 1995; Halstead & Fernsler, 1994; Coward, 1990; Nelson, 1996). The second, and more usual, addresses quality of life from the perspective of treatment utility. Should further surgery, chemotherapy or radiation be advised, or would the treatment itself be detrimental to quality of life? Biomedical research in this area primarily looks at easier to administer or more accurate assessment tools to measure quality of life (Haydon, Moinpour, Metch, Feigl, O'Bryan, Green & Osburn, 1993; Farquhar, 1995; Ferrell, Hassey-Dow, Leigh, Ly & Gulasekaram, 1995). In much of this literature, quality of life is measured by biomedical markers such as decrease in tumor size and/or the ability of the woman to engage in activities of daily living (Payne, 1992; Ferrell et al, 1995; Roberts, Thorne & Pearson 1993). Many researchers acknowledge the difficulties inherent in assessing quality of life (Hunt, 1997; Swartz, 1997).

There is considerable nursing research devoted to the effects of treatment for cancer and quality of life. For example, fatigue as a frequent symptom of treatment and one that is detrimental to quality of life is being extensively studied by nursing researchers (Berger, 1998; Nail, 1996; Nail & Jones, 1995; Pierce & Richardson, 1996). Recently, there has also been an increasing body of nursing research devoted to assessing a variety of health-promotive strategies designed to enhance quality of life for people living with cancer (Richardson & Ream, 1997; MacVicar & Winnington, 1986; Thibodeau & McRae, 1997).

Another facet to quality of life is that addressed by nurses, social workers, counseling psychologists, and many others who have developed practice and research interests around looking at different ways to support women who live with breast cancer (Seligmen, 1996). Breast cancer support groups, self-help groups, one-on-one counseling, classes in meditation, availability of healing touch, and a variety of other innovative opportunities may be available to women who have the resources and knowledge to seek out available services. I have become very aware, however, of the white, educated, middle-class tenor of such services, and we have initiated discussion in our community about ways we could address this observation.

Oppositional Discourses

Oppositional discourses occupy a position on the margins of current knowledge about breast cancer. As such, they also occupy the margins with respect to power or authority. These discourses problematize what we count as knowledge and, as well, the politics embedded in the context and construct of meanings about breast cancer (Lather, 1991). These discourses do not represent a cohesive singular view of reality, although they do represent collective opposition to the dominance and power of the biomedical discourse.

The Discourse of Alternative/Complementary Therapies

> The conventional and the alternative/complementary approaches to disease and illness tend to differ from one another, not only in their practices and techniques, but also in the belief systems that underlie their activities. They presuppose fundamentally different outlooks on the nature of birth, life and death. The medical paradigm that currently prevails in our society...has become so deeply entrenched that we often do not realize that it is simply one option among many. But there are other forms of medicine that represent different ways of understanding life and of promoting healing, and that, contrary to what the

> dominant medical establishment would have us believe, have demonstrated outstanding records of success (Robbins, 1996, p. 227).

Oppositional discourses represent a place in the breast cancer story where many voices exist and compete to be heard. Possibly two of the more vocal and accessible to the public are those of Ralph Moss and John Robbins. Moss, a former Assistant Director of Public Affairs at Memorial Sloan-Kettering Cancer Center, is the author of many books and a PBS award -winning documentary, *The Cancer War. The Cancer Industry* (1996) and *Questioning Chemotherapy* (1995) are two of his books written specifically with the purpose of exposing some of what Moss calls the myths and misconceptions about cancer generated by biomedical discourse. For example, he acknowledges the success of chemotherapy in treating particular forms of cancer such as acute lymphoblastic leukemia, choriocarcinoma, testicular cancer, and Hodgkins disease – relatively rare types of cancer. For the common cancer, however, he states that there has been little progress. Robbin's 1996 book *Reclaiming Our Health* is also written with the intent of exploding the medical myth. Both of these authors challenge biomedical discourse about cancer and put forward so called 'alternative/complementary' therapies as an option we should consider in the treatment of cancer.

Moss and Robins describe how radiation therapy and chemotherapy are intimately interwoven with images and language of warfare.

> Like the costs of military spending, the costs of fighting cancer are astonishing. Treating a typical cancer patient today runs about $100,000. ... In the US there are now more people making a living from cancer than dying from it. (Robbins, 1996, p. 229)

Robbins points out that images and language that depict the body as a battlefield and disease as an attacking army lead to a belief in the body as an environment that must be subdued and controlled, a continuous source of danger. These images are also useful in justifying the enormous amounts of money spent on developing and using these high-technology forms of treatment. Worldwide profit from chemotherapy totals 8.6 billion dollars (Robbins, 1996). Alternative/complementary therapies challenge the usefulness of a war metaphor and note that war images and the notion of a battle being waged also serve to devalue a person's experiences, feelings, and own bodily knowledge.

Alternative/complementary discourses question the efficacy of both radiation and chemotherapy in treating many cancers. There does seem to be agreement that early Hodgkins disease, lymphosarcoma, localized prostate cancer, and localized tumors of the head, neck, larynx, and cervix are helped with use of radiation therapy (Robbins, 1996; Moss, 1996). For cancer of the breast, however, there is some controversy surrounding the use of radiation. There are studies that demonstrate that radiation following lumpectomy decreases the local recurrence rate, but has no effect on improving survival (Batt, 1994; Moss, 1996; Robbins, 1996). Despite the dilemma presented by these findings, use of radiation is routinely recommended following lumpectomy (CMAJ, 1998).

Critics of radiation therapy charge that the potential dangers of radiation require further study, and that women need to be given more complete information about efficacy related to recurrence and survival, as well as with regard to untoward effects (Bertell, 1997a, 1997b). Large doses of radiation can cause nausea and vomiting, loss of appetite, and reduction in bone marrow function, along with adjacent organ and tissue damage. Irving Gofman, MD and Professor Emeritus of Molecular and Cell Biology at the University of California at Berkley, goes much further than merely questioning the efficacy of radiation therapy in the treatment of breast cancer. He estimates that three quarters of the annual incidence of breast cancer in the United States is caused by ionizing radiation (Gofman, 1995; Bertell, 1997a, 1997b).

Aternative/complementary discourses also have much to say about the use of chemotherapy as a favored form of treatment. This is a place where the language chosen in biomedical discourse is particularly illuminating. As Moss (1995) charges, doctors often speak encouragingly about response rates approaching sixty to seventy-five percent. Naturally, a person with cancer is encouraged and impressed by such information. What remains unsaid is that tumor shrinkage does not necessarily correspond to increased survival time. It is a linguistic dodge to link tumor shrinkage to success in treatment, and yet this is the criterion accepted as evidence of successful use of chemotherapy.

Biomedical discourse also measures success for chemotherapy by pointing to increased five-year survival rates. As Robbins (1996) points out, breast cancer, like many other cancers, is being diagnosed earlier; thus the meter that measures five-year survival from time of diagnosis starts running sooner. Five-year survival rates may be improving but mortality from breast cancer remains virtually unchanged (National Cancer Institute of Canada, 1999). The above examples reflect the power of biomedical discourse to selectively highlight particular pieces of information while at the same time rendering other pieces silent, for example the ravages of chemotherapy.

Robert Kotlowitz, writing in the New York Times about watching his wife undergo chemotherapy, had this to say:

> I began to think of the photographs I have seen of the first debilitated casualties of poison gas during World War One ... my wife suffers from the same helplessness, the same enfeeblement after chemotherapy, with one major difference: she suffers under medical guidance (Quoted in Moss, 1996, p. 243).

Oppositional discourses about treating breast cancer reflect multiple voices. The issues raised by these multiple voices are, however, remarkably similar. Proponents of alternative/complementary therapies and feminists, for example, challenge the basic beliefs and values underlying biomedical discourse. In contrast to viewing cure as the valued outcome and the body as unreliable and needing to be controlled, as in biomedical discourse, oppositional views hold care and healing as valued outcomes and see the body as its own best source of healing. They argue for a variety of natural remedies in the treatment of cancer. Moss (1995) and Robbins (1996) present convincing clinical data to support further study of more natural forms of therapy. They also point out that many of these so-called unconventional therapies (not sanctioned by biomedical discourse) have never been studied. This is a site in cancer discourses where many voices compete to be heard but only the biomedical is sanctioned. It is also a site where knowledge is contested vigorously and where "power-over" relations are obvious.

The American Cancer Society, supported by the Canadian Cancer Society, publishes a list of *Unproven Methods for Cancer Management* (Moss 1995) The list is afforded the status of being scientific information and provides the basis for making particular treatments illegal. Practitioners attempting to use these blacklisted methods have been harassed, excluded from the medical profession, put in jail, and had their offices closed and records seized (Moss, 1996; Robbins, 1996). Yet when Moss studied the data on these unproven methods, he discovered that "72% of the treatments on the unproven methods list have never been shown to be ineffective by any sort of rational scientific procedure...for less than 20% does the American Cancer Society offer any documented evidence of failure" (Moss, 1996, p. 116). Why is only one truth acceptable? Why should there be a monopoly on accepted practice? Are the interests of the public really being served by labeling non-biomedical practices as quackery, or are the voices promoting partnerships between conventional and alternative/complementary therapies simply disenfranchised?

Robbins (1996) tells the story of George Springer MD, who has successfully combined the use of traditional medicine with the so-called unconventional methods in his treatment of breast cancer. He developed an antigen skin test (no radiation required) that detects breast cancer up to six years before it can be detected with the use of mammography. This skin test is reliable 90% of the time, thus drastically reducing the incidence of both false positive and false negative results so common with mammography. After diagnosis, his treatment protocol works to strengthen the woman's immune system with such treatments as antigen stimulation of the immune system, high doses of vitamin C and E, and dietary changes.

> With conventional treatment, only 20% of stage III women and less than 5% of stage IV women are alive after ten years. In Springer's group after ten years, however, 75% of the stage III women were alive, and a truly phenomenal 60% of stage IV women (Robbins, 1996, p. 301-302).

As of 1996, Springer was still in practice. Robbins answers the question, would he recommend referral to Springer if one of his loved ones were diagnosed with breast cancer? with a resounding "Yes".

One of the most powerful ways that medicine prevails as dominant is by its ability to demand standards of proof for non-sanctioned treatments that are not necessarily applied to conventional treatments. Biomedical discourse does not seem to raise the question, however, if our treatments are so successful, why have we had so little success in decreasing the mortality rate from breast cancer?

Women's Own Stories

Women's own stories offer a particularly illuminating perspective on breast cancer, that of insider, living in and through a variety of discourses (Carter, 1996; Fasket & Lafia, 1997; Kahn, 1997). Naturally, women's stories are all different. In reading many women's stories, one similarity did stand out for me: not one was like the media-propelled cancer story of heroic personal growth in the face of adversity (Duncker & Wilson, 1996, Batt, 1994). Women write with authenticity and great personal courage, sharing with their readers their most intimate thoughts, feelings, and challenges. They do so for a variety of reasons. For some it is for release, an attempt to make sense of a senseless disease; for others it is an attempt to empower other women. For all, it is a way of giving voice to what has been left unspoken. What follows is a collage of a few of the stories I have read. It is a weaving of many different voices from women who speak from both the center and the margins of our society (hooks, 1984).

Most women's stories highlighted, albeit in different ways, how their life had been changed forever by their diagnosis of breast cancer (Wittman, 1993; MacPhee, 1994; Butler & Rosenblum, 1991; Meyers, 1997). Halvorson-Boyd and Hunter (1995) use the metaphor 'dancing in limbo' to create an image of this monumental change and then how they actually deal with difficult questions like: will I live? how will I know if I'm going to live? And, what if I'm going to die? Halvorsen-Boyd and Hunter explain 'limbo' as

> A region on the border between hell and heaven where those who are not responsible for their fate await judgment day. These souls can neither be punished in purgatory nor received into heaven. They must simply wait
>
> (Halvorsen-Boyd and Hunter 1995, p. 1).

This metaphor, 'dancing in limbo,' actively challenges the myth that successful medical treatment heralds the end of the story, and that women simply pick up their lives and carry on with gratitude for their enhanced sense of clarity about the purpose of life. In this myth, cancer is a blessing in disguise. As many women write, "The real story does not end happily ever after. Instead we live in limbo (Halvorson-Boyd & Hunter, 1995, p. 1). Other women echo these thoughts.

Cancer Through the Eyes of Ten Women (Duncker & Wilson, 1996) is a collection of stories, poetry, and art, a collage of different ways for women to portray their thoughts, feelings, and experiences about living with breast cancer. A variety of metaphors, such as cancer as host, guest, terrorist, or mother, were used to illustrate the breadth and range of meanings experienced by this group of women. Debbie Dickinson (1996) imagines herself as a musical mosaic, different instruments and voices, sometimes in a beautiful melody but often in a harsh conflictual crescendo. Patricia Duncker acknowledges and lives the anger, challenging the myth of a heroic, selfless woman who finds a beautiful world through her experience of breast cancer.

Juliet Wittman, in describing her experience of breast cancer, finds a metaphor about gardening useful. She illustrates her belief in keeping her body in the best condition possible so that her normal defenses could be utilized.

> When I first became a gardener, I remembered, I'd panicked at the sight of an aphid or squash bug, imagining my garden and strong green seedlings devastated overnight. Yet over the years I'd learned that a few pests were necessary. They kept their own natural predators in the area. A hole nibbled in a tomato or a worm nestled in the tip of an ear of corn; these were simply part of the natural process, not harbingers of natural destruction. There were so many factors – the quality of the soil, the viability of the seed, the proportion of rain to wind to sun, the sturdiness of the seedlings, the proximity of garlic, marigolds, nasturtiums and other natural repellents – that determined whether the appearance of a single Mexican bean beetle was simply a nuisance or an indication that the entire bean crop was doomed (Wittman, 1993, p. 20-21).

Substituting a war metaphor with a gardening metaphor serves to illustrate the capacity of language, discourse, and metaphor to create and sustain particular images and practices, while marginalizing or frankly denying legitimacy to others. Illuminating the metaphor in biomedical discourse is one way of freeing us from it and opening up possibilities for new metaphors, new images, and transformed practices (Cheek & Rudge, 1994).

Dominance of a war metaphor in the construction of cancer might have blinded us to the critical difference between cure and healing. Cure may be thought of as a physical reality, the disappearance of a disease. In the fight against cancer (like war), silencing of the guns, even for a short time, and the perception of having defeated the enemy (tumor shrinkage), are illusory. The disease of cancer, like a war, is not just an acute emergency but rather a chronic condition, with periods of acuity and an unknown course and future. Healing, on the other hand, takes place in many dimensions of life – whether or not the disease is gone. Some women believe that conventional cancer treatment often fails to cure and frequently undermines healing (Soffa, 1994; Mirian, 1991; Lanove, 1991).

Our Gift of Love (1996) is written by a group of thirty-one survivor-authors. Their stories are told from many different perspectives, but all emphasize that breast cancer does not just happen to the woman herself. It happens to her partner, her family, her friends, daughters, and sons. The authors recount their stories of diagnosis, surgery, chemotherapy, and radiation treatment. They speak of the emotional shock of finding the cancer, and the "spiritual struggle of facing mutilation and potential death" (vii). They also write from a position of hope, how to come to terms with life after breast cancer, how to seek support and how to live a more consciously aware life. Val Wilcox writes about her mastectomy this way:

> Shapelessness of Shock
> Like a pathetic pup
> Whimpering and licking wounds
> Of a just-lost fight,
> She lay in a hospital bed
> Push-buttoned down.
> Lying flat like that
> She could see her uneven
> Body configuration
> Right breast convex, as always,

But to the left
This now unnatural cavity
Taped with packing and tubes.
Though everyone exclaimed
Over her good fortune
At finding the cancer so soon,
Her head still whirled
At the speedy pace
Of surgeons' oncologists'
And loved one's faces
Floating through misty – buffered
Places of drug-induced reality.
Too serious changes came
Too fast – and was the last
Of how things used to be (Wilcox 1996, p.19).

Rosalind MacPhee, a Vancouver area resident, was diagnosed with breast cancer in 1991. Her book, *Picasso's Woman: A Breast Cancer Story*, was winner of the 1995 Canadian Authors Association Literary Award for Non-Fiction. It is a book I found impossible to read without experiencing tears, laughter, and a sense of awe at her courage and her honesty. She chronicles her story in a forthright literary style that had me feeling as if I was there with her. Much of Rosalind's story is about her struggles with relationships, her attempts to protect her family (especially her two daughters), and her bodily experiences as she underwent treatment. There is also much evidence of her struggle with having breast cancer when she had none of the known risk factors and was a fit, physically active woman who took excellent care of her health. Rosalind died in 1997 before being able to present at a Vancouver conference on breast cancer.

Women who live in the margins of our Canadian society are very seldom heard through professional literature, nor are they commonly the authors of personal narratives about their experience of breast cancer. Colemeda, a Native American herself, constructed illness narratives and life histories of thirteen Northern Native women as part of an ethnographic research project. She states "In this book, I give voice to thirteen Northern Native women who have traveled on an extraordinary journey with an assassin called breast cancer" (Colemeda, 1996, p. xxi). She explains her goal as "striving to restore visibility to the voices of marginalized women" (p. xxii). These stories provide the reader with a unique sense of the cultural, environmental, language, and isolation issues faced by Northern Native women who must be treated for breast cancer far from home and in a white, western, English-speaking health care system.

Cancer in Two Voices (Butler & Rosenblum, 1991) is another example of writing by marginalized women, a lesbian couple that individually journal their separate and together experiences as Barbara's journey with breast cancer unfolds. After Barbara's death, Sandra fulfills her promise and pulls their story together in book form. This is a story that weaves together many different voices and that gives the reader a sense of how, individually and together, these two women lived in and eventually challenged particullar discourses. One aspect of this story that is particularly illuminating is Barbara's willingness to chronicle her journey with metastatic breast cancer. Because this book was published after her death, we have a unique glimpse into a facet of a woman's journey with breast cancer that is seldom written about.

> I'm falling apart. During the year and a half of chemotherapy, I kept myself together, even cheerful, and had a good attitude. But now that's over, I feel my grief acutely. It is relentless and I have troubles all the time. There are many troubles. There is bleeding from the nose. There is bleeding and intense anal pain. There is hyperventilation, retention of bodily fluids and tears in my eyes that don't flow through the tear ducts but collect as if I had two sponges in those sockets. And there is the weight of my body, distended, misshapen, unfamiliar, uncomfortable, and unsexual. And unhappy. There is the dry skin. The difficulty swallowing. The black streaks in my nails. The funny sensations on my tongue (Butler & Rosemblum, 1991, p. 80-81)

Aware of these silences, Musa Meyers has written an entire book about living with metastatic breast cancer. Her title, Holding Tight Letting Go (1997), is a reminder of the complexity of recurrence. Women need to continue with life while paradoxically preparing for death. Women must also face the isolation that seems to come with recurrence. No one wants to acknowledge this potential reality.

> There's an elephant in the room.
> It is large and squatting, so it's hard to get around it.
> Yet we squeeze by with 'how are you? And 'I'm fine'.
> And a thousand other forms of trivial chatter.
> (Kettering, quoted in Meyer, 1997, p. xiv)

Women's own stories have provided me with another way of knowing (Carper, 1978; White, 1995), a way of knowing that is authentic and deeply personal. Attending to these voices has provided me with knowledge, insight, and a heightened sensitivity to thoughts, feelings, and experiences I could never have imagined. I see more clearly how reality for nurses, doctors, and cancer specialists might be radically different than that of the woman living with breast cancer. I see the power relations inherent in contradictory, competing discourses, and the impact this has on women. Feminist activist literature begins from an ideological stance that is critical of dominant culture and its positioning in one reality. I will conclude this literature review with a discussion of feminist activist literature, almost all of which was found outside of the disciplines of nursing and medicine.

Feminist/Activist Discourse

I have categorized discourses for the purpose of making a point, that there are a variety of ways to speak about breast cancer and a variety of ways for women to be spoken into particular discourses. Feminist/activist and alternative/complementary discourses are woven throughout women's personal stories about being diagnosed and treated for breast cancer (Gabe & Colnan, 1989; Masaide, 1991; Brown, 1995; Wilkinson & Kitzinger, 1993; 1994). Feminist/activist discourses share with alternative/complementary discourses a critique of the business monopoly and the beliefs and values held by biomedical discourse. Additionally, feminist/activist discourse challenges the power/knowledge relationships enjoyed by biomedical discourse

(Steingraber, 1997; Altman, 1996). There are many themes to this body of literature written from an ideological and/or personal perspective.

Audre Lorde (1980) writes one of the most compelling personal stories about breast cancer that I have read. She speaks from a position of other more marginalized than most, that of a black, lesbian feminist. Lorde, named the Official State Poet of New York in 1991, was diagnosed with breast cancer and had a mastectomy in 1978. She died of breast cancer in 1992. In the introduction to her Cancer Journal she writes:

> I do not wish my anger and pain and fear about cancer to fossilize into another silence, nor to rob me of what-ever strength can lie at the core this experience, openly acknowledged and examined. For other women of all ages, colors and sexual identities who recognize that imposed silence about any areas of our lives is a tool for separation and powerlessness, and for myself, I have tried to voice some of my feelings and thoughts about the travesty of prosthesis, the pain of amputation, the function of cancer in a profit economy, my confrontation with mortality, the strength of women loving, and the power and rewards of self-conscious living
>
> (Lorde, 1980, p. 10)

Lorde offers these words as a challenge to the silence and invisibility that surrounded breast cancer at that time. She states, "Silence has never brought us anything of worth" (p. 10). Through Lorde's voice we hear anger and outrage against dominant discourses. She provides us with more than a story about living with breast cancer, she provides us with a strong voice of resistance.

Lorde's journal entries show her fear, pain, loss, sadness, and anger as she experiences the loss of her breast. Much of her dialogue centers on the issue of looking normal. Her personal struggle with Reach to Recovery volunteers, nurses in the hospital, and nurses in her doctor's office who kept trying to convince her to wear a prosthesis becomes one of the contested bodily sites where Lorde claims the right to prevail. She links the use of prosthesis to hide the reality of breast cancer as another symbol of the invisibility and silence that surrounds this disease. In describing a visit to her surgeon's office, Lorde talks about how good she felt, all things considered, until the nurse:

> Usually supportive and understanding ... looked at me urgently and disapprovingly as she told me that even if 'it didn't look exactly right it was better than nothing' and that as soon as my stitches were out I could be fitted for a 'real' form. 'You will feel so much better with it on,' she said. 'And besides, we really like you to wear something, at least when you come in, otherwise it's bad for the morale of the office'. I could hardly believe my ears! I was too outraged to speak then, but this was to be only the first such assault on my right to define and to claim my own body
>
> (Lorde, 1980, p 59).

Lorde reflects on her experience in the doctor's office and offers a conceptualization of her one-breastedness as an honorable wound, much like Moishe Dyan's empty eye socket.

> Women with breast cancer are warriors, also. I have been to war and still am ... for me, my scars are an honorable reminder that I may be a causality in the cosmic war against radiation, animal fat, air pollution, MacDonalds hamburgers and Red dye number 2, but the fight is still going on, and I am still part of it. I refuse to have my scars hidden or trivialized behind lambs-wool or silicon gel. I refuse to be reduced in my own eyes or in the eyes of others from warrior to mere victim, simply because it might render me a fraction more acceptable or less dangerous to the still complacent, those who believe if you cover up a problem it ceases to exist. I refuse to hide my body simply because it might make a woman-phobic world more comfortable.
>
> (Lorde 1980, p. 60).

Lorde makes clear a relationship between the act of covering up or hiding the fact of breast cancer, and the ability of medicine to keep the ravages of breast cancer hidden and women with breast cancer apart and invisible. "For instance, what would happen if an army of one-breasted women descended upon congress and demanded that the use of carcinogenic, fat-stored hormones in beef-feed be outlawed?" (Lourde, 1980, p.16)

Lorde expresses eloquently her own subjectivity and her refusal to be positioned by a patriarchal, heterosexist, biomedical discourse that refuses to hear or acknowledge her subjectivity and lived experience of breast cancer. She clearly articulates a position of resistance, and yet it is interesting also to note how her subjectivity has been constituted by the images and language of the war metaphor.

In contrast, some women choose not to embark on their journey with breast cancer with a feeling of haste and instead decide to challenge medical authority and recommended treatment. Virgina Soffa, diagnosed with breast cancer at the age of thirty-eight, chose this path. She evaluated every treatment option presented to her with the question, what effect will this have on my immune system? She refused to have her lymph nodes removed for staging, saying: "I probably needed my lymph nodes more than they needed to be analyzed....I wanted my lymph nodes (the filtering system of the body) to help me eliminate cancer cells" (Soffa, 1994, p.15). Soffa chose instead to treat her breast cancer with a combination of alternative therapies. She consistently refused chemotherapy or radiation treatment in the belief that the potential harm to her immune system, as well as the noxious effects on her body and spirit, would be counterproductive.

Other feminist/activist voices also challenge the taken-for-granted way that staging is presented as part of the usual surgical protocol (CMAJ, 1998). What is often missing is a discussion about the likely and potentially serious side effects, and the potential for harm to the immune system (Batt, 1994; Soffa, 1994). Sharon Batt, a Canadian feminist/activist living with breast cancer, describes her interaction with her surgeon this way.

> 'Is it risky'? He says it could leave my arm paralyzed. I'm incredulous. 'Permanently'? Perhaps permanently. ... 'The operation won't affect the cancer, I say accusingly – it won't stop it' ...'and my arm could be permanently paralyzed'? Perhaps-we have to cut nerves. 'I don't see the point'. To complete the staging! He's exasperated. We need the operation to complete the staging. I stare blankly (Batt, 1994, p. 9).

Hooper provides us with a brief glance at some of her thoughts and feelings as she enters the medical system for her diagnosis and treatment.

> The moment you get cancer you are plunged into the medical gulag, a universe as complex and multilayered as Dante's purgatorio, each level with it's own special torments. (to your right, ladies and gentlemen, the Realm of the Incurables; through that door wander the Maimed and Mutilated with their prosthesis ...). No longer are you a simple civilian (Hooper, 1995, p. 109).

Batt also has something to say about the system.

> The institutionalization of our 'problem' distances us from our lived reality. The state system, designed to 'control' cancer, in reality controls the woman – and particularly her conflict with cancer – more effectively that it controls the disease. We are labeled 'patients'. We are thrust (no time to waste!) into a medical system governed by undisclosed rules. Here 'compliance' gains approval. Physicians speak to us in the private jargon of medical science, or with an infantalizing 'there there dear' paternalism. 'Recovery' programs encourage us to 'look normal' and 'get on with life'. Soon charities descend, urging us to 'fight cancer with a check up and a check'. The money goes into 'support programs' in which we have no say, or to researchers studying questions unrelated to our own (Batt, 1994, p.287).

There is much for health care professionals to hear in these women's words and many questions to ask ourselves.

Another powerful theme running through the feminist/activist literature relates to the question, how is the environment implicated in cancer? Biomedical discourse positions prevention of breast cancer squarely in the hands of women themselves. Individual lifestyle factors, menstrual and childbirth history, and genetic heritage are the areas targeted for action. Mammography screening has become linked in the minds of many with prevention, and much attention has been paid to increasing women's participation in regular screening at younger and younger ages. More recently, Tamoxifen, a powerful anti-estrogen drug, has been heralded as a breakthrough in prevention. Feminist/activists question much of this discourse. The knowledge that approximately eighty to eighty-five percent of women who get breast cancer do not have any of the identified risk factors is not a part of biomedical discourse.

Environmental activists charge that corporate and political interests are served by ignoring compelling evidence of environmental links to cancer. They also argue that a focus on individual risk factors aids in maintaining the hegemony of biomedical discourse, with its emphasis on screening, surgery, chemoprevention, chemotherapy, and radiation treatment. This emphasis on personal responsibility obscures the complexity of breast cancer and masks the lack of knowledge we have about the causes and course of this disease (Sherwin, 1996; 1997).

During the First World Conference on Breast Cancer, held in Kingston, in July 1997, I experienced my first exposure to a group of passionate and knowledgeable women committed to getting the environment on the political and research agendas around the world (Davis, 1997; Steingraber, 1997; Brady, 1997; Ouane, 1997). I came away intrigued with what I had learned, and also aware of how complex and difficult to research these areas would be, that is, if one judged science by traditional positivist measures.

Sandra Steingraber, scientist, poet, writer, political activist, and cancer survivor talked about her book, *Living Downstream. An Ecologist Looks at Cancer and the Environment* (1997), in which she recounts what we do know about our environment and cancer. She tells a compelling story about the increasing incidence of cancer and its tendency to concentrate in particular geographical regions. She links these hot spots to our ecological surroundings and our relation to food and agriculture (soil contaminants, additives and hormones), air (pollutants we breathe and the role of wind in carrying pollutants), water (contaminated lakes and rivers), and fire (dioxin). She provides evidence of environmental links with cancer based on animal studies and statistical associations. She reminds us that twenty-five years ago the Surgeon General warned us about the dangers of smoking based on evidence similar to what we have now with regard to environmental pollutants and cancer. Only recently was the specific cause-effect link between smoking and lung cancer identified. Sandra raises the very important question, are we going to wait for direct cause-effect relationships to be identified, or do we need to start acting now?

Conclusion: Raising Questions

I have told a story about breast cancer using a variety of bodies of literature. This is a multi-layered, multi-faceted, and multi-voiced story, full of similarities, differences, and contradictions. I have needed all the discourses, biomedical, alternative/complementary, women's, and feminist/activist, in order to tell many whole stories. Biomedical discourse, apparent through much of the nursing and medical literature, does not make a place for multi-voiced stories. Nor is there a place made for acknowledgement of power/knowledge relations. Biomedical discourse assumes a sense of authority about breast cancer. This authority emerges from the acceptance of this discourse as legitimized knowledge and as fact. Biomedical discourse then gives rise to the construction of particular meanings, nursing and medical practices, methods of inquiry, and what we count as true knowledge about breast cancer.

Knowledge development located in dominant paradigms encourages the silencing of the political nature of inquiry and the marginalization of those who adopt a different view of the world (Lather, 1991). It seems then, from this review of the literature, that women's constructions of their experience of living with breast cancer is an under-researched field, particularly given the absence of women's voices in biomedical literature. When biomedical discourse is the only way nurses and doctors know, then authentic participation by women in their living with breast cancer is impossible. This study seeks to uncover and illuminate women's voices and their constructions of living with breast cancer.

General Research Question

For women living with breast cancer, how are discourses and health care practices implicated in relations of power, and how do these discourses and practices inter-relate and inform each other in the care of these women? What are alternative possibilities in creating new discourses and practices for women living with breast cancer?

Specific Research Questions

1. In what ways do women with breast cancer make sense of, engage with, and position themselves within and among existing discourses?

2. How do women make their voices heard, and what might women-constructed discourses be like?

3. What are the conditions that facilitate/constrain women's positioning within discourses and in creating new discourses?

4. What are alternative possibilities for understanding and action?

CHAPTER THREE
CHARACTERIZING THE METHODOLOGICAL TERRAIN

This chapter begins with a discussion of research paradigms, and links my choice of the critical paradigm with the research questions I posed in Chapter Two, my location within critical science, and the methodology of feminist postmodern research. I then move from this general theoretical discussion to a more specific conversation about how the study was actually conducted. The chapter concludes with a discussion of the analytical process and the manner in which participants' data was eventually structured.

Illuminating the Theoretical Landscape

Knowledge Development for Health Care: Researcher Identity and Perspective

When I think about knowledge development for health care, I reflect on my own professional growth over the past ten to twelve years, and on the historical time in which I chose to begin graduate study in nursing. The mid-eighties heralded a fairly dramatic shift in notions about nursing research. The dominance of the positivist research tradition was being questioned, and new research methodologies such as phenomenology and grounded theory were being pursued by nurse researchers (Benner, 1984; Thompson, 1987; Munhall & Oiler, 1986; Morse, 1991). Certainly in New Zealand, where I attained my masters degree, there was support for moving away from just one way of doing nursing research. The quantitative qualitative debate was at its height in many disciplines, nursing among them (Munhall & Oiler, 1986; Harding, 1986; Guba & Lincoln, 1994; Dzurec, 1989; Allen, Benner & Diekelmann, 1986; Reason, 1994). Emerging understandings of the complexities of health and illness, as well as the relational and interactive nature of persons, their illnesses, and the world in which they live were likely motivating factors in the acceptance by nursing of new paradigm scholarship. Additionally, enhanced understandings of being a gendered profession and the impact of gender on health care practice likely played a role in the acceptance of multiple paradigms for nursing scholarship.

When reflecting about knowledge development for health care, and in particular for women living with breast cancer, I think about different ways of viewing the nature of practice, the multiple subject positions that women may hold, and the nature of both the disease and the illness experience of breast cancer. I think about the belief system that has been an integral part of the heritage of nursing and I think about my belief system, my role as researcher, and the roles of those who participate with me in a research project. These are paradigmatic questions.

I am committed to scholarship that affirms the strengths and capacities of women and that confronts, in an openly political way, issues of power/knowledge and diversity among women. Women's own words, descriptions of their experiences, their beliefs, fears, and anger are valid sources of data. What counts as knowledge or comes to be known as a dominant discourse and validated as true knowledge about an illness can be used in a variety of ways. Sometimes such validated knowledge has been used to perpetuate dominant structures and practices that may not have been in the best interests of women.

I have also become aware that what sometimes counts as truth has well-hidden political, social, economic, or discriminatory implications. The experience of being an object of research is another form of oppression; thus the process of doing the research and a woman's experience of being a research participant are as important to me as outcomes of any research that I undertake. Women experience multiple positions of self, but dominant modes of thought may confer particular subject positions that might be in contradiction to a woman's felt subject position. Thus personal agency is an important concept in a woman's ability to engage with health care-providers. Research methodologies that invite passivity are harmful to a woman's sense of personal agency. These beliefs and values that I have just articulated reflect my orientation or world-view towards research and to a particular ontology and epistemology.

Paradigm Discourse

A paradigm or world-view defines for its believers a sense of what the world looks like, and a basic set of beliefs that guide research (Guba & Lincoln, 1994). These authors explain that paradigms define the nature of the world, the individual's place in it, and the range of possible relationships to that world-view. For researchers, paradigms define what falls within and outside the limits of legitimate inquiry.

The basic beliefs that define research paradigms can be summarized by a response to three interconnected questions (Guba & Lincoln, 1994, p. 108):

1. The ontological question: What is the nature of reality and, therefore, what is there that can be known about it?

2. The epistemological question: What is the relationship between the knower or would-be knower, and what can be known?

3. The methodological question: How can the inquirer (would-be knower) go about finding out what he or she believes can be known?

An important part, then, of authentic inquiry is to achieve a coherent fit between these three questions and the research design (Harding, 1986). Equally important is the fit between the researcher's personal world-view and the paradigm chosen for inquiry.

Paradigms are human constructions; they do not represent a reality for which proof can be found (Guba & Lincoln, 1994). Rather, a paradigm relies on its utility or its ability to find answers to questions of importance to the discipline. Choice of a research paradigm or world-view, then, is never a neutral act (Cheek, 2000; Lather, 1991; Street, 1992). I have articulated particular interests in deciding which questions to ask and which to exclude about women's experiences of living with breast cancer. Given the questions I have asked, I locate myself within a particular world--view, that of critical science.

Paradigm discussions have proliferated since the 1970s following the publication of Thomas Kuhn's influential book, *The Structure Of Scientific Revolutions* (1962). This book has influenced the way we look at science ever since. Kuhn argued that science does not represent a universal truth but rather a philosophical orientation to what comes to be known as knowledge. He postulated that science does not accumulate knowledge in an additive way, as if there were truths out there to be discovered. Instead, he claimed that knowledge accumulated during dramatic shifts in perspective or world-view by a particular group within the community of scientists.

There have been many discussions about Kuhn's work in professional literature, in particular with regard to nursing research and education, and there has been fervent debate about the relative merits of one paradigm or another. Drawing on Lather's (1991; 1999) work, I argue against overzealous allegiance to one paradigm or another, and agree with Thorne, Kirkham & Henderson (1999) that choice of paradigm is a personal act based on many factors. Thorne et al argue persuasively that we too often see defenders of one paradigm claiming a position of superiority over those working in other paradigms. Positioning oneself as representing new paradigm discourse may too conveniently position others as unenlightened and failing to move with the paradigm shift currently occurring in nursing. Again, I agree with Thorne et al that such a view may actually inhibit productive debate and limit productive knowledge development.

I have articulated my personal world-view about research with women and discussed in detail what I perceive as gaps in knowledge about women's experiences with breast cancer. My personal interest in being involved with women in developing women-centered, emancipatory knowledge and in effecting transformation in health care practice is consistent with my location in critical science. "Since interest free knowledge is logically impossible, we should feel free to substitute explicit interests for implicit ones" (Reinharz, 1985, p. 17).

Critical Science

Critical science is concerned with empowerment and emancipation, that is, the ability of individuals and groups to take charge of their own lives in autonomous and responsible ways (Lather, 1991). Reality within this paradigm is assumed to have been shaped by social, political, historical, and economic influences. Reality has come to be seen as just the way things are, or unchangeable. Guba & Lincoln (1994) call this an ontology of historical realism. As with the historical hermeneutic paradigm, the distinction between ontology and epistemology is erased. Epistemologically, the researcher and participants are interactively linked, with the values of the researcher and others invariably influencing the inquiry.

Critical science sees knowledge production and knowledge circulating activities as politically invested and raises the question, in whose interests has this knowledge been generated? (Burt & Code, 1995). In my examination of discourses surrounding the disease, the illness, and the experience of living with breast cancer, I elucidated the way in which breast cancer has been constructed and managed within a biomedical model of care. The ways in which a woman's reality of having breast cancer is impacted by biomedical discourse was illuminated, and I highlighted the absence of women's voices in this discourse. Questions were then raised about how biomedical discourse positions women as object, and how unequal power relations exist, making it impossible for women to authentically participate in decisions or make choices for themselves.

I have been concerned with developing a research methodology that places women in the center of knowledge development about breast cancer with the aim of enabling women to become increasingly self-reflective actors in the creation of new discourses. This research extends a trend to increasingly diverse research methodologies with similar aims of recognizing the dominance of particular discourses, power relations, and other taken-for-granted beliefs and practices in health care (Horsfall, 1995; Henderson, 1997; Carter, 1993; Coward, 1990; Dzurec, 1995, Hagerdorn, 1995; Tang & Anderson, 2000; Anderson, 1991; Stacey, 1997; Allen & Hardin, 1998).

My desire in this research has been to focus on discourses of possibility: a reciprocal shaping, interplay, or weaving of discourses reflecting knowledge(s) and practices for the care of women with breast cancer. And I have been concerned that the research process itself, and the knowledge constructed from the research, be emancipatory, that is, knowledge that is socially critical and politically oriented toward transforming oppressive practices and power relations (Street, 1992; Lather, 1991; Cheek, 2000). "Emancipation becomes the act of finding one's voice where women come into a sense of their own power and develop new relationships within their own contexts" (Grundy, 1987, p. 107). Emancipation can only occur in a context of respect, equality, and being heard, where women are present in discourses and see themselves as actively authoring their own story in the way they choose (Weiler, 1987). Praxis research, informed by a feminist postmodern theoretical perspective, fulfills these aims (Lather, 1991; Street, 1992).

Praxis Research

Lather describes praxis research as being concerned with the knowledge that "in our action is our knowing", and with the question, "how do we develop critical insights into particular discourses as we simultaneously live in and are constructed by them?" (Lather (1991, p. xv). How also do we turn critical insights into emancipatory action? These questions remained in the foreground as we, the participants and I, proceeded through the research process. I will return to a discussion of these questions in Chapter Eight.

The notion of praxis is central to critical emancipatory science. Praxis, a concept first articulated by Friere (1972) can be defined as "informed practice based on self-reflection" (Grundy, 1987, p.163). It involves choosing actions informed by theory with both theories and actions open to critical scrutiny. Stanley defines praxis as "knowledge of and knowledge for social change" (Stanley, 1990, p. 15). Praxis involves critical self-reflection that alters our understandings of our world and enables us to take action. Street explains this well.

> This concept of collaborative and emancipatory research begins with the problems of the participants and proceeds through a process of action and reflection to an understanding of, and ability to change, the social situation that oppresses them; it is in this process that people change themselves and their understandings of themselves" Street, 1992, p. 119).

In praxis-oriented research, then, knowledge developed must both illuminate and be illuminated by the experience of women living with breast cancer; and I as researcher must be committed to open ended, dialogical knowledge development. Knowledge and meanings are constructed together through dialogue (Lather, 1991).

Feminist Thought

Feminism is both a way of thinking and an oppositional social movement that has as its goal the transformation of the position of women in our society. The word feminism appeared for the first time in print in an English weekly publication on April twenty-fifth, 1895, in describing a woman who has in her the capacity for fighting her way back to independence (cited in Gray, 1996).

Versions of feminism have multiplied and altered over these many years, but generally share one thing in common, a recognition that women are oppressed and emancipation from that oppression is a worthy goal. Different feminist theories posit different explanations for this oppression, and therefore different strategies for overcoming it. All feminists, however, believe that privilege is afforded particular people based on socially constructed characteristics such as sexual orientation, gender, or race. Feminism focuses on examining this privilege, or lack thereof, and recognizes the overlapping and intersecting multiplicities of oppression (hooks, 1984; Gray, 1996). Feminism also recognizes that women's felt experiences are real and constitute knowledge, even though a patriarchal notion of objective reality discounts the validity of women's understandings because they are merely subjective. Feminist research is openly ideological in its goal to correct both the invisibility and the distortion of female experience in ways relevant to ending the unequal social position of women (Lather, 1996a).

Feminists argue that traditional science originated within a patriarchal view of the world and emerged from dominant class, gender, and racial groups. Women were not regarded as legitimate knowers. The questions asked, and therefore the answers obtained, reflected dominant interests. In contrast, a feminist perspective highlights the ideological nature of the knowledge generated, as well as the power relations inherent in what knowledge a society counts as legitimate.

The inclusion of a feminist orientation to this research would appear to be logical at first glance, based on the fact that this study seeks to understand the experiences of women with breast cancer from their perspective. A priority of this research is that it be with women and for the benefit of women. Following Lather (1991) and others (Street, 1992; Anderson, 1991; Mies, 1983; Maynard & Purvis, 1994; Stanley & Wise, 1993; Fine, 1994, Nash, 1994), I argue that the inclusion of a feminist perspective adds something more to this study. Feminist thought seeks to critique knowledge generated without women's perspectives being taken into consideration, as well as to develop women-centered knowledge. Additionally, feminism has an action component that speaks to the development of knowledge useful in the implementation of social change (Mies, 1983). Lather, in arguing for a feminist praxis orientation to research, explains it this way:

> I base my argument for a research approach openly committed to a more just social order on two assumptions. First, we are in a postpositivist period in the human sciences, a period marked by much methodological and epistemological ferment. There has been, however, little exploration of the methodological implications of the search for an emancipatory social science. Such a social science would allow us not only to understand the maldistribution of power and resources underlying our society but also to change that maldistribution in ways that help create a more equal world. My second argument is that research that is explicitly committed to critiquing the status quo and building a more just society --, that is, research as praxis adds an important voice to that ferment (Lather, 1991, p. 50-51).

A feminist perspective to research requires that the data reflect women's points of view and their experiences as they engage with health care providers, and as they construct and re-shape meanings about their living with breast cancer. Similarly, a feminist perspective involves participants as co-researchers and as active agents in transforming health care practices as part of their involvement in the research process. Moreover, feminist research focuses on women's strengths, capacity, and sense of agency, as opposed to isolating their struggles or deficiencies.

Postmodern Thought

Postmodern thought adds a further dimension to my chosen research methodology, as I have clearly rejected the notion of a single truth about what living with breast cancer is like. Postmodernism emphasizes the relationship between language (voices and discourses), what society counts as truth about a particular disease or illness experience, and the consequent construction of a social reality (Cheek, 2000). Postmodernism, then, focuses my attention on language, discourse, and a "world of multiple causes and effects interacting in complex and non-linear ways" (Lather, 1991, p. 21).

Postmodern thought analyses language as the place where meanings are produced and a person's subjectivity is constituted. Language does not just reflect an already given social reality, it constitutes social reality for us (Weedon, 1987). To put it another way, postmodern thought argues that language creates the way we interpret our experiences in the world. If language creates our understandings, then how we come to know what we know is determined by the language to which we have access (Allen & Hardin, 1998). Postmodernism critically examines the ways in which language may be constraining and limiting, allowing only certain aspects of experience to be discussed and given credence.

In examining science, postmodernists have noticed how the power and structure of language have created women's realities in ways that may sustain their oppression (Gray, 1996). Our subjectivity and the way we construct, for example, breast cancer depend on the range and power of existing discourses, our access to them, and the political strength of the interests they represent (Weedon, 1987). Postmodern thought argues, then, that the language used in talking about breast cancer does not label a real world or truth but, rather, is a story that is socially or historically constructed through discourse. That is, language is not value-free but carries authority by virtue of power given to the discourse by society (Cheek & Rudge, 1994; Cheek, 2000; Kvale, 1995). Feminist postmodern adherents critically examine science, theory, and knowledge, noting ways in which women's own experiences can be denied and made invisible. This school of thought advocates a process of critical questioning that denies one universal answer (Gray, 1996).

The word discourse has become a commonplace word that has been used in many ways. A discourse is always spoken about in relation to a discursive object; in the case of this research, the discursive object is breast cancer. My reflections on the literature about breast cancer illuminated a variety of discourses and illustrated the different language used and meanings produced by the different discourses. A definition of discourse that I have found useful is that given by Davis and Harre.

> [A discourse is] an institutionalized use of language and language-like sign systems. Institutionalization can occur at the disciplinary, the political, the cultural, and the small group level. There can also be discourses that develop around a specific topic, such as gender or class. Discourses can compete with each other or they can create distinct and incompatible versions of reality. To

> know anything is to know it in terms of one or more discourses (Davis and Harre, 1990, p. 44).

Postmodern thought also attends to how power is exercised and how individual or group consciousness is shaped by discourses (Weedon, 1987; Lupton, 1995; 1994). Foucault (1980) talks about power and knowledge as being mutually generative. That is, knowledge initiates power and power generates knowledge. Discourse is where power and knowledge come together and where what can be counted as knowledge is made evident. A dominant discourse legitimates the questions that may be asked and determines who has the authority to attempt to answer those questions. Enthusiasts of a particular discourse are able to exert power over adherents of another discourse (Turner, 1995; Cheek & Rudge, 1994; Cheek, 2000).

Discourses represent political interests and compete for power and status in our society. A discourse must be in circulation to have a social effect; thus marginalizing or silencing a particular discourse will render it politically ineffectual. The ability of one discourse to become dominant or politically sanctioned renders the discourse and its adherents powerful. In turn, they are empowered and sanctioned to create the knowledge that sustains the discourse. As Lather notes; "discourse and politics; knowledge and power are hence, part of an indissoluble couplet" (Lather, 1991, p. vii).

Phelan explains that Foucault's "criterion for distinguishing among discourses has to do with their relation to power and specifically, to their openness to change, and to the possibilities for agency within them" (Phelan, 1990, p. 434). This is an important point, and one I have paid particular attention to as I have had a focus on the capacity and agency of women with breast cancer throughout the research process.

One of the key concepts of postmodernism is the call for many discourses and a multiplicity of voices and truths, rather than a search for a single truth or totalizing theory. Postmodern feminism thus represents a movement away from historical feminist themes of universality and essentialism, and toward themes of diversity and difference (Flax, 1987). This theoretical position represents a recognition of and an acceptance for the heterogeneity of women's experience. As Phelan (1990) reminds us, there are many different sites of oppression for women just as there are many sites of resistance. The feminist postmodern theoretical perspective underpinning this research directs me to reflect on these different sites of both oppression and resistance.

It was my reading of the professional literature about breast cancer that led me to the questions I posed for this research. The unquestioned nature of biomedical discourse and its dominance in the literature made me wonder why women's voices were so silent, and further to question some of the assumptions underlying such profound silence. Powers explains how an examination of discourse brings into question the assumptions concerning the naturalness of current theory and practice with regard to a body of knowledge.

> When analyzing a discourse it is crucial to consider what conflicting groups of people are saying within the discourse, who gets listened to most often and why, what the hidden agendas are, who gets chastised for their deeds or writing, how the discourse becomes widespread and to whom, and how the existence of the discourse is said to be necessary and to whom (Powers, 1996, p. 211).

What Powers highlights here is the capacity of discourses to provide a framework for valuing one way of talking about phenomena over other ways. So discourses differ in the authority society confers on them. Foucault (1980) describes biomedical discourse as dominant in Western society and exclusionary with regard to other forms of discourse. Discourses influence what is socially accepted and what is excluded from attention. The capability of one discourse to dominate and exclude other discourses reveals the underlying relationship between knowledge and power (Powers, 1996). A key question, then, in analyzing any discourse, is, whose voice dominates and whose is silent? Foucault also alerts us to the relationship between power and truth. What we may view as truth is, in fact, a product of dominant discourse. Thus, truth claims of biomedical discourse are claims to power on the basis of expertise or ownership of this particular discourse.

Sharpening the Focus: A Feminist Postmodern Methodology

Tensions and Affiliations: A Discourse of Feminist Postmodernism

In the previous sections I have engaged in a general discussion about choice of research paradigm; emancipatory, praxis-oriented research; and the theoretical perspectives of feminism and postmodernism. The merging of feminism and postmodernism is not without complication, however. I now turn to a discussion of some of the issues debated in the literature about merging these two theoretical orientations in a research methodology.

Benhabib (1995) argues that within the western capitalist democracies feminism and postmodernism have emerged as two of the leading theoretical currents of our time. This is not too surprising as they share an affinity for criticizing enlightenment notions of grand theories and the scientific method as the path to truth. Benhabib (1995) along with other feminists (for example, Flax, 1990; Cheek & Porter, 1997; Stanley & Wise, 1993) raise questions, issues, and concerns about an uncritical and unreflective acceptance of postmodernism. The major concerns of these critics have been summarized by Di Stefano (1990). First, she challenges the claims of postmodernism as being those of privileged, white western men. As Nancy Harstock has asked,

> Why is it that just at the moment when so many of us who have been silenced begin to demand the right to name ourselves, to act as subjects rather than objects of history, that just then the concept of subjecthood becomes problematic? Just when we are framing our own theories about the world, uncertainty emerges about whether the world can be theorized (Harstock, 1990, p. 164).

Di Stefano also notes the lack of attention paid to gender in the writings of prominent postmodernists, and she wonders if that insensitivity to gender would make a feminist politics impossible. Other authors such as Giroux (1991) and Ramazanouglu (1993) note that Foucault's conceptualization of power challenges the way feminists have thought about men having power over women.

More encompassing criticisms focus on the postmodern view that all knowledge is related to power and is contextual, relative, and temporal. Porter then raises the question, is this emphasis on rampant relativism in fact another way of perpetuating the status quo? (Cheek & Porter, 1997) He elaborates on this theme by stating that while a postmodern analysis can be useful in nursing to critique a "dominant discursive regime, it cannot be used to support an alternative" (Cheek & Porter, 1997, p.113). He goes on to caution nurses to be wary of such relativistic negativity.

Despite these concerns, there are many feminists who support the use of postmodern theory in nursing research (Lather, 1991; Street, 1992; Dzurec, 1989; 1995; Dickson, 1995; Anderson, 1991; Traynor, 1997; Fraser & Nicholson, 1990; McCormick & Roussy, 1997; Rodney, 1997; Tang & Anderson, 1999). They put forward various counter arguments to those presented above, and generally make a case for the use of postmodern thought in feminist research.

Cheek and Porter (1997), in a comprehensive 'conversation' about the possibilities and problems of using a postmodern perspective and the work of Foucault in nursing research, provide an excellent overview of this complex topic. Julianne Cheek takes the position that Foucault's work is important in the challenges it offers to taken-for-granted aspects of contemporary health care. In using a postmodern lens, our understandings of health, disease, and illness become problematised. How these concepts are shaped by discourses, which in turn promote particular practices or ways of treating disease and exclude others, become sites of inquiry. The universal authority of experts can be challenged and the exclusion of other discourses can be isolated for study.

Cheek also makes the point that identifying a discourse (biomedical for example) as dominant does not mean that it must be replaced or displaced. Rather, Foucault challenges us to "recognize it for what it is – a dominant discourse embedded within which is the power/knowledge that both produces and maintains such dominance" (Cheek & Porter, 1997, p. 109). I see this as one way that Foucault offers possibilities and promise to knowledge development for women living with breast cancer. Questions such as, good for whom? as determined by whom? and, on what basis? become legitimate, thereby offering a more critical look at what society counts as legitimate knowledge about breast cancer.

Foucault's conceptualization of power everywhere, and as productive and not merely repressive, poses a strong challenge to feminist thought which, has focused on the power men hold over women. Feminists have also been challenged by other marginalized groups for this simplistic view of power. For example, domestic workers cite their experience of women exercising power over them while other women note their experiences of racism, classism, or heterosexism perpetuated by women of privilege (Ramazanoglu, 1993; hooks, 1984). Cheek and Porter (1997) and others (Groz, 1994) propose that Foucault's view on power as productive, and his emphasis on how power is exercised rather than how it is possessed, is in fact helpful to feminist thought. As Cheek states:

> The issue is not so much how to remove or eliminate power but how to understand it ... such conceptualization involves nurses working with power rather than against it, recognizing that they themselves are a part of a present in which the task is not to overcome powerful others but to use our understandings of the operation and effect of power to further nursing. (Cheek & Porter, 1997, p. 14)

Finally, the criticism has been advanced that because Foucault challenges the notion of one truth, there can not be the possibility of certain knowledge. Cheek responds to this charge by raising the question, why does there need to be certain knowledge?

> Why can there not be a multiplicity of positions from which to analyze and critique aspects of reality?. Why does not having certain knowledge remove the grounding for alternative modes of knowing? Surely alternative modes of knowledge represent different positions with respect to representing and viewing aspects of reality. Foucauldian analysis offers a project of possibility in the sense that it offers the recognition of such positions and the effect they have on what is seen (Cheek & Porter, 1997, p. 113).

A feminist postmodern lens is useful in the examination of dominant and silenced discourses, and in locating power/knowledge relations within and among discourses, thus providing a vehicle for addressing the research questions I have identified. Having located myself theoretically in feminist postmodern praxis-oriented research for the study of women living with breast cancer, I now turn to a more focused discussion on methodology.

The Research Journey: Doing Feminist Postmodern Research

Doing feminist postmodern praxis oriented research involved a clear choice on my part to forsake the notion of a generalizable truth outcome of this research. It also involved the recognition that finding truth is not a function of the quality of one's research methodology (Dzurec, 1995; Lather, 1986 b). Feminist postmodern research recognizes that knowledge is socially produced, and that subjectivities are constituted through discourse. Thus it was women's interests, values, and words that framed and underpinned this study.

Participant Selection

I made many decisions about who to engage in this research. Because I wanted to study women's experiences throughout the various stages of living with breast cancer, I decided to be open with regard to where women were in their breast cancer journey. I also wanted women to choose to participate through an active decision on their part, and not because their doctor or someone else asked them to. Through my work with nurses, the Cancer Center for the Southern Interior, and The Cancer Society, I had many opportunities to talk with women with breast cancer. Thus I was relatively well known in the community and conscious of the necessity for care with regard to requesting participation in the study. For that reason, I chose a once-removed position of recruitment. That is, I distributed a letter of introduction about the study and myself to health care professionals and women in the cancer community, and asked them to pass the letter on to any potential participants (Appendix I).

The nature of the study necessitated women's participation in reflective dialogue with me over time, so I needed to be clear that they had to be willing and have an interest in thinking and talking about their experience of living with breast cancer. General criteria for inclusion in the study included being diagnosed with breast cancer and an expressed willingness to participate in suggested data collection methods.

Once I had received ethical approval for the study from the University of Victoria, I drafted the letter of introduction and made it available to women in the community. Following the distribution of those letters I received seventeen phone calls from women interested in learning more about the study. I talked with all of them on the phone about the nature and purpose of the study, and the kind of participation I would be asking for. I then set up our first meeting at a time and place of their choice. All seventeen agreed to participate, and signed consent forms at that first individual meeting. I was conscious of the fact that I had only intended to work with ten participants, but I was overwhelmed with the interest and enthusiasm of the women who contacted me and decided to include all interested women. All meetings, conversations, and interviews occurred at a time and place of the participant's choice. Most often I went to their homes, but occasionally we met at my university office. Because I continued to do volunteer work in the community, I did meet some participants on an irregular basis outside of formal interview times, for example at health fairs or breast cancer forums sponsored in our community.

At the first meeting with each participant we reviewed my ethics proposal, consent forms (Appendix II), confidentiality issues, and potential time commitment.

I also felt it was necessary to discuss the theoretical perspectives of feminism and postmodernism that framed this research. Although my conversation with each participant was different, I talked with all about the focus of the research being their experiences with breast cancer, and the intention that the research would be used to improve care provided to women. I spoke about my focus as being on their personal and collective strengths, and that similarities as well as differences among study participants would be noted. At this point I usually did not talk about power/knowledge relations, although with a few participants the topic did emerge through our conversations. I also offered access to all previous writing I had done in the course of my studies, and several participants requested different papers, which I subsequently delivered to them.

Throughout the two years of research, there has been open and on-going communication among participants and myself. Many women phone me with news of a television show that might interest me, or a new book that they have just read. We have shared conference materials, books, stories, and research materials.

Feminist Postmodern Methodology

There were several important tenets of feminist postmodern research that I attended to over the course of the research. These tenets address such issues as the universality of the category woman, and who is able to speak for women; reflexivity in the researcher; and the researcher participant relationship.

Postmodernists and, more recently, feminist researchers have questioned the universality of the category woman, and ask, which women? which women's experience? and, who can legitimately speak for women? (Burt & Code, 1995; Flax, 1990; Fine, 1992). I have been clear that I speak about the specific group of women who became participants in this research. I have also presented the methodology in a clearly context-dependent, historically located, and non-generalizable way (Allen & Baber, 1992; Josselson, 1996; Devault, 1990; Lather, 1988).

Foucault emphasizes a rejection of essentialism in favor of the notion of difference and multivocality. These are useful concepts in designing research that is for the benefit of women (Nicholson, 1990; Flax, 1997, 1990; Lather, 1991). Likewise, the postmodern idea that women's subjective understandings of their experiences and positions are constituted by dominant discourses reminds me to pay attention to how dominant discourses interact with power/knowledge in the research situation for both myself and for the participants (Gray, 1996).

Another tenet of feminist postmodern research that I have paid attention to as the research proceeded was the need to present myself as a real situated woman. Fraser and Nicholoson (1990) argue that a researcher who is explicit about situating herself in the research less easily invites the danger of false generalizations than does one theorizing under the guise of researcher objectivity. I have critically reflected on the nature of the research process and the relationship I have with the participants through journal entries and conversations with colleagues, women in the study, and my dissertation supervisor. I have also been explicit with participants about the nature of the research methodology and my positioning within the research. Participants have felt able to approach me with concerns, questions, and information, and have had the opportunity throughout the research to comment on the process (Fornow & Cook, 1991).

Gray's (1996) discussion of the need to examine one's own personal assumptions before and during the research process is something I have paid attention to throughout the entirety of the research process. Her caution that it is especially important to note any discrepancies between personal beliefs and assumptions about living with breast cancer, and the beliefs and values inherent in the chosen methodological framework, is another issue I have continued to reflect on as the study proceeded. I attempted to be transparent with participants at the beginning of the research regarding my personal beliefs and values, and I made a deliberate choice of research paradigm and methodology that is congruent with my personal philosophy. On several occasions, participants described a situation with a health care provider and I felt strongly about some aspect of their encounter. I took care to remain neutral so as not to impose my own perspective on the situation and would often replay the tape recording to check myself.

Allen (1997) discusses a variety of ways the researcher can maintain reflexivity throughout the research process. He claims that it is important to focus not only on the research process from the researcher's perspective, but to find innovative strategies that enable the research participants to provide feedback on how the research process is for them. I have remained in regular touch with study participants over the two years we have been working together, and I have been active with regard to initiating conversations with them about being in the research. Additionally, I have made all my writing available to them and, on request, have written up their data in ways chosen by them. All participants received their interview transcripts, some wished to have copies of the interpretive summaries I wrote for each participant, and all have had a summary document that describes the nature and content of this dissertation and the women-generated discourses that emerged from their collective stories.

Another tenet of feminist research relates to the researcher participant relationship, which must be open, honest, non-exploitive, and involve reciprocity (Oakley, 1981; Devault, 1990; Josselson, 1996). Much has been written about this tenet and the difficulties inherent in unequal power relations. Mies (1983) describes this idea as conscious partiality. She expands on this statement by talking about the view from below as compared to the view from above. She describes the view from above as being evidenced in a hierarchical researcher-researched relationship, and where the research findings have been used as an instrument of domination. The view from below encompasses a non-hierarchical relationship where the research must be in the interests of participants. It is important to acknowledge that, much as I might aspire to equalize power relations and engage with women in the research process, I do come from an implicit power base. My privilege is extensive: white, of the dominant culture, educated, a nurse, and a well woman (Gray, 1996). I have read and continue to read and reflect on the concept of privilege (Frankenberg, 1993). Participants in the study have had many opportunities to comment on their experience of being in the research. Their comments and experiences were captured throughout the study, and at final focus group meetings and individual final interviews once the research was completed. Their voices will be heard in the final chapter.

Mies, in advocating for a praxis orientation to research, had this to say, "The contemplative, uninvolved, spectator knowledge must be replaced by active participation in actions, movements and struggles for women's emancipation" (Mies, 1983, p. 124). She noted that the concept of integrating praxis and research was first formulated by Mao Tse Tung in 1968 in his essays on contradiction and praxis. Mies concludes that the integration of research into social and political action for the emancipation of women, the dialectic of doing and knowing, will lead to more realistic theories. McCormick and Roussy (1997) claim that a feminist postmodern framework lends itself to praxis-oriented research with its overt commitment to the improvement of women's lives and its political intent to change or transform oppressive conditions for women. Thus, feminist postmodernists conclude, research should not be done for the sake of knowledge itself but for the purpose of making a difference in the lives of women, an activist stance to research (Hagerdorn, 1995). Lather (1988) favors these transformational, advocacy approaches to inquiry and believes that postmodern approaches should be praxis-oriented and openly committed to a more just society.

I have conceptualized this research as having a praxis orientation and presented it to potential participants in this manner. Many of the women in the study were openly thrilled with this orientation and throughout the two years of the research have been looking forward to the time when we move to the transformational action piece.

While openly advocating praxis-oriented research, I also needed to recognize that women might, and likely will, be in very different places with regard to their ability and desire for transformation. Women's sense of personal vulnerability and usual ways of being will influence their response to this part of the research. In fact, the women in this study are all active in the breast cancer community and committed to varying forms of advocacy. I will return in the final chapter to a discussion of the ways in which the participants and I have proceeded and plan to proceed with the praxis part of the research.

Setting for the Study

The setting for this study was a mid-sized region in South Central British Columbia. The area is served by three hospitals (one being a regional referral center), community nursing services, and, most recently, The Cancer Center for the Southern Interior.

Research Path

Feminist postmodern praxis-oriented research is directed toward emancipatory and dialogical methods of individual and collaborative critical reflection. Feminist consciousness-raising groups provide an example of an emancipatory dialogical model (Henderson, 1997). It is important to note that, although I defined a set of data collection methods in my proposal, the intent of emancipatory research is that participants and researcher together negotiate their way through the process. I did modify my plans as the research proceeded and also as new issues arose for participants.

Participants were asked to engage in the following, and these data collection methods occurred for all but one participant who was unavailable for the second interview:

1. An open dialogical interview with myself at the beginning of the study. All interviews were taped and transcribed. During this initial encounter I asked about their diagnosis of breast cancer and the events that have occurred for them since. I wanted to learn about their experience of being diagnosed and living with breast cancer. I wanted to hear their story, from their perspective, and so did not have formal interview questions.

2. On-going individual reflections about their experience of living with breast cancer and of their experience of being a participant in this research. These reflections took many different forms depending on what individual women chose. For example, some participants chose to share their writing or art with me, while others preferred to

reflect in conversation with me as the study progressed. Several participants had kept a journal during the time of diagnosis and treatment, and a few continued to journal. Some of these were shared with me.

3. Participation in a second interview, in which women looked over their own data (a summary or their transcript) and talked about what is currently going on with them with regard to their story about living with cancer. I had several revised time lines for suggested interview intervals. Participants were very patient with me, as my personal and work life sometimes intruded in ways that made keeping to a pre-set schedule impossible.

Throughout the course of the study, sixteen participants were formally interviewed twice. One participant was only interviewed once and then moved, and I have not been in touch with her again. Five participants were interviewed three times and one participant was interviewed four times.

I kept in mind the questions I had posed for myself at the beginning of the research, but made no attempt to formally ask all of these. I reviewed the data from each interview with the research aims and questions in mind and followed up with particular participants regarding certain study questions, but I did not formally construct the interviews (Appendix III). In addition to the interviews just described, I engaged in many telephone calls, visits, and volunteer-related activities with various participants. When I reached the point in the research of having a fairly coherent picture of what form the data would take I held focus group meetings where, together, we shared our perceptions of the process and product of the research. I discuss this further in the final chapter.

The nature of breast cancer is such that recurrences and complications can occur at any time. Such was the case for several participants in this study. Some women were unable to attend focus group meetings, and these women I met with individually. A few requested additional interviews as they wanted their experiences recorded, and this is on going at this time.

I think of this research as a beginning of a continued research program and so continue to be in contact with many participants around issues in our community and improving particular practices. We have many ideas for further work in this area.

Co-Researchers? -- Our Relationship

A feminist orientation to research offers excellent direction with regard to developing research relationships that are non-oppressive and democratic. Authentically living these values is not something one can say happens because I, as researcher, followed certain procedures, or utilized feminist principles in my interactions. The reality of having relationships that are emancipatory and fulfilling can only be attested to by participants in the day-to-day encounters with myself, and in their responses to being in the research. I made a conscious effort to explain the intent and orientation of this research at the beginning and throughout the study, and I have responded to requests for information about the research from participants. I personally experienced feelings of comfort and mutuality throughout the research process. Participants have been asked to respond to questions regarding their experience of being in the research, which I will discuss in Chapter Eight.

Self-disclosure became an interesting source of reflection for me as the study progressed. I had never thought that being open and self-disclosing with participants would be difficult. But I found myself caught off-guard when first asked by one of the women in the study if I had ever had cancer. I wasn't sure what to say because my own cancer at age thirty was not something I had ever talked about. I hesitated, and then answered that yes, I had had cancer. We then spoke about the way I had dealt with it at the time. I had basically kept it a secret, and to this day many people in my life do not know that I ever had cancer. I also talked about not being sure why I had handled it in that manner then, but how I would likely deal with cancer very differently now. Subsequently, at an international conference I was again asked that question. I was able to reflect with the audience how I had been taken off-balance by the same question from one of my participants, and how there had been good learning for me in the incident. As researchers it is not usually difficult to believe we are open with our study participants, because we are in the position of choosing what it is we feel confident in self-disclosing.

I have a unique relationship with each woman in the study. Some have participated in all requested interactions but are not involved with either myself or other participants in other ways. Some of the women in the study know each other and have regular contact through various activities, and many know me as a member of the community. I have a profound respect for all participants in this study and have felt privileged with the openness and enthusiasm they have demonstrated. All have had the opportunity to respond to the question, how has it been for you to be part of this study? I will comment on this more in the final chapter. Informally, participants have been unfailingly generous with their comments about my work with them. All participants have remained active and involved with the study despite the fact that we worked together longer than initially planned.

I embarked on the study with the intention of using feminist principles of interviewing and group work (Butler & Wintram, 1991; Chinn, 1995; Van Nonstrand, 1993; Henderson, 1997; Lather, 1991; Oakley, 1991; Anderson, 1991). I saw consciousness-raising as a specific methodological tool and as a general orientation or way of seeing that would be useful (Henderson, 1997; Cook & Fornow, 1991). I believed that through consciousness-raising we (participants and myself) would engage in a process of exploring the discourses that surround living with breast cancer and our positioning within these discourses. I believed that unraveling discourses and the manner in which our voices have been systematically rendered mute would open a space for alternative insights, visions, and ways of speaking about breast cancer (Thompson, 1987; Cash, 1996).

MacKinnon (1989) claims that consciousness-raising enables the articulation and legitimatization of the invisible, the subjective knowledge, and the struggles women engage with as they live with breast cancer, all of which remain marginalized and illegitimate ways of knowing. Premised on dialogue, consciousness-raising politicizes the personal and engages women in the possibility for transformative action (Henderson, 1997). I am astonished with the purity of these theoretical understandings and the way this research process unfolded. Without consciously directing the conversations we had, or being cognizant of method while we were talking with each other, we did come to new understandings, challenge practices, and envision ways in which health care for women with breast cancer could be different.

Protecting the Participants: Ethical Concerns

Feminist postmodern inquiry is explicit about the relationship between researcher and participant, and it was important for me to be clear about reciprocity in the relationship. As I said in the foregoing section, I continually made myself available with regard to issues, questions, resources, or information women participants might like to have. Participants did get to get to know me as a woman and as a nurse with many years of experience. I was open about the intent of the research in the beginning, and throughout the research process I re-oriented and spoke to where we were in the process, so that participants could see our partnership in the development of knowledge.

Specifically, I took the following steps to safeguard participants' rights.

1. A letter explaining the study was sent to the community health and hospital nurses, breast cancer support groups, and other health care providers in three local communities (see Appendix I). Women interested in knowing more about the study were asked to contact me by telephone. If further interest was shown, I arranged a meeting at which time the study and commitments were more fully explored and informed consent obtained. I consciously avoided approaching potential participants myself, as I did not want anyone to feel an obligation to participate because they knew me.

2. Participants were assured of confidentiality through a commitment to the following strategies: (a) use of pseudonyms in all transcripts and public material produced from the research; (b) transcriber would be asked to sign an agreement of confidentiality; (c) all identifying data were kept in a secure location with access by the researcher only; (d) tapes would be returned to participants or destroyed at the completion of the research; (e) data was kept secure by the researcher until no longer of use and then would be destroyed.

In fact, as the study progressed I reversed my decision regarding hiring a transcriber. In listening to the interviews myself I became acutely aware of how difficult it would be to maintain confidentiality in the kinds of discussions we were having. It became apparent to me that the participants themselves might be identifiable, even without the use of names, as might some of the health care providers mentioned in the interviews. I then decided to transcribe interview data myself.

Confidentiality has also been a challenge because many of the women in the study know each other and talk among themselves about being in the study. I chose to acknowledge that reality with my participants, but I have been clear that I cannot share any information regarding either who is in the study or what is currently going on with individual women.

Participants have not been concerned about anyone knowing they are participating in the study. In fact, several have said they would prefer their real names be used and not pseudonyms. These participants signed an additional letter providing permission to use their given first name.They were assured of their right to offer comments, suggestions, or concerns, and of their right to withdraw from the study at any time. They were also informed that they might choose their level of participation in the study, and that they could turn off the tape recorder at any time during either group or individual discussions.

In reality, the women in this study were and still are keenly involved in the research. No one withdrew or requested that material not be used. One participant did move and has been unavailable for further interviews. All have had access to complete transcripts and any writing I have completed.

Reading the Texts and Constructing the Narratives

Confronted with over one hundred and fifty hours of interview data, I must confess that I had only a hazy idea of what form or shape the analysis should, or would take. Unlike some research methodologies, such as grounded theory, critical methodologies do not come with a clear set of steps or rules for analysis. I knew that feminist and postmodern perspectives would be my guides, but what I would actually do was not clear at the beginning. It was not until I immersed and re-immersed myself in the texts created through the conversations that the participants and I had that I was able to gain a sense of direction. In fact, I tried a variety of different ways of looking at the data over a period of many months.

At the outset, I knew that I did not want to ask specific questions of each participant during interviews. I opened the first data-collecting interview with the comment that I was interested in hearing their story about being diagnosed and treated for breast cancer, and then I listened for the next three to four hours. I seldom needed to even ask questions for clarification, as the stories were told in vivid detail. Before scheduling the next interview I would transcribe the text and copy it for participants. I did ask specific questions at the second interview (Appendix III), clarified points from the first, and caught up with what was going on for them with their breast cancer.

Just so the reader understands that the research process rarely, if ever, proceeds in the manner planned, I admit to having several interviews that were difficult to transcribe. A few of the participants had very soft voices, one from treatment for thyroid cancer. Two tapes were inaudible in certain places. Because I listened to each tape immediately after the interview, I was able to fill in some blanks from memory. In other cases, I clarified pieces of the story at the next interview. In one situation, the tape recorder simply did not work and I repeated that interview with the kind help of that participant. One participant was from the Vancouver area and we did the initial interview over the phone while I made notes. I later sent her a copy of the interview and she filled in missing pieces. We have since met several times to converse about the nature of the research and the way I am working with the data.

The women were in very different places with regard to the phase of their journey, and therefore I did different things with different participants over the course of the two years. For example, there were women in the study that were still in active treatment, and we would often talk about ways of dealing with particular symptoms. There were women who suspected a recurrence but had not yet captured their doctor's attention. In these cases we might problem-solve our way through various options. There were also women who experienced crises in their relationships with health care providers and would call me to talk through solutions.

Once I completed the formal phases of data collection (informal contact was and remains ongoing) I wrote interpretive summaries for each participant. This served several purposes. It was a way for me to put each woman's history and story together and get a sense of each of them in their similarities as well as differences. I was then more ready to move out of each woman's individual story and focus on the collective. I provided a copy to those participants who wished to have one. I also provided my committee supervisor with copies, which enabled her to gain a better appreciation of the women who participated in this study. This process facilitated many readings of the data at an individual level.

It was when I attempted to look at the data in the collective sense that I really missed not having a specific set of rules to follow. With the purpose of setting some sense of direction for myself, I started looking at individual participant's texts and reading through them with my study questions in mind.

1. In what ways do women with breast cancer make sense of, engage with, and position themselves in discourses?
2. How do women make their voices heard, and what might women-constructed discourses be like?
3. What are the conditions that facilitate/constrain women's positioning within discourses and in creating new discourses?
4. What are alternative possibilities for understanding and action?

In looking at women's texts with these questions in mind, I could very easily pick out and label bits of text that related to each question. I proceeded with this through all participants' texts and then started to theorize the composite text. It was at this time that I began to think I was fore-grounding my own perspective and not letting the texts reveal themselves (Opie, 1992).

I returned to reading and re-reading about praxis-oriented research, and tried to distill the essence of this methodology. In its most cogent form, praxis research is directed toward emancipatory knowledge development and transformations in women's own understandings of their experience of living with breast cancer, and the health care environment in which this occurs. With this in mind, I returned to each woman's text in a reading for her discourses. I consciously put my theoretical perspective aside and let participants' texts reveal themselves. In this way, I identified a variety of discourses that felt better than previous attempts, but still somehow not right.

During this time I was talking with several participants about what I was doing and was listening to their comments. I began to think about the differences in women's experiences and in what mattered most to them. Returning to the data with these thoughts in mind, I again re-constructed the discourses I was seeing.

As I continued to live with the data and stay in relationship with the participants, I moved continuously back and forth among women's voices and the questions that had served as the impetus for the study. I was not finding it difficult to identify discourses within the data but, rather, having difficulty framing them in a way that honored the voices and feelings of all the women in the study and, as well, created a coherent picture of the infinite differences as well as similarities among them. Additionally, I needed a way to frame their discourses that captured the process of living through and with breast cancer.

As I worked and re-worked with the data there were questions that kept recurring. These questions guided my thinking and eventual conceptualization of women's discourses.

1. What discourses can I identify within the data?
2. How might these discourses be conceptualized in an overarching way and in a manner that has meaning for study participants?
3. How can differences as well as similarities within and among women's discourses be illuminated?
4. How do women work with dominant discourse in the creation of their own?
5. How are women's discourses similar to or different from, biomedical discourse?
6. How are women's discourses heard? What parts of the discourses are spoken aloud, spoken in the time or place, or recalled retrospectively as participants talked with me or others in their lives?
7. What purpose does constructing women's own discourses serve?

With this new construction, I read individual transcripts for fit, and then I moved back and forth within the group text. This conceptualization (presented in Chapters Five and Six) enabled me to see the way in which particular discourses were evident in all participants' texts. Additionally, I could highlight the ways in which women's discourses were similar and the ways they were different. Stories about their journeys were important pieces of women's discourses, and it was at this point that I decided to separate the journey from women's discourses. In reading participants' words, it seemed to me that the nature of their journey with breast cancer was a contextual piece of their discourses, and a part of their story that gave shape and form to their discourses. Illuminating women's journey with breast cancer also highlighted specific areas of potential advocacy work in the community.

Separating women's journeys from their discourses also highlighted the entrenched nature of medicalization, and the systems and institutions in place that sustain health care in it's current mode. Visualizing a composite picture of the breast cancer experience is not easy for health care providers because of the discontinuity of care provided. Explicating the journey helps us understand a woman's experience in its entirety, and provides a sense of where and how changes in practice might be instituted.

I continually interrogated this final construction against feminist postmodern tenets and the purposes of the study. Additionally, I was conscious of the promise I had made to myself and to the women in the study that this research would be for the benefit of women living with breast cancer. The final construction would need to account for the similarities and differences in women's experiences, and provide direction for further action and improvements in the care of women living with breast cancer. I also kept in mind that there were many different ways of structuring data and that this particular structure would be presented as provisional and as representing one out of a range of positionings (Strickland, 1994; Josselson, 1996). The way I have chosen to present women's journey with breast cancer and their discourses is inclusive of the data and true to participants developing stories, but it is only one way of many that I could have structured the data.

I had originally intended to hold focus group meetings earlier in the research and have participants more involved with the emerging construction. As I got more involved with the data and the different ways I was working with it, I decided to wait until I had a better sense of what the data might look like before meeting with all participants. In conversing with many of them over the months of analysis, they made it clear to me that they wanted to see a more finished product and could not imagine what I was actually doing with their stories. What they said they needed was something to react to. I continued to talk over the way I was seeing the data with participants who had said they wanted to be involved in talking with me about my process.

Once I felt a sense of fit with women's texts and the way I had structured the data, I wrote chapters describing their journeys and their discourses. I then wrote a summary document that described what this dissertation was looking like at this point in the process. Once I had those pieces of writing completed, I phoned all participants and offered them full copies of all the chapters I had ready, the summary document, and the opportunity to attend a focus group meeting to talk through the process and the results of our work together. Because some women were unable to attend the first focus group meeting, I have had a variety of arrangements in place. Almost half of the participants were able to attend the meeting. Three canceled that evening for various reasons. I distributed the summary document (Appendix IV) to all participants who requested it ahead of the meeting, while the rest received it at the meeting . At the meeting (lasting three and a half hours) we talked about the way in which I conceptualized and wrote their texts and I provided copies of the chapters I had ready (Chapters Four, Five Six and Seven) in draft form. All participants understand the process I will undergo before a final dissertation is ready and understand that there will be changes. Participants at the meeting requested copies of the final dissertation.

For the participants unable to attend the meeting, I was in touch with them at a time convenient to them. We then talked about my process and I provided them with any copies of writing they wished to have.

In this chapter I have moved from a theoretical discussion about paradigms, critical science, and feminist postmodern perspectives to a more focused discussion of the research path the participants and I followed. I have attempted to make the actual process of conducting the research transparent for both the reader and the women who worked with me in the study. I will introduce the reader to the participant group in Chapter Four.

CHAPTER FOUR

INTRODUCING THE PARTICIPANTS

In the previous chapter I described in some detail the path traversed by the women participating in this study and myself. This chapter begins a discourse about the outcomes from the research by introducing the women as a group and each participant as an individual. Overall demographic data and an illustrative profile of the group as a whole is presented first. I then provide an individual portrait of each of the women in the study, while taking care to maintain their privacy. Each of the women reviewed her individual vignette and made any changes desired.

Introducing the Participants as a Collective

The seventeen women who participated in this study were self-selected; that is, they responded to a letter from me requesting participation in a study about women living with breast cancer. They called me to ask for further information about the study and were then enrolled in the study if they so wished. In that way, this group is unique. In other ways, this group of women is representative of the breast cancer community in this region. Participants ranged in age from their mid-thirties to late seventies at the time of the study. The majority were either peri- or post-menopausal at diagnosis, but six women were pre-menopausal. As I stated earlier, I wanted to recruit women in various stages of the breast cancer journey and the women in this study did represent every facet of the stages and phases of living with breast cancer. One participant had been living with breast cancer for twenty-six years while another participant had only recently been diagnosed. Most of the women in the study had completed their initial treatment and were under active surveillance by the health care community during the time of the study.

Nine women had mastectomies as their first surgery; only one participant had a bilateral mastectomy. Eight women had lumpectomies, and one of those women subsequently had a mastectomy for recurrence of her breast cancer. All the women who had lumpectomies received radiation treatment, with the exception of one study participant, who reviewed the literature on lumpectomies and radiation as well as her own pathology results and subsequently refused follow-up radiation treatment. Six participants knew their lymph node status was positive, but interestingly some women in the study did not have any information on lymph node status. Seven women received chemotherapy during their initial treatment and only one woman has gone on to receive a second round of chemotherapy for a recurrence of her breast cancer. Eleven participants in the study are, or have been, on tamoxifen, but during the time of the study two women have taken themselves off the drug.

Three participants have had breast cancer twice, and two women in the study had other types of cancer before their breast cancer diagnosis. The time between initial breast cancer and a recurrence differed for all three women. For one woman it was thirteen years between breast cancer diagnoses, while for the other two women it was between one and three years. The majority of women in this study had been living with breast cancer for between two to three years at the time of data collection.

Five participants have had re-constructive surgery; a blend of breast reduction surgery, saline implant, and trans-flap breast re-construction. These women vary in age from early forties to early seventies.

I had wanted to recruit women who represented various life stages and life stories for this study, but I did not want to deliberately seek out women representing particular backgrounds. All women in the study are Caucasian, several are widowed, some live with partners (male and female), and others are divorced and living alone. Two women have never had children, several still have children at home, while the rest of the participants have grown children who live away from home. All of the participants have financial resources, although a few women experience financial concerns through inability to work because of their illness. All of the participants reside in South Central British Columbia and the Vancouver area.

At the time of writing, one participant has just completed another regime of chemotherapy, one is sure that her cancer has returned but this has not yet been confirmed by her doctor, and one participant has just completed treatment for another type of cancer, diagnosed about three years after her breast cancer diagnosis.

Profile of the Participant Group

This study is about women's experiences of living with breast cancer and their voices and discourses documenting their journey. As such, it is vital for the readers to feel a sense of knowing the individual women who have contributed so much to the study. My dilemma is to somehow provide the reader with that sense of knowing, while at the same time protecting the identity and confidentiality of both the participants and the various health professionals involved in their care. I have not changed any aspect of the participants' biographies but I have omitted some details that might identify specific women.

What follows is a brief portrait of each participant in the study. The women involved in the study reviewed their own biographies and made any changes they wished.

Participant One: Ellen (ES)

Ellen was in her fifties when diagnosed with breast cancer. She had a suspicious mammogram and was told "not to worry about it" by her family doctor. Two years later she noticed that her nipple was inverted, and she was subsequently diagnosed with breast cancer. At the time of her surgery, the lump was very large and lymph nodes were positive. Lymphedema remains a problem.

Ellen read the letter of introduction to the study and immediately decided that she wanted to participate, as she felt that she had important things to say about her care and being a part of the study might help other women from going through what she did.

She sought me out at my work place and we talked about her experiences for over two hours before making a date to proceed with the consent and formal interview. The initiative that Ellen displayed here is indicative of the way she has proceeded through the surgery, treatment, and surveillance protocol over the past two years.

At this time Ellen is in remission and actively caring for herself with a variety of self-developed treatments, exercise, painting, and writing. She has overcome the periodic and debilitating depression that plagued her earlier in her journey and has managed to develop a supportive relationship with her oncologist. Ellen is fluent in English but it is her second language and fairly recently learned.

Participant Two: Elizabeth (EC)

Elizabeth was post-menopausal when diagnosed with breast cancer and her children were away from home and independent. She had a biopsy after an abnormal mammogram but was told "not to worry" about her biopsy results by the surgeon. Elizabeth continued to have regular mammograms over several years. The reports on these noted that there was an abnormality. Her doctor again told her that there was nothing to worry about and so she merely continued to have regular mammograms.

Several years went by and finally Elizabeth became concerned that she was still getting the same note on her mammogram results. She decided to investigate for herself and phoned the radiologist, who told her that when the surgeon had done the biopsy he had missed the lump entirely. Elizabeth then referred herself to another surgeon and was diagnosed with breast cancer but with negative lymph nodes. She wonders if she would have confronted the original surgeon if the lymph nodes had been positive.

Elizabeth is several years past initial treatment with no further difficulty, although she experiences lymphedema. She is followed by her family doctor and feels comfortable with that. Elizabeth describes herself as a private woman who offers support to other women with breast cancer on an informal basis.

Participant Three: Jill (JL)

Jill was diagnosed with breast cancer following a regular mammogram eight years ago and was peri-menopausal at the time. Her children were living away from home and were independent. It was a small lump and her doctors felt confident that they got it all. Recently, Jill underwent another biopsy for a lump in her other breast. This turned out to be benign and Jill was discharged from the Cancer Clinic and is now followed by her family doctor.

Jill is active in the breast cancer community in both formal and informal ways, and enjoys traveling. Jill is a retired health care professional who has worked as an advocate for others both during and after her own diagnosis and treatment. She continues to involve herself in the community, doing many hours of volunteer work and being there for other women with breast cancer on a more informal basis as well. She describes herself as outgoing and a verbal woman and says that she processes her feelings through talking with others.

Participant Four: Maureen (MW)

Maureen was diagnosed with breast cancer four years ago. Eight years prior to that she had received a diagnosis of terminal abdominal cancer. Her children were away from home at the time. Maureen's husband was and still is her partner in caring for her and her cancer.

Maureen had chemotherapy treatment for her abdominal cancer but continued to worsen. She was finally referred to the palliative care program and home nursing care. That was when things began to turn around somewhat for her and she could at least be kept more comfortable. As months passed and she, in the words of her doctor, "was still alive", Maureen was referred to a specialist in Vancouver.

At that time the specialist did not expect to be able to cure her, but thought that surgery could relieve the pain and swelling and increase her comfort. After many hours of surgery and days of being unconscious, Maureen woke up to the news that they had in fact been able to get all the cancer.

Being diagnosed with breast cancer, and the information that it was a small lump with no node involvement, made this particular cancer straightforward in Maureen's mind. She had been energetically involved in advocacy work since her recovery from her abdominal surgery, and had remained actively involved with several groups supporting people with cancer until recently. In the last few months Maureen has felt the need to take a time out from that work and pursue other interests.

Maureen is followed by her family physician and feels safe with that care, but remains quite aware that, while breast cancer may be behind her, she is susceptible to other forms of cancer. She takes pains to live each day and rejoice in what life has to offer. Recently, Maureen has been diagnosed and treated for another form of cancer.

Participant Five: Jessica (JD)

Jessica is another participant who discovered breast cancer after treatment for another cancer, in her case thyroid cancer. Jessica was 51 years old at the time of her diagnosis with breast cancer and had children both away from home and one still at home with her and her second husband. She had had several biopsies in the past and was having regular mammograms and clinical exams because of recurring breast cysts. She was also doing breast self-examination and found this lump herself. She did not expect that it would be malignant, as the others had always turned out to be benign.

Jessica was diagnosed promptly at a Breast Health Center out of province and was stunned by the news that it was breast cancer. She had positive lymph nodes and received both chemotherapy and radiation treatment. She completed her treatment ten years ago and is still followed at the out-of province-cancer clinic.

Jessica participates in some community activities for breast cancer but describes herself as a quiet person who prefers to stay in the background.

Participant Six: Lynette (LM)

Lynette was diagnosed with breast cancer at the age of thirty-nine. She had two small children at the time, and was professionally employed. Lynette was treated with surgery, radiation, and chemotherapy. Her lymph node status was negative but the hospital lost her tissue so her tumor estrogen status was unknown. Somewhere along the way in treatment her staging was misrepresented. Although she had been told verbally that she was stage one breast cancer, she later discovered that her doctors had recorded stage three on her charts.

Lynette remained in her work and marriage while her children were growing up but she has made many changes since they became independent. She has divorced, moved provinces and cities twice, and supported her sister who died of breast cancer. She says she is the longest living survivor she knows!

Since moving to the Central Interior, Lynette has become very politically active in local and national breast cancer advocacy groups. She works at this like a full time job, despite the fact that she has had to go on long-term disability and suffers debilitating effects from her previous treatments. She describes her early years with breast cancer as a time when she minimized the disease and treatment and made a point of bringing her children up to be independent in case, as she said, she "wasn't going to be there".

Participant Seven: Mary (MH)

Mary was diagnosed with breast cancer at forty-nine years old. Her own two children were away from home, but she had a stepchild living with her and her partner. She found the lump herself and did have positive lymph nodes. One of the many things that has been hard for Mary regarding her treatment was the fact that the doctor was only able to get one lymph node which did show malignant cells. She has questions as to why he only got one lymph node, and also how the testing of a single node might affect the accuracy of her staging. She was initially treated with surgery, radiation, and chemotherapy, which she finished two years ago.

Recently, Mary was diagnosed with a recurrence of breast cancer. She had been reporting the existence of a lump under her arm that was painful and getting bigger but was told that it was scar tissue and "not to worry about it" by her doctor. She eventually was referred to her previous surgeon and had a biopsy that showed abnormal cells. After considerable delay and distress with her care, Mary chose to change surgeons and underwent extensive testing and, finally, further surgery in Vancouver. At this time she is just completing a regime of high dose chemotherapy.

Prior to this recurrence Mary was actively involved in the breast cancer community. She was unable to work at her job full time after her initial treatment and was told that she must work full time or quit. Mary did quit, although she has financial concerns; one of the most pressing is medical coverage as her partner is attempting to begin a new career.

Participant Eight: Judy (JS)

Judy had been having regular mammography for many years. As a fit and very health-conscious woman, she routinely followed screening recommendations and participated in health promotion activities. Her family was independent and away from home at the time of diagnosis. Judy was devastated by the diagnosis and had not thought she would ever get breast cancer. She had a mastectomy and has not required any further treatment.

Judy has been active in the breast cancer community since her diagnosis, and she is passionate about working toward better care for women and being there for other women who are diagnosed with breast cancer. Judy is knowledgeable about breast cancer and critical of the way the media represents risk for breast cancer. She (along with other participants) believes that more attention needs to be paid to the use of estrogen and environmental pollutants.

Participant Nine: Sharon (SC)

Sharon was in her late fifties when diagnosed with breast cancer. She had been off work with other illnesses prior to her diagnosis, her children were away from home, and she had relatively recently gone through a difficult divorce. Sharon was put on tamoxifen as her only treatment following her surgery, but she never really felt right while on it and so took herself off the tamoxifen during the study.

Sharon has investigated breast cancer from many different perspectives and remains open to new ideas and research. She has been involved in the breast cancer community in a variety of ways and, more recently, Sharon has moved into more of a leadership role. The mind-body connection fascinates Sharon, and much of her reading and investigation are in this area. She has been cancer-free since her initial diagnosis but comments on the never-ending awareness of the potential for recurrence. She tries to develop and nurture a live-for-the-day philosophy.

Participant Ten: Jane (JB)

Jane was 46 years old at the time of her diagnosis, divorced and with one child away from home. She was dating when she received her diagnosis, although that relationship did not last. Jane had a long history of cystic disease and had a previous benign biopsy that left her with keloid scarring. A lump in her other breast had been detected but, because of the previous scarring, the doctor elected to watch it. Jane had been having regular mammograms, and one year after the lump had been detected there were changes on the mammogram that prompted further investigation. Because of her previous history with cystic disease, she did not expect the diagnosis of breast cancer.

There were many difficult things for Jane to deal with during her diagnosis and treatment. She had a real fear of hospitals and all things medical, she was very alone throughout her surgery and radiation treatment, and her relationship with her boyfriend was deteriorating. As a single woman, another major area of concern for her was the dilemma of when and how to tell a potential new boyfriend that she had breast cancer and that she did not know what the future held. Jane is followed by the cancer clinic and is the one participant who participated in only the first interview.

Participant Eleven: Faith (FP)

Faith was forty-one years old when diagnosed with breast cancer and, unlike many of the participants in the study, was not shocked with her diagnosis. Her mother had recently died of breast cancer and other members of her family had had breast cancer as well. As a result of her family history, Faith had been having regular mammography examinations since her late thirties. At the time of diagnosis, Faith was divorced but in a stable relationship.

Faith underwent the surgery and radiation treatment in Vancouver, with the support of family and friends. Her children were teens at the time and living at home. They have remained a focus of her concern throughout her journey with breast cancer. She has special concerns for her daughter and is still thinking about genetic testing.

A year and a half after her initial treatment, Faith had another abnormal mammogram and further treatment for that recurrence. She has been free of cancer for three or four years now.

Although busy with family and work, Faith devotes time to support work with other women living with breast cancer. She is also keen to be involved in research and has participated in drug trials, nutrition and life style research, as well as this study. She is followed closely and remains optimistic and positive. The care and attention of the cancer clinic and health care professionals inspires her confidence and, although she is realistic and knowledgeable about the disease of breast cancer, she is able to live her life in a full and upbeat manner.

Participant Twelve: Leena (LC)

Leena has had breast cancer twice, and also has had a daughter die from ovarian cancer. Leena's involvement in leading support groups over the past thirteen years began as a result of her daughter's illness and in response to a wish of her daughter to initiate a support group. None had previously existed in this community, and both Leena and her daughter felt the lack of one close to home.

Leena's diagnosis was made on mammography. She experienced extensive opening of the surgical wound immediately after her operation but was at home at the time and experienced difficulty in getting attention from her surgeon. It was several months before proper healing occurred.

Leena is treated with tamoxifen and was so relieved not to have chemotherapy that she says she can handle the side effects of the tamoxifen with no difficulty. She feels confident with her care although she does explore other ways of healing in a rather cautious manner. She and her husband are making lifestyle changes such as moving out of the family home into a smaller home and are enjoying the recreation and social activities available.

Participant Thirteen: Dorothy (DN)

Dorothy was in her fifties when diagnosed with breast cancer on a routine mammogram. This was a totally unexpected diagnosis and she was devastated by it. She knew one of the surgeons in the city and chose him for her surgery. Dorothy had a mastectomy and has been on tamoxifen. Her children were away from home and she lives with her husband. They have a son who was born with a disability and has required much care throughout his life. Dorothy describes herself as someone who can advocate for others easily but not so easily for herself.

As a consequence of her breast cancer, Dorothy has become much more of an advocate for both herself and others. She is involved locally, provincially, and nationally with breast cancer groups, and recently her work has taken on more of an active advocacy tenor. She is due to go off the tamoxifen as soon as her five years are up and expresses some concern about that. She describes it as a good feeling to be on it as a security blanket. Dorothy is followed by her family doctor and continues her volunteer work. She is interested in various forms of healing and has completed several courses in healing touch. As well, Dorothy remains up to date with biomedical knowledge about breast cancer and routinely attends local and national conferences.

Participant Fourteen: Marjorie (MM)

The next three participants chose to be interviewed together. They have been friends for many years and are of similar ages.

Marjorie was diagnosed with breast cancer at sixty-one years of age. She had had a mammogram at her daughter's insistence. This was many years ago and there was only one oncologist available in the city. Marjorie was unhappy with his care and transferred to a larger center and the cancer clinic there. She has remained under their care ever since.

Like many of the women in the study, Marjorie was under a great deal of stress at the time of diagnosis. She was divorced, supporting her daughter in university, and in danger of losing her home and property due to financial difficulties.

Marjorie has two sisters. When her cancer was discovered on mammography, she encouraged both to have a mammogram. One sister, who lives in the same community as Marjorie, also discovered breast cancer and has to date, been successfully treated. Her other sister, who lived in another part of the country, had a mammogram and was told she had a cyst but needed no further treatment. Two years later she was diagnosed with bone metastasis secondary to breast cancer and has since died. Marjorie and her remaining sister are part of genetic testing through the cancer clinic.

Marjorie is presently experiencing pain and difficulty with movement. She is waiting for a bone scan and further tests. At the time of writing, some of these difficulties seem to be resolving.

Participant Fifteen: (Pam PM)

Pam was recently diagnosed with breast cancer and is on tamoxifen. She has been unhappy with the treatment she has received from her doctors, and Marjorie has been encouraging her to transfer herself to another cancer clinic. Marjorie has been Pam's primary form of support. Both are in tune with medical knowledge and expertise, and they talk together to attempt to make sense of the tests, lab results, and new symptoms.

Pam was also under stress at the time of diagnosis, primarily financial challenges that stretched out over many months. Her children are away from home and she lives with her husband.

A huge dilemma for Pam has been the tamoxifen prescribed by her oncologist. She does not like the way it makes her feel and is convinced that it was the cause of the small transient ischemic attack (stroke) that she experienced recently. She would like to go off the tamoxifen but her oncologist is adamant that she should stay on it. Marjorie supports this view and encourages Pam to remain on the tamoxifen. Pam does volunteer work with the cancer clinic and helps her husband run a small home-based business.

Participant Sixteen: Deb (DM)

Deb was diagnosed with breast cancer twenty-six years ago. She was a mother of four children, the eldest twelve years old and the youngest only two, when she was diagnosed with breast cancer. She went to the doctor with a very sore, bruised, and hard breast that she thought she had injured herself. It was a huge shock to everyone that it turned out to be cancer and she was rushed into treatment. She had a radical mastectomy in her local hospital, followed by radiation and chemotherapy at an out-of-town cancer clinic.

Deb talks about this time in a very matter of fact way. She comments, you did what you had to, recovered as quickly as you could because people were depending on you, and then you got on with your life. She also said that it was the worst thing that could have happened at the time. There were no support groups and Deb did not talk about her breast cancer. It was a small town, however, and so everyone knew about her breast cancer and most people thought she would die.

At the time of the interviews Deb was widowed, her children were away from home, and she lived independently in the large family home. She continued her gardening, family gatherings, and work in her orchard, despite severe lymphedema that has plagued her since her original surgery. Deb died shortly after our second interview from heart problems.

Participant Seventeen: Barb (BW)

Barb was diagnosed with breast cancer following a routine mammogram. She was in her late forties. The diagnosis was totally unexpected; breast cancer was just not something she worried about getting. Like many women in this study, Barb describes her life at the time of diagnosis as extremely stressful. She and her partner had been going through a rough time, and in fact Barb's breast cancer was the impetus for an eventual breakup.

Barb's experiences with the healthcare system were difficult. She experienced intense emotions and delays during her treatment and was forced to expend much energy in order to navigate through the system and deal with health care providers.

Barb says she has learned much from these experiences. She is now in charge of her own care and returning to some of the activities and interests she enjoyed before her diagnosis of breast cancer. At the time of these interviews, many of these intense emotions were being worked out, mostly by herself and with the support of formal groups. Barb is followed by the cancer clinic and continues much healing work on her own.

Conclusion

In this chapter the reader has been provided with a profile of the study participants and the individual women in the study. Chapter Five chronicles the story of the journey women traverse as they are diagnosed and treated for breast cancer and then enter the time of living with a potentially life threatening and chronic disease.

CHAPTER FIVE
LIVING THE JOURNEY WITH BREAST CANCER

Introduction

With the support and consent of the participants in this study, their story of living with breast cancer has been conceptualized in a way that answers the original study questions but does so in the form of describing their journey with breast cancer and their discourses as these emerged through the telling of their story. This chapter relates an account of the journey that begins with a suspicion of breast cancer and continues for the rest of the women's lives. Chapter Six relates an account of the language and words that create the discourses that women construct as they live in and through their journey with breast cancer.

Creating a composite story from the words, thoughts, and feelings of women living with breast cancer is useful in its own right. Hearing women's voices about their own experiences offers health care providers the opportunity to enter the world of women with breast cancer in a way that is impossible when women's voices are silent. Hearing women's voices can help us see the disease and illness of breast cancer in new ways, and it offers the opportunity to view the many and varied ways that biomedical and public discourses interact with women's personal discourses.

Telling a story about the experience of living with breast cancer also illuminates the variety of ways that women make sense of their journey with breast cancer, engage with dominant discourse, and make their voices heard as they live with breast cancer. Stories about living with breast cancer are also useful in other ways, and in this research they were foundational in providing a starting point for discussion and analysis of the ways in which women attain a sense of personal agency, develop transformative knowledge, and move toward personal and collective praxis. This is the topic of Chapters Seven and Eight.

The story of the journey with breast cancer belongs to the women who participated in this research. I must acknowledge, however, that the words written here are mostly mine and taken from the texts we created as we conversed about their experiences in living with breast cancer. That is, the way the journey is portrayed has been constructed from their texts and the way in which the participants voiced their experiences about living with breast cancer.

A friend and colleague of mine from New Zealand has been working for many years with people living with cancer. She reminds me that storying is a journey in itself with many stops and starts, twists and turns. A story of one's life with cancer would rarely be told in a straight line. Women's stories about their journey with breast cancer contain fragments of their old stories, that is, the ones they have told many times; but these stories also contain elements of the new -- the story they discover as we converse together (Martin, 1999).

The Journey in Context

For most of the women in this study, being diagnosed with breast cancer and embarking on the beginnings of an unplanned and uncharted journey was a complete and devastating shock. Even for the one or two participants who had some reason to think about or contemplate the possibility of being diagnosed with breast cancer, the sense of what was ahead of them was hazy and incomplete. Participants talked about being in a place in their life where they were attempting to make sense of or figure out many different things. Dealing with divorce, employment stress, children leaving home and relationships with family and friends were on women's minds. In the middle of attempting to create a coherent story of their own life, they were faced with a diagnosis of cancer. Readjusting their individual life story to accommodate living with breast cancer became a monumental and ongoing task.

Knowledge women had accumulated over the years about creating a fulfilling life for themselves had to be recreated with this new crisis. The stories that women told about their journey with breast cancer exemplified the differences among participants in their life context. Believing that knowledge is relative, contextual, and temporal, it seems important to illuminate some of the contextual factors influencing the ways in which these women described and lived their journey with breast cancer.

Life Space

There are many different facets to the life-space women occupy during the time they are diagnosed with and treated for breast cancer. A conspicuous and frequently discussed aspect of life space was the woman's paid work situation. For a few women in the study this was not an issue, perhaps because they were either retired or had never worked outside the home. For many others, however, the effect their work situation had on their experiences before, at, and after the time of diagnosis was substantial.

For some women their work situation was a source of support, both financially and emotionally. For example, Lynette was in the middle of a busy and challenging work situation and due to write examinations in pursuit of further education when she received her diagnosis. Within hours, she was released from all responsibilities, her supervisor had cleared the way for a deferral on her exams, and she was booked for surgery at the institution where she was employed. Lynette received her diagnosis while at work and by phone.

> [L's doctor on the phone with her] L - I tried to reach your husband but I couldn't - and uh, I'm really sorry but I have to tell you that your tissue was malignant and uh, I want you to see a surgeon at 2 this afternoon. and I've also called your boss and I just don't want you to be alone right now. So she [L's boss]came down to my office - I remember I felt absolutely nauseated and I had to lie on the floor of my office and when my boss came - I didn't have the door locked - she - she came in and just sat close and just comforted me - and then my husband came. We went down to her office and she went in to the executive director of the hospital - he was a physician whose attitude was our employees first. And before I knew what had happened I was booked for surgery (LM, 1998).

Faith also received support from her work place and commented that " I had leave from work so I had no financial worries which many people do -- so I was very fortunate in that work covered me..." (FP, 1998).

In contrast to a context of help and support from her work place, Mary was in a different life space at her place of employment. She was already stressed by work and travel commitments when she learned that she had breast cancer, and in fact she had delayed seeing her family doctor about the lump she had discovered because of her busy work schedule. Mary talked about how from the time of diagnosis her breast cancer was treated as an inconvenience to her supervisors at work and she felt pressure to be treated and return as quickly as possible. Most difficult for Mary, however, was the pressure to return to work full time.

> I had been told that I couldn't come back unless I came back full time and continue to do the full scope of my job. My doctor has said she doesn't want me to do that and I don't want to do that. My doctor has written a letter saying I could work part time but they have refused (MH, 1998).

Mary's experience was more negative than that of others, as the end result was that she was forced to leave her work and her long-term sick benefits ran out. The consequences have been stressful. Finances have been a source of concern, but even more frightening was the loss of health care benefits. The seriousness of this hit home when Mary had a recurrence of her breast cancer and required further treatment.

In contrast, Jane had the full support of her place of employment for a gradual return to work and decided on a day to day basis the number of hours she would be at work. Accommodations were made to facilitate this schedule and Jane felt supported by all her work mates.

There were other participants in the study who talked about feeling pressured to return to work before they felt ready. Maureen did bow to the pressure and found herself ill shortly after.

> ... and before long I was expected to go back to work and everything was expected to be normal again. As far as I'm concerned nothing will ever be normal again - ever. And I did go back to work. I knew at the time it was too soon. I knew in my heart but society expects - I guess it was our old beliefs - if you're not sick you work
>
> (MW, 1998).

A portion of this life space for women is the pressure they feel from society to get back to normal and therefore to work as soon as possible. Many succumbed to the pressure so as to avoid the covert or, sometimes, overt messages about malingering.

Related to the space a woman is in with regard to work is the number and complexity of other responsibilities she is managing when she discovers breast cancer. The healthcare system functions at its own pace and is unforgiving of people who can't conform to its demands. This regularly caused conflict for women in this study. All participants had numerous responsibilities. A few women were caring for preschool children, several had older teens at home, some were caregivers for other family members, and some were supporting children in university. Many had other family or friends to turn to, but there were a few women who had difficulty clearing their lives in such a way that they could focus on their illness. As Deb said, " you did what you had to do as fast as you could and then you got back to your family and looked after them. There was no time to think about yourself" (DM, 1998). To varying degrees other participants also voiced this sentiment.

Participants also talked about the kinds of relationships they were in at the time of diagnosis. For many it was the support and love of family and friends that got them through. For a substantial number of women, however, love, kindness, and support were not what they experienced. Several women were living alone when they discovered their breast cancer and remained alone throughout their treatment. For some that was a choice they made, while for others the choice was not theirs.

> I found it very difficult. I live alone and had been alone for a long time and my support network is my girl friends. I didn't talk with them right away - I just found it really difficult. I didn't know what to say - what do you say? .... And I did have a boyfriend and we had been seeing each other for two and a half years. And as soon as I was diagnosed he started pulling away. And then after I had the surgery itself - the partial mastectomy - it was over. He just couldn't deal with it. ... the phone calls got less and less and the visits didn't happen. When I went to the cancer lodge I asked him why he wasn't phoning. He just said - well I try and phone you and some idiot answers. I said - those idiots are cancer patients

> they man the phones voluntarily. I'm not in a room with a phone, they have to come and get me. Anyway, I knew it was over (JB, 1998).

Where a woman is in her life space when diagnosed with breast cancer influences in many different ways what her journey with breast cancer is like and the form and substance of many of her discourses. It may be that some of the differences within women's discourses are a result of being in different places in their lives when diagnosed with breast cancer.

Own Beliefs and Expressing Feelings

There were two major themes related to beliefs and expressing feelings that pervaded the data for many participants, one related to beliefs about cancer, and the other related to ability or space to express negative feelings.

As I have noted before, all participants voiced fear and concern about their future; however, as I worked with the data it became apparent that for some women this was a more vivid and deeply held fear than for others. Several participants talked about their belief that 'cancer equaled death'. Jane, Ellen, and Barb were three participants who were particularly vocal around this theme.

> And then you start getting your house in order and thinking - I don't know how long I'm going to be here. Where is this leading and then you start worrying about what you're leaving. I found that I spent a lot of nights going through papers downstairs and destroying a lot of stuff that I didn't want my kids to find after I was gone - personal notes, things that I had gone through in my life. I just trashed them. All I needed was the word cancer and that was enough for me (JB, 1998).

> I thought well if I'm going to die why not do something I've always wanted. The worst thing is to sit down and contemplate, you dig yourself into a hole. Why do I bother and then I think why not? We bought a new RV after my cancer. I've always wanted to travel Canada. ... Went on a trip - might as well be miserable away. I hadn't been sitting at home - I had been doing things. But if I'm going to

> die I want to see Canada. I didn't want to sit at home and be miserable all the time (ES, 1998).

> Cancer equals death in my head. Cancer equals a death sentence. ... because I equated cancer with death - I was thinking what did I want with the time that was left. I knew I wanted some joy in my life. ... I remember thinking I am going to live - I needed to totally re-focus. I didn't have anyone to talk about it with - everything was inside. I had been thinking along one path and now had to think along another. I decided to only do what I wanted in the little time left (BW, 2000).

Many women in the study talked with me about the intensity of their feelings, and most acknowledged that they had generally kept these feelings to themselves. Some participants acknowledged that our interviews together were the first time they had voiced some of these feelings. For some participants, remaining silent about strong and possibly negative feelings had a significant impact on their experience with breast cancer. Ellen recounted a story of receiving pills from the nurse in the chemotherapy unit after her first treatment. She thought she was to take the six pills given to her all at once, which she did. She experienced severe abdominal pain and went to great lengths to keep the extent of her agony to herself.

> They almost killed me. I was convulsing, screaming for pain. We were snowed in on the acreage. I sent him (husband) to shovel snow on the roof and put loud music on so no one would hear me. The doctor told me to come to emergency but we couldn't get out. So he told me to take gravol - or - to keep the acid down. That helped some but the pain was awful (ES, 1998).

Barb kept a different kind of silence.

> I got my dad and partner together and told them basically what the surgeon had told me - 'everything is fine'. With that I isolated myself. Later my dad patted me on the head and said - 'I'm so glad it was good news. I was blowing up inside but keeping it there. My partner and I did not have a history of talking

> well together. I thought that maybe if we could learn to talk about this it would help - but she couldn't talk about it. ... I was traveling just after getting the news. I sat in the back crying. I must have had sunglasses on because no-one noticed. I was a wreck but had isolated myself when I minimized it like the doctor had (BW, 2000).

There were other participants who voiced their thoughts and feelings liberally and were clear in talking with me that it was essential for them to do so. As Jill recounts, voicing her feelings, all of them, was crucial to being able to make her way through the experience of breast cancer. There were many in the study who shared this perspective.

Familiarity with the Health Care System

There were women in this study who were familiar with and comfortable in making their way through the complexity of our health care system. There were also participants who enjoyed privilege in this system, sometimes because of their own work and sometimes because of already developed relationships with health care providers. Often the journey was described as smooth for this group of women. That is, they got what they needed when they needed it, and were not faced with undue waits or delays in their care. For other participants, however, their knowledge of how the system worked and their perception of their journey was not so positive. There were several participants who recognized that they were very frightened of hospitals and all things medical and were in fact not good patients. Naturally this added to their agony at a time when they were most vulnerable. Jane illustrates this idea poignantly.

> He told me I could have reconstruction later which I wouldn't dream of doing. I mean I'm not going to freely walk in there and say - here you go. If I never see that place again - fine with me. ... because I don't like hospitals. I don't like the procedures - I'm not a good patient. ... but I had no idea of the magnitude of that when you actually have to walk into that place [cancer clinic]and realize you're a patient – your're not visiting here. ... and I couldn't cross the street. I was at the corner and I knew I had to go over there and I couldn't do it. And so I kind of skirted around the block and I started getting palpitations, my chest felt like it

> was going to cave in and I couldn't breathe. I felt like I was going to choke and I couldn't breathe. I walked around the corner and saw the lodge on the other side of the street. Oh, perfect - I thought. I'll go into the lodge first and that will be a little softer approach. Then I'll go to the center after. But when I went into the lodge - everyone is very ill and they don't look well. And I just lost it big time. I just stood there and the lady asked me - is there anything I can help you with and I couldn't even speak. I was just bawling. And the only thing there was Charlie - they have this huge black and white over fed cat and I picked him up and I just drowned him and I didn't want to put him down. It was he was the only thing warm and fuzzy and everything else was ugly. It was awful and a lady actually walked me across there - took me - cause I couldn't (JB, 1998).

Embarking on the Journey with Breast Cancer

Prominent in the discourses of the women in this study were stories about their individual journeys with breast cancer and their thoughts, feelings, reactions, and actions as they made their way through the complexity of the health care system and interacted with health care professionals, family, friends, and other relevant people in their lives.

All participants talked about their journey with breast cancer in a chronological fashion, even though some had difficulty recalling the specific order of early events. I will portray this journey in a chronological way with the proviso that this is not a linear stepped journey but rather an intertwined matrix of phases and stages that overlap on each other, run backwards and forwards at the same time, and depend very much on other people for both the quality of the process and the outcome itself.

All women have different experiences and different ways of living the journey, even the same woman at different times. Thus, the account that follows is not intended to present a single truth about how women experience living with breast cancer but rather illustrates the many and varied ways that women experience this living with breast cancer and the many and varied forms the journey takes.

An important characteristic of this journey is the inability to know when or if ever it will be over. There is only one certainty for the woman who finds herself on this journey with breast cancer; she remains on it forever. Once a woman has breast cancer she never feels totally safe again and the fear of a recurrence of cancer is always with her. "I'm always waiting for the other shoe to drop" or "Every change in my body could be a signal of more cancer" are commonly voiced fears. Women do talk about the day-to-day fear of recurrence or another episode of cancer receding somewhat as time passes, but it never completely goes away, and thus the journey is never complete. For women in different life circumstances, this never ending journey and the fear that accompanies it has different meanings. Thus individual women narrate their journey with different emphases, truths, angers, and fears.

It is important to note that the women recounted much of their journey with breast cancer from a retrospective perspective. That is, they were remembering back to how it was for them at the time of diagnosis or treatment. There was, however, much of the journey being recounted in the here and now. Some women were in the surgical or treatment phase during the time of data collection. For other participants, those pieces of the journey had occurred from six months to twenty years before. Interestingly, many women also spoke prospectively, that is, what they think they would do if such and such happened. All women also spoke about the here and now, what had changed for them, what they were still working on, and what they would like for their future.

All participants in the study talked about their sense of personal risk for breast cancer. Only one woman who had a very clear and direct family relationship to breast cancer acknowledged the feeling and the knowing of personally being at risk. Faith commented "I knew I would get it, I wasn't surprised when they told me" (FP. 1998). All other participants had either unconsciously or consciously determined their risk as minimal or non-existent. This was despite the fact that most women in the study did have regular or fairly regular mammograms.

Once faced with a diagnosis of breast cancer (not a straightforward process), participants felt compelled to confront, at least personally, public discourse about the common risk factors for breast cancer. The ones that caused them some considerable difficulty were related to personal lifestyle: obesity, high fat diet, lack of exercise, and not having children. Women expressed anger and a certain defensiveness in needing to refute those factors as being the cause of their breast cancer. Most had made changes in their diets some time before their diagnosis, most were physically active, and none could be considered obese. Sadly, several participants spoke about their dismay at the way their bodies had betrayed them. Judy described how she had been a lifelong fitness advocate, had always eaten well, had her children early, and had no other risk factors. She and many others experienced anger whenever they came across such discourse, and many dismissed public discourse on the topic of risk and cause as simply not being true.

Some women in the study talked about the lack of attention to environmental factors as a contributing cause of breast cancer, while others stated flatly that the cause is unknown and clearly the risk factors so often mentioned are not all that accurate. Many participants commented that risk discourse serves to make women feel guilty and angry and perhaps masks the little that science actually does know about what causes breast cancer and who is really at risk.

Clearly, then, the notion that women who feel at risk will be most attentive to screening procedures cannot be taken for granted. It might be that screening has more do to with a general paying of attention to one's health. Women in this study talked about going for mammograms because they knew they should or because it was a part of their yearly checkup. "Spring is an awful time of year anyway so I always do the check-up thing then" (JS, 1998). Some were encouraged to do so by their daughters. Two participants in the study found the lumps in their breast before mammography was readily available and were diagnosed with a needle biopsy. For many of the participants, however, being told that their mammogram showed something that should be investigated heralded the first conscious suspicion of breast cancer.

Suspicion and the First Inkling/Hint Of Breast Cancer

Judy recounts having her regular mammogram and not giving it another thought until receiving a phone call from the clinic to return for another x-ray.

> And I'll never forget it. It was the 27th of March. My doctor phoned and she said - the mammography department just phoned and they want to take another x-ray. They want you to come back again, it's nothing serious, we just found a little something there. ... so okay I went back in. I was scared stiff but I went back in.

> ... and of course no one says anything to you. Then they phoned me again - would you come in again? Now I know this is it. I'm doomed. So back in I go - like in an hour. So I'm back in there again and they take the mammogram and I'm in the little room getting dressed and the nurse comes in and says - Mrs S we have your doctor on the line. Well that's it. I know - I know they're going to tell me ... and I was just trembling and practically in tears ... (JS,1998).

As one would imagine, this is a tense and unfamiliar place for women to reside and a phase of the journey that is fraught with uncertainty. Whether the woman comes to her family doctor with a suspicious lump or change in her breast, or she receives news that something is not right after a routine mammogram, she will be in a state of limbo about what it all means for some time.

All participants could vividly recall the feelings they experienced during this phase of diagnostic uncertainty, although for most women the details were sketchy and difficult to recount in specific detail. Some participants told stories of haste and of feeling unable to catch up with what was happening to them, but a surprising number of women also recounted delays for appointments and diagnostic procedures, feeling dismissed with equivocal results and, for a surprising number, being sent home with the reassurance that it would be watched and they should not worry. For a significant number of participants this meant a delay in diagnosis, and certainly for a few this delay meant that the cancer grew in size while they were being watched by their doctor.

However this first phase of the journey played out for individual women in the study, all experienced it within the context of their own life world, and all experienced severe and ongoing disruption to their regular routines and responsibilities. This was a taken for granted aspect of the diagnostic phase on the part of the health care system. Women were to be available on request and yet amenable to delays in appointment times and receiving results of diagnostic tests.

Almost all women in this study were reassured by their doctor prior to further investigation and biopsy that it probably wasn't anything and they shouldn't worry.

> I was doing BSE [breast self examination] like I always did and I felt a small lump in my left breast. I went and had it checked out. She [doctor] was quite

> sure it wasn't anything but she said I'm going to send you to the breast center - they deal with the mammograms. ... so they did a mammogram and they didn't see anything. They did something else then - I can't remember ... and nothing showed up and so my doctor sent me to a surgeon. He said - we'll wait a month. I don't really think it's anything but we'll wait a month and see if it's still there. Of course it was still there ... and he did a needle aspiration - what ever they call it. And then he called me at home and it was malignant. I was totally shocked - he phoned me at home. My husband was on the road and my son was home - we had just had dinner and I felt like someone had hit me in the stomach. (JD, 1998).

Women acknowledged that they believed the message not to worry was an attempt on their doctor's part to be reassuring, but the doctor's assumption that nothing was wrong left them ill-prepared for a diagnosis of breast cancer. One might think that the diagnosis of breast cancer would be straightforward following a biopsy, and certainly the participants in this study believed that the doctor would be able to tell them that it was either cancer or not. However, scientific proof is not so straightforward, and many women were still in limbo even after several mammograms and biopsies.

A prominent element of this phase of the journey for women with breast cancer is the waiting for results and the waiting for a plan of action. There were many differences in how this phase of the journey played out for the women in this study. For some it was relatively quick, and in fact they were diagnosed and had had their surgery almost before they knew what had happened to them. Dorothy (DN, 1998) spoke about knowing it was breast cancer within a few days and having the surgery within a week and a half. For others this phase dragged out agonizingly and became one of the worst memories of the whole journey. Barb (BW, 2000) had a prolonged and difficult period of three months before she had a definite diagnosis of breast cancer. Even then there was a great deal of uncertainty about her treatment plan, which was changed several times. Barb found this a very difficult phase of her journey and recounts her attempts to get information from her surgeon and a referral to an oncologist.

> I was expecting the results that week but they were not there. My own GP [family doctor] phoned to tell me the margins were not clear. That was really scary as I couldn't see the surgeon until July 20th as he was on vacation [three weeks away]. I was in limbo all that time. ... I did go to see an oncologist after seeing the surgeon - she said - why are you here? Then she reviewed my chart and her attitude just turned right around. ... surgeon was going to have a conference with the cancer clinic but one week later he still had not done it. I didn't have any answers and no reassurance as to why I didn't. At this point I decided that these people didn't know what they were doing and it was up to me ... (BW, 2000).

A significant contextual piece of the diagnostic phase of the journey with breast cancer is the isolation and lack of knowledge that women experienced. It was only by luck or chance that a woman would be connected to other women with breast cancer or offered books or information about diagnosing and treating breast cancer by her doctor. The women in this study who knew their surgeons personally were more likely to be provided with such resources. As is likely true in many places, there are particular surgeons in the region who never distribute information, just as there are some who routinely do so, even though all surgeons who work with women with breast cancer are provided with information to distribute to their patients.

Thus, many women in this study received their diagnosis of breast cancer with little if any information. Some were knowledgeable about the Cancer Society and were able to get information that way, while others knew someone with breast cancer and were able to talk with them. Many women, however, went into the next phase of treatment without access to pertinent information about the treatment protocols available.

Another difficulty with this phase that women talked about was the disjointed system of care. For most of the women prior to their diagnosis with breast cancer, their family doctors had been the primary source of medical care and information. With a suspicion of breast cancer, women were suddenly thrust into a maze with various health care professionals providing specific areas of expertise relevant to the diagnostic phase. Thus women with a suspicion of breast cancer would come under the care of technologists and radiologists at the mammography clinic, a surgeon, and then the radiology department at their local hospital. Participants would then usually have a biopsy done by a surgeon, and then a pathologist would determine whether the tissue was benign or malignant. Women would most often receive the results of their breast biopsy from the surgeon and then might have to undergo further surgery. This process already involves a minimum of five health care providers, only one of whom they have likely had any previous relationship with. This complicates the process for women in specific ways and was a prominent theme in their discourses about breast cancer.

Being told that one has breast cancer is a facet of the journey that remains in the consciousness of women forever. All participants could remember vividly how they were told and who (if anyone) was with them. The where and how of communicating the diagnosis varied considerably. Some women were told that they had breast cancer in the day care surgery unit (an open room with both men and women recovering from surgery behind cloth curtains). Some women waited varying lengths of time for the pathology report and then were told the news in their surgeon's office. Some women received the news by telephone.

Once a diagnosis of breast cancer was given, a variety of scenarios played out. For all the women in the study, however, the knowledge that life would never be the same and that breast cancer could be life threatening was first and foremost in their minds.

Yes, It Is Breast Cancer

> I knew it was cancer before the biopsy ... I'm sure he knew [surgeon] and I knew. No hopes of it not being. ... and then S [Breast Cancer Visitor] came into the room [after surgery] and she told me that she had had breast cancer and that was the first hope I had. ... up until then I didn't know anything ... everything happened very quickly. I had no connection with anyone with breast cancer before surgery. I wasn't given a connection and that's why I would like to see that done here (DN, 1998).

Initial surgical treatment usually followed quite quickly for women once a definite diagnosis was decided upon. Women in this study had varying degrees of participation in the decisions around the kind of surgery to have, that is, mastectomy or lumpectomy, but all participants were satisfied with the kind of surgery they did have. For the participants who were treated many years ago, there was no choice offered. Some women had access to information -- books, the internet, friends, or a doctor who spent extra time with them and provided them with enough information that they felt comfortable participating in the decision regarding type of surgery to have -- while others relied more heavily on their surgeon's preference.

There were considerable differences in women's actual experience of their time in hospital and their surgery. For most it was an agonizing time. Fear and lack of experience with hospitals, poor nursing or medical care, difficulty with the anesthetic, or postoperative complications were some of the experiences women described. Ellen (ES, 1998) had a particularly difficult time in hospital and in this piece of her written story she recounts her pre-operative experience.

> By now I run through the rest of the narrow hallway. The tall girl in front of me operates her long legs faster than me. She pushes and balances a wheel chair in front of her. I huff and puff by now. Once in a while I reach down to my right foot in a desperate attempt not to lose my foam rubber slipper. I am cold, my legs are bare and the hospital gown nearly covers my nakedness. Now comes the end of the tunnel. That is how I call the connector from one hospital building to another. In two minutes flat she has crossed the connector. Good timing. The government has saved a lot of money. Two patients are handled at once. Great. Now she swings around the corner, one arm she lifts up, the forefinger points to the opening in the wall and I guess that must be the next waiting room. She, by now I had named her Brunhilda, does not stop for a second. Off she runs with the wheelchair to another destination. Out of breath I fall into the next chair. I freeze, I shake. My husband gives me his jacket (ES, 1998).

Ellen goes on to describe her experience of the operating room.

> ... two minutes later I sit in the chair again covered with my husbands jacket. 'I need your glasses please'. A friendly nurse reaches out toward me. Can't I keep

> my glasses on? I am nearly blind without them. 'No, rules and regulations forbid the wearing of glasses'. She is a nurse of consequence. [Walking to the operating room]. This hall is wide. It is filled with fog. My eyes are not able to see the blue lines. A nurse leads me toward the execution chamber. By now my fear has turned into reasoning. They won't shoot me because that is against the law. And they will knock me out to cut off my breasts. That I am sure of. I keep on to reason with myself. I am glad I am here and not in the war zone. There the hands cut off the breasts and then they nailed her to the gate. ... slow I walk, my foam rubber shoes slip again but I do not care. There through my cloudy eyes I see the long table. 'Don't fall, the nurse holds my arm tight. Up the stairs - you go up now. She still holds my arm. Two steps I make out and carefully I make my way up. I am ice cold, stretched out onto the table. I wander back to the war zone. That feels good - they cover me from my waist down with a warm blanket. Through the mist I see the nurses and a man in the background. ... stretch her arms wide out he [doctor] tells the nurses and I freeze (ES, 1998).

The difficulties that Ellen experienced were due to a variety of factors; her previous history in war torn Germany, her incarceration as a child for tuberculosis, the lack of preparation for surgery that she experienced and the haste with which everything occurred. See Appendix V for Ellen's own story of her time in hospital.

Women in this study had been treated as long as twenty-five years ago and as recently as one week prior to the interviews. One of the major changes that has occurred over the past few years is the shortened hospital stays. Women treated even three years ago were in hospital two to five days following mastectomy, and women who had lumpectomies were in hospital at least overnight. With recent health care financial constraints, more women with breast cancer are treated in day care surgery, and even women who have mastectomies are seldom kept overnight. One participant who had a bilateral mastectomy was in hospital only two nights. This means that many women return home with a drain inserted in the incision and are required to care for it themselves. Referrals to Home Care Nursing have been eliminated. Several women in the study experienced serious complications with drains malfunctioning or incisions splitting open and required further treatment.

> I had a drain in there but there was nothing coming out of the bag. On the third or fourth day I was walking from the bedroom to the kitchen and I felt a splotch - the whole kitchen floor was filled with blood and fluid. I called to E [husband] - I've opened up, I've ruptured. I held myself together while E got on the phone. Oh, my god, I haven't been draining - I've exploded. I told E to get a plastic sheet on the bed and to get my nightie off and dress me so I could go to emergency. I had a towel wrapped around me and I was holding it together. I hadn't looked yet - so I did and I was wide open, down to the bone. We had a sterile dressing - it didn't hurt. He should have put mattress sutures in - I have a large breast. At emergency the nurses kept looking and saying - oh my god. The doctor suctioned the blood clots and sutured me closed. I took high doses of antibiotics. I was fine - it was a good thing I had been a nurse. I found out later that the tube had been in the wrong place and hadn't drained. I had been uncomfortable but not really in pain - but of course I didn't know what to expect. Later I phoned [the surgeon] - oh well, he says, that is one of those things that does happen. I'm not really surprised. Said he didn't want to see me (JL, 1998).

Those women who had lumpectomies underwent radiation treatment, but not all had understood that this particular treatment was recommended following lumpectomy surgery. Interestingly, few women in the study knew that radiation could only be given to a part of the body once, so that breast could not be radiated again. Only one participant refused to have radiation following her surgery.

Most participants had their treatment out of the region because it is only recently that these facilities have been available locally. For various reasons, some women chose treatment out of the province. Depending on life circumstances, such as work status, family responsibilities, and other factors, women regarded this time in different ways. For some it was a time out from a busy schedule, a time for themselves, and a chance to interact with others with cancer and learn more about breast cancer. Faith (FP, 1998) had excellent arrangements made for her children at home and used her time away as a vacation. She attended the relaxation groups at the clinic, walked in the beautiful fall weather, and met with friends. She says that the people she met while at the lodge remain close friends, and they still are there for each other when support is needed. For other women this time away was a burden, sometimes financially and sometimes emotionally. Jill (JB, 1998) remembers her time in the lodge as very difficult. She says she tried to make the most of it and did engage with others while there, but the people there with serious illness and those experiencing recurrences really frightened her. A few participants chose the more drastic form of mastectomy surgery because they didn't feel they could be away for the time required for radiation treatment.

All participants experienced some degree of difficulty with radiation treatment. This took different forms but all participants experienced fatigue and skin changes. Interestingly, many women commented on the manner in which they were required to disrobe on entry to the treatment room and then walk over to the table naked. One participant was so uncomfortable with this protocol that she questioned it and was able to have it changed. The radiologists commented that there was no reason -- they had never thought about it before.

> The actual treatment was hard. It was a huge room with a table a long way from the door. You had to strip to the waist at the door and then walk to the table - three young men standing around the table. I had to walk across the room naked - I was so uncomfortable. They were nice once I got there. They strapped me on to the table and I asked - what if there is a fire? They talked about the construction - bullet proof and not to worry. ... the third treatment I told them - I'm really uncomfortable waking across the room.. is there any reason why I can't wear my gown until I get to the table and then take it off? They said - no - so I said then why have you had me strip? We've always done it that way. Nobody has ever told us that. I talked about dignity and I did get that straightened out (JL, 1998).

For all participants the question of whether the lymph nodes were positive or not was a huge concern. The wait for these results was very difficult. Women certainly knew that positive lymph nodes meant that some spread of the cancer had taken place, but they also linked positive results with the need for chemotherapy treatment and that seemed to be the one kind of treatment that women dreaded.

> ...surgery was fine but I was disappointed that he didn't get much in the way of lymph nodes ... he only got one. And that was involved - had cancer in it. So that leaves you in a really - the one he happened to get - was that the only one with cancer in it or was it a whole lot of them that had cancer? We have no way of determining staging he [surgeon] told me. He said they can't tell when they're pulling them out - they're just fatty tissue. But that annoyed me. And it was more than a week before I knew the lymph node was involved. I thought I was only going to have radiation - and no - now you're going to be booked with an oncologist to talk about chemo ... now you're going to do this and now you're going to do this - I mean I'm very lucky that I like to read...(MH, 1998).

The results of lymph node biopsy took varying lengths of time to be communicated to participants. Again the wait was described as very difficult. Differences in women's experiences in the number of lymph nodes the surgeon was able to sample, and therefore the number available for biopsy, were also a source of concern. Some women were told that only one lymph node had been recovered while for other women the number tested ranged from two to nineteen. There was one woman in the study who did not have any lymph nodes removed and she was unclear as to the reason for this.

Participants understood that their lymph node status determined the further course of treatment and whether or not they would likely be referred to an oncologist and the Cancer Clinic. Those with positive lymph nodes went on to have chemotherapy, while those with negative nodes had a variety of experiences. Some were discharged from the surgeon's care and referred back to their family doctor for follow up, while others were referred to the Cancer Clinic for further evaluation. Women with estrogen positive tumors were likely to be put on tamoxifen. For some participants this was seen as a reprieve from chemotherapy and a form of security blanket, while for others the thought of taking a hormone drug was unsettling. There were participants who were uncertain about their estrogen status.

The participants who did have chemotherapy experienced different regimes and had varying degrees of difficulty with the treatments. All experienced hair loss, nausea, vomiting, fatigue, unpleasant mouth sores, and lack of taste and appetite. Interestingly, this was not a vivid topic of conversation. Participants who had received chemotherapy responded to my questions about the experience but did not initiate the conversation about their difficulties, with the exception of brief comments about the fatigue and generally feeling unwell.

One of the major issues for women during this time was the nature and timing of information they were given with regard to dealing with the symptoms and side effects of chemotherapy. Participants who were connected with other women who had experienced chemotherapy were able to gain information and support from them. Many women, however, underwent their chemotherapy before they had had the opportunity to connect with the breast cancer community, and thus were on their own throughout the time of treatment. Naturally the length of time from initial diagnosis to completion of active treatment varied considerably among participants.

Once active treatment finishes, women enter a time of surveillance and vigilance. Again, various protocols are observed, so that some women will report to their oncologists every three months, others will be on a one-year appointment schedule, and still others will be referred back to their family physicians. Differences among doctors and the women's stages of breast cancer determined varying protocols of surveillance. Thus, some women had regular blood tests, mammography, and physical exams, while others had more advanced tests such as bone scans. On the other hand, some participants experienced what they considered inadequate surveillance. The thread holding these various protocols together was the anxiety the women experienced both before and while waiting for examination results, and the concern with which each new or different bodily feeling was encountered. Mary exemplifies some of these dilemmas in her conversation with me about one of her first examinations at the cancer clinic, following completion of her radiation and chemotherapy treatment.

> I complained to her [oncologist] about some pain under my ribs. She said she didn't know why I would have pain and then told me - 'there is nothing wrong

> with you. Your blood tests are coming back fine'. I asked her why had my blood tests been fine before and I had cancer? So blood tests didn't make me feel very good. I was worried about aches and pains and of course they always tell you they come from the chemotherapy and radiation treatment. It takes a long time for them to go away. I had a lot of that and I was very tired. And that's another clue to me - maybe it's coming back. ... but she dismissed me. I asked - when do I come back. You don't need to come back - you're fine - you're over. And she was flippant - that's the word. She knows her job but didn't allay my fears at all (MH, 1998).

Vigilance and Living in Limbo

Women might be discharged from the health care system after active treatment is completed, but their personal sense of vigilance with regard to how their body is feeling and the presence of any new or unusual breast symptoms remains with them forever. Women in this study all spoke about the ongoing fear of recurrence, however long it had been since the original diagnosis of breast cancer. They talked about waiting for the other shoe to drop and the knowledge that they were just as likely as the general population to get cancer again. They also talked about their feelings of vulnerability and fear of an uncertain future.

> When I asked what was the future [at cancer clinic following completion of treatment] - what was the follow-up, he [oncologist] replied - oh well you will be followed - whatever they decide. What other tests can they do to make sure the cancer hasn't come back someplace else? They're not going to do any tests, he replied. I asked him about a bone scan - what would you want a bone scan for? If we find it has come back in your bones there is nothing we can do anyway - so what would you want to know that for? I just looked at him ... and that was the end of the conversation
>
> (MH, 1998).

It is often this period in the journey when women living with breast cancer begin to reevaluate their lives and goals, connect in strong ways with other women with cancer, and try to make sense of all that has occurred for them over the diagnosis and treatment time. Like all phases of this journey with breast cancer, women traverse this time in their own way and with their own individual concerns. It is the time when women often look back on what has gone before and begin to question, search for more information, and deal with the emotions that may have been set aside in the haste and chaos of diagnosis and treatment.

Women say they never feel totally safe from the notion of another cancer or the possibility of death, even if many years might have passed since their original diagnosis. Most acknowledge that, as time passes and their body seems to be more theirs again, the fears ebb and days might go by without their thinking about cancer. For some women in this study the fear is rekindled with a particular symptom or an irregular mammogram and they are thrust back into the system again.

Women in this study constructed their journey of living with breast cancer for me as we talked and as the study progressed. What I have tried to accomplish in this chapter is to portray for the reader that construction as women themselves described it to me. All participants responded to the question, tell me about your breast cancer, by talking about their journey. It seemed to me that this was an integrative and overarching discourse; an attempt to bring together their experience of being diagnosed and treated for breast cancer in their everyday life space and within a health care system where biomedical discourse focused on disease and technical treatment. Women's discourses (Chapter Six) were constructed around the content and process of their personal journey in our contemporary health care system and around their way of being in the journey: their thoughts, feelings, experiences, and struggles. The next chapter looks at participants' discourses and provides the reader with an additional sense of participants' breast cancer stories.

CHAPTER SIX

CONSTRUCTING THE STORY: WOMEN'S DISCOURSES ABOUT LIVING WITH BREAST CANCER

Introduction

In conjunction with the previous chapter, I continue the construction of participants' stories about living with breast cancer. This chapter serves to uncover and illuminate women's voices as they talk about their thoughts, feelings, experiences, actions, and reactions as they traverse their journey with breast cancer. Women's discourses are presented as they emerged through the data; thus the language and words of the study participants frame the discourses that speak to their experience of re-defining life and self, being a patient and in treatment, and living in and through their journey with breast cancer (Tang & Anderson, 1999).

Use of the concept of discourse was a deliberate methodological choice because of the relationship between power/knowledge and discourse. Through an examination of biomedical and women-constructed discourses, one is able to illuminate and name power/knowledge relations. There is no breast cancer in the absence of biomedical discourse, thus women living with breast cancer cannot avoid becoming immersed in it. Biomedical discourse is the only acceptable way to talk about breast cancer in the diagnostic, treatment, and follow-up phases of women's journey. Unlike some other disease processes (chronic fatigue, for example), a range of other possibilities does not exist. Women must learn and navigate the biomedical. Thus women with breast cancer are faced with the necessity to juxtapose their need to learn biomedical discourse with their need to give voice to their own experiences of living with breast cancer. In many cases, participants came in conflict with biomedical discourse in the creation of their own discourses. This chapter foregrounds these processes.

In concert with the study questions that have guided this research, my intent here is to foreground women's own voices and highlight the way in which dominant biomedical discourse claims truth about breast cancer and authority with regard to what the experience is like for women (Tang & Anderson, 1999).

The discourses that emerged from the data, along with the discourse of journeying presented in the last chapter, frame the participants' story of living with breast cancer. These are not individual stories as such, although each woman has her own, but rather a compilation of women's discourses that aims to provide the reader with a sense of the process of incorporating breast cancer into their lives and their sense of self as women.

This chapter begins by discussing Foucault's concept of discourse as it relates to women constructing their own discourses and to the context in which this process of discourse production occurs. The reader is then provided with a construction of participant-centered discourses that emerged through women's stories.

Discourse and the Construction of Participant's Stories About Living With Breast Cancer

Discourses are ways of thinking and speaking about aspects of reality. They consist of a set of common assumptions that provide the basis for constructing reality in particular ways, and so both constrain and enable the construction of knowledge (Cheek, 2000). It is in recognizing that a particular discourse is only one way to view the reality of breast cancer that a space is opened up for other discourses or ways of thinking and speaking about breast cancer. Examining women's own discourses, then, offers us another perspective and can contribute to a many layered and multidimensional understanding about living with breast cancer. Discourses influence how women see themselves and are created in the telling of their experiences, thoughts, and feelings; thus they emerge through the context and reality of women's lives.

Discourses are constructed and the journey is conceptualized by women in a quest for cogency, so that individual women are able to make sense of the disease, the illness experience, the journey, and questions like: Why am I here? What does the future hold? And, Where am I going? Discourses also serve in the quest for cogency regarding such questions as, how do I live with and continue on with this life-threatening illness?

How Women in this Study Constructed Discourses

One of the important ways that discourses about the journey and the creation of a cogent illness story occurs is through contact with the health care system and its biomedical discourse, the society or community in which a woman lives, and the public discourses about breast cancer that are generated within that community. As well, women construct discourses within the framework of their spiritual background, their own life history, age, particular life circumstances, and degree of marginalization or inclusion in their community. One outstanding characteristic of women-centered discourse is the way in which it is constructed through interaction and in relation with others.

Constructing a story about their journey with breast cancer and women-centered discourses didn't seem to be a choice for the participants in this study. Constructing their own discourses seemed to be imperative, albeit in different ways and with different degrees of refinement in the participant's ability to make sense of breast cancer and move forward to incorporating altered reality into their life story. Some participants did talk about wanting others to construct their story for them, but for these women the realization that this wasn't working hit them hard and often served as a sort of impetus for more work on their own behalf. Barb was one participant who commented on her early reliance on 'the professionals' to create her path with breast cancer. She was devastated when she realized that they couldn't or wouldn't be there for her in the way she needed. In her words, "that's when I realized I was on my own and I basically fired them" (BW, 2000).

The work involved for participants in constructing their own discourses must be acknowledged. There is enormous pressure to fall into or conform to biomedical discourse and to make that discourse prominent in the story. Women did this to differing degrees, but the more disparate the dominant discourse was from their own experience, the more rapidly they felt the need to begin work on their own story. Ellen was a prominent example of the need to create her own story of healing. She accepted medical treatment as a first line of assault on her cancer, but she knew also that she must do her own work and that her knowledge of her own body and her knowledge of alternative forms of healing would complement the medical treatment she was getting. Being discouraged from pursuing these other forms of treatment by her doctors did not stop

Ellen, and she created her own discourse of healing and care for herself. Because her work was not accepted by her doctors, she kept her own healing work to herself.

Conceptualizing Women's Discourses About Living With Breast Cancer

In reviewing women's transcripts over the two years of data collection, and more recently in the formal analysis phase of the research process, I have constantly asked myself what discourses do I hear time and time again, how do they relate to each other, and do these discourses capture the data and women's experiences in the way that we, the participants and I, set out to do.

I conceptualized discourses in many different ways as I worked with the data, and I finally settled on the following framework. Remember that, although I present these discourses in a linear fashion and I have ordered them in a particular way, each discourse mingles with others; they do not appear as a first or second order discourse but rather are intermixed throughout all the data for each participant and among participants. They are categorized for clarity but boundaries are not distinct. Remember also that I do not present these discourses as representing truth about breast cancer but as representative of the voices of the participants in this study.

For each discourse I will first describe the parameters of the discourse, that is, what is the discourse is about generally and how the discourse emerged through the voices of participants. Next I will present the elements of the discourse and provide participants' own words to define the shape, similarities, and differences within the discourse. Finally, I will comment on whether or not biomedical discourse seems to problematize women's own discourses and, if so, in what ways. The eight discourses identified from the data are:

1. Struggling to Know and Making Sense of Breast Cancer. The elements of this discourse include resources, need to learn biomedical discourse, hot spots with regard to a more intense need to know, many ways of knowing about breast cancer, and meeting resistance.

2. Acquiescence/Accommodation. The elements of this discourse include the good woman, good patient, willingness to accept expertise of health care providers and accommodation to the system, and, finally, excusing health care providers.

3. Being in Relation: With Self, With Body, With Others. The elements of this discourse include receiving and giving support and relationships with health care professionals.

4. Generating and Sustaining Hope for Self. The elements of this discourse include false hope and generating hope for self.

5. Being In Limbo and Feeling Powerless. The elements of this discourse include the diagnosis and treatment path and potential for recurrence.

6. Being Self Vigilant/ Object of Medical Gaze. The elements of this discourse include pre-diagnostic vigilance, being self vigilant, and being the object of medical gaze.

7. Resistance. The elements of this discourse include cause of breast cancer, excusing rude behavior, and challenging medical practices.

8. Coming Out the Other Side, Constructing Personal Capacity. The elements of this discourse include engaging in self-care, knowledge of past capacity, and how am I different?

Discourse: Struggling to Know and Making Sense of Breast Cancer

Parameters of Discourse

This was a pervasive and strong discourse in the data. All participants expressed the need to make sense of their experience of being diagnosed with and treated for breast cancer. Additionally, all participants talked about the complexities associated with the enormous task of getting the information they felt they needed, and the requirement to immerse themselves in biomedical discourse in some way. Women experienced varying degrees of difficulty with the task of coming to understand and make sense of breast cancer. Moving on in the journey and coming to some sense of coherency about their personal illness story seemed to be more onerous for some participants than others and in some part seemed to be related to difficulties associated with coming to know about breast cancer.

Some women commented directly that "knowledge is power" (MW, 1999) and that "knowing takes away the fear" (LC, 1999), while many other participants said repeatedly that they needed to know everything and that it was wrong to say women don't want to know. For participants in this study a discourse around making sense of breast cancer emerged or gained prominence in the data as soon as there was a suspicion of breast cancer. Interestingly, most women revealed that they knew little or nothing about breast cancer before that.

Elements of the Discourse

Resources

All of the participants in the study had personal resources, that is, an ability to read and absorb material as well as access to libraries and bookstores. The Cancer Society and a provincial Cancer Clinic were also useful resources, but only accessible if participants knew about them and how to access information from them. Women used these resources (and others such as the internet) at different times in their journey.

All participants talked about how valuable other women with breast cancer were to talk with. Many women were lucky to either know someone with breast cancer or to be referred to another woman with breast cancer by their doctor, either as soon as breast cancer was suspected or soon after. Lynette talks about her experience of finding out it was breast cancer and that she would be having surgery within two days (two days from diagnosis to surgery was not the typical experience of women in the study).

> About any information about breast cancer - I had no time and we didn't have the internet then and in fact I hadn't known one person with breast cancer - and on the Saturday night I had to phone a colleague ... because we had a director's meeting and I had been going to call her Friday and tell her I wouldn't be going because of Ottawa and I ended up telling her and she spent an hour and a half on the phone with me. Do you know what a mastectomy looks like and I said no - I haven't got a clue and so she went through it all with me and anything I could think of to ask - I asked and she told me. ... yeh so helpful - it concretized - the doctor didn't explain that I would have an incision, or that some muscle would be gone - so she gave me some really helpful information and I will be forever grateful to her (LM, 1998).

Another participant had a similar experience of having a friend who had been through breast cancer and who reached out to Elizabeth in a strong way

> and so she has given me support. And she would collect books and periodicals and so I had a wonderful supply of reading. And also I think - one of the first times I went to the cancer clinic Dr Susan Love's book was in the library and I took it out
>
> (EC, 1999).

Many participants, however, did not have access to what they called the information they needed until the treatment phase had commenced. A particularly significant factor in when and how well women were able to access information was how accessible health care providers (in particular surgeons) were, and even more important how forthcoming they were with information. Dorothy had chosen a surgeon that she had known through church. He met with her and her husband in the hospital library for over an hour on a Sunday morning -- "telling us exactly what it could be, what the odds were, what he would suggest" (DN, 1998). Dorothy acknowledges that even with this time and attention from her surgeon -- "things were a blur". Many other women acknowledge the difficulty of taking in and retaining information at the beginning of their journeys.

Another participant, Sharon, remembers her surgeon giving her a piece of information that just clicked for her.

> One of the things when I had the surgery was - the surgeon said to me - you know I think we can get it - and that was the first little inkling I had that maybe I wouldn't go with the radiation because it destroys all the tissue it passes through. So that is so important to me - to hear that one clue that makes me feel like well this is the way we do it - because you're not a statistic (SC, 1999).

Other women had different experiences and went in to their diagnostic phase and then surgery with insufficient information. Because this was such a dominant piece of this discourse I discuss it separately.

Need to Learn Biomedical Discourse

All of the women in this study expressed faith and confidence in biomedical knowledge with regard to treatment, and all in some way went to great lengths to make themselves conversant with this discourse. Some participants commented on the disparities in surveillance protocols among health care providers and in reported research results which made constructing a cogent story about living with breast cancer more difficult for them.

Many participants made the link between the need to know biomedical discourse and their ability to ask questions, make informed choices, and participate in their own care. Marjorie (1999) had access to a medical textbook on cancer, which she read cover to cover and, as she put it, " then I was able to speak the same language". Leena (1998) recalls that she "studied everything I could at that point ... I looked through all the most current stuff ... I really did research it because I wanted to find out as much as I could". Mary and Judy are other participants who immersed themselves in biomedical discourse.

> I'm very lucky that I like to read and I've read as much as I possibly could but I am one of those people - I like to know everything. When I was in Vancouver having radiation I asked for all my records. I hadn't seen the path report - I know some people don't want to see those ... and then there are some people like me who need to know every detail --- there were things that were difficult to understand but I looked them up (MH, 1998).I did a lot of reading when I was first diagnosed - the Susan Love book - it's my bible. I just devoured it - cover to cover. And that's no little feat. And a lot of times I scared myself because you try to line yourself up and you say - oh that's what he said I had ... because you're only in his office maybe ten minutes. You know your world crumbles and you've been in that room for ten minutes...(JS, 1999).

Perhaps the most exceptional example of immersing yourself in biomedical discourse is Lynette, who has for the past year been taking extensive course work through a program called Project Lead. This program is a thorough review and update of cancer biology, genetics, and diagnostic and treatment protocols. The latest research is reviewed and critiqued, and common areas of research that have not yet found their way into usual practice are highlighted. While few participants had engaged with biomedical discourse to this extent, most were conversant enough to discuss with their various doctors the particulars of their breast cancer and to understand choices and implications of test results. For many participants, however, this did not occur quickly, and many went through the initial treatment with what they considered inadequate information. Lynette was among this group at the time of her diagnosis and treatment.

Hot Spots With Regard to a More Intense Need to Know

Women are naturally very anxious and fearful with regard to the results of the diagnostic tests that precede a diagnosis of breast cancer. What many participants did not realize is how ambiguous results may be, so that accurate and timely information may be impossible to obtain. Many participants in the study underwent more than one or two mammograms before going on for further evaluation. Judy is one of these women and, while she understood that accurate information isn't always possible immediately, the waiting for definitive results was agonizing.

> I went to the regular screening place and everything was fine and I'll never forget it. ... My doctor phoned me and she said the mammography department phoned me and they want to take another x-ray - they want you to come back in again. it's nothing serious we just found a little something there. ... so I was scared stiff but I went back in. Well we're just going to do the magnification ... so I had that done and of course no-one says anything to you - they're very secretive. Your doctor will talk with you. ... and then they phoned me again - Mrs S could you come back – okay back in - like in an hour...(JS, 1998).

What was also very common related to this discourse of making sense was the lack of preparation participants experienced for many of the tests that followed mammography. Following are some examples of women's voices within this discourse.

> I asked the nurse about the wire insertion. Does it hurt? The nurse said she didn't know. I was really up tight about having the wire stuck in me. ... [down to x-ray] I interviewed him [radiologist]. He told me exactly what he was going to do - showed me the wire told me he would freeze it - didn't think it would hurt. I could see the wire going in he moved it around and I could see the whole thing. I

> was asking questions the whole time. I don't know if he would have explained everything if I hadn't asked and that's the thing. They forget - assume you know - they do it so often. I am a person who wants to know everything (JL, 1998).

> I was okay really until I saw the needle ... I had no idea what to expect. ... it could have been an easier experience if I had known what to expect and what was going to happen (BW, 2000).

> I was given the wrong information and so I was sitting and sitting waiting to be picked up [from x-ray]. I was in the wrong chair but no one told me. When it was discovered I was late for surgery. I was running after the porter in a hospital gown, my slippers falling off, bare legs and ice cold. I don't know why it's like that. They could have told me to wear a warm gown (ES, 1998).

There were many participants in the study who had difficulty recalling this time well, especially with regard to the sequencing of events. For those who did talk about the diagnostic phase, it was apparent that few knew much about what to expect and that this added to their fear and anxiety. In addition to lack of knowledge about tests, many women in the study also experienced a lack of knowledge about the after-effects of their biopsy surgery. Barb comments that she

> was not prepared for what to expect. The scar was not neat, it was bigger than I thought it would be and a funny shape. There was a lot more pain, I couldn't brush my teeth, run or play tennis. I was not at all prepared for the procedure or the aftermath (BW, 2000).

Many Ways of Knowing About Breast Cancer

All women in the study relied on biomedical discourse as their first and foremost source of knowledge, but most also relied on a variety of other ways of knowing about breast cancer. Prominent among these other ways of knowing was a woman's own knowledge about her body and an exploration of the so-called alternative or complementary discourses. Both bodily knowledge and the use of other types of therapy are discussed in other discourses. But what is significant here is the way in which participants blended these other ways of knowing with biomedical discourse, and in most cases did so without the support of the health care professionals involved in their care.

Ellen is a woman who stands out as incredibly knowledgeable about a wide variety of discourses, trusts her bodily knowledge, weighs the effects of the various treatments she designs for herself, and at the same time keeps an eye on the relative cost of a particular treatment and the benefits she obtains. As with most other women in the study, her decision to take on treatments other than those offered by medicine resulted from an immense need to do something for herself.

> I knew I should have the chemo - the naturopath I saw wanted me to refuse but I didn't. I did see the naturopath during the chemo though. He gave me all kinds of things - that wasn't a good thing to do - he didn't explain anything. My stomach really suffered. Some herbs can be devastating - anyway I stopped when I couldn't feel they worked. I wanted to do something on my own. ... then I saw a Chinese doctor in Vancouver. I showed him what I had been given. He sorted - don't take this one, it's hard on your heart - this one is okay. He helped me a lot - got my energy back ... I like to study - self-help, nutrition, herbs - I read a lot. I went to the Health Fair and got some information. Help doesn't come cheap. You have to analyze - everyone is in business. ... I wanted to do more than the chemo - it was such a strong thing to take I thought maybe something would help. He [naturopath] gave me stuff that was so hard on my stomach - I've still got it but I'm not using it. After I found out how hard it was on my stomach - I - no that can't be good for me. It intensifies the pain and discomfort. But Dr C [Chinese Doctor] he was the one who said drink essiac tea - in the book you gave me [I had loaned E a book by Susan Weed]. I bought it [tea] once but the recipe is in there so now I buy the ingredients and make my own tea. But later on I'm doing so well - I say why am I doing all this? I don't think I need all this - and I've got my nettles and dandelion roots. I don't take any dandelions out. I pull the root, wash it and eat it right there. I found in so many books - dandelions are the best to cleanse. ... like with the broccoli - I just have to tell myself it tastes good

> (ES, 1999).

We had many hours of discussion about her reading, alternative health care practices, herb growing endeavors, and a variety of other self care activities that Ellen engages in regularly.

Meeting Resistance

Unfortunately, a significant number of participants met with resistance in their quest for knowledge about breast cancer. This was certainly not always active resistance in the form of, "I don't think you should know that". The resistance was more likely related to inaccessible health care providers, as, for example, was the case for Barb.

> I was booked for the surgery on one of two days in June. As the day got closer and I still hadn't heard anything, I called the doctor's office and then the hospital - no-one could tell me anything. The next day I rode my bike to the office and then called the hospital again. I was going nuts. I had this vision of the cancer cells multiplying - increasing and no-one is doing anything (BW, 2000).

Pam experienced direct refusals in her requests for information. The first time was in relation to a question she had regarding her mammograms.

> So when they found this shadow and discovered a cancer - they said it was at least ten years growing. But how come it never showed up in any of the mammograms before? This was the size of a golf ball. I asked - would you look back and see if anything showed the last couple of years and they wouldn't do that (PM, 1998).

Several participants also experienced their doctor questioning their ability to read and understand biomedical discourse, although there is an inherent contradiction in this stance or belief. Some of the surgeons distributed a book called *The Intelligent Patient's Guide to Breast Cancer*, a book written by several well-known British Columbia oncologists and specialists in breast cancer. It is an excellent translation, if you will, of biomedical discourse about the diagnosis and treatment of breast cancer. Many participants found this book invaluable. On the other hand, women asking for their pathology reports, their full charts, or the results of blood tests were often met with a comment like, "You wouldn't understand that", or "I will take care of all of that for you". This did not deter women from pursuing the information they wanted, but it did make them angry. As Maureen said -

> Some doctors say that most women would not understand that kind of information. Well I don't know why they would say anything like that. Are they presuming that we don't have any brains or that we don't think for ourselves. Well if they were willing to do all that research for me and to pull all that information up for me and sit me down and take an hour or so and explain it to me - I think that would be wonderful. But they can't do that. They don't have the time to do that with every patient. So it's our responsibility to do it for ourselves? And yes - we have brains and we can read. We can understand and I just feel it's a kind of put down to talk to us like that
>
> (MW, 1999).

This is a tremendous area of concern for women, not only because it hampers the getting of the information that they need desperately, but also because comments such as made by several doctors to the women in this study undermined their confidence in themselves at a time when they needed all their personal strength.

Does Biomedical Discourse Seem to Problematize Participants' Discourse of Struggling To Know and Making Sense Of Breast Cancer?

The discourse of needing to know and making sense of breast cancer was a vital one for the women in this study. The quest to know began in earnest with the suspicion of breast cancer and extended with varying degrees of intensity throughout their journey. The tendency of some health care professionals to believe that they knew best both what kind and when information should be given interfered strongly with participants' ability to get on with the work of making sense of breast cancer diagnosis and treatment. Women in this study did not let inaccessibility or reluctance on the part of their health care providers to give information get in the way of finding out what they needed to know. But it did make their task more difficult, and for many in the study it delayed their ability to construct a cogent illness story. For some participants a lack of information early on in their diagnosis and treatment meant that they were dependent on the judgment of their doctor regarding treatment decisions, a situation that they talked about in retrospect as increasing their vulnerability and fear.

All women in this study expressed an urgent and unwavering compulsion to know about their breast cancer. For most women that compulsion was all-inclusive, that is, they wanted to know everything. And when they said everything, they meant the exact type of breast cancer, the number of lymph nodes taken and their status, all options with regard to treatment, what procedures and surgery would entail, the extent of their disease, and the chances for successful treatment. This is clearly more extensive than what is advocated through biomedical discourse and, more particularly, the practices in this community associated with providing information. A dominant message I hear in the medical community is that information should be doled out and that the timing of when information should be given is crucial. These are not messages to be disregarded necessarily, as participants often talked about being unable to hear discussions about their breast cancer at the beginning of their journey and the need to have the information they needed when they needed it. Thus, some women commented that they didn't want information about chemotherapy if they were not going to have that particular treatment. But more significantly, doctors often believe and practice in a way that puts them in an all-encompassing decision making place. When they believe women need the information they will provide it. Participants in this study did not find this satisfactory.

Part of biomedical discourse that defines the doctors as experts means that women are often not given referrals to other women with breast cancer -- even if there are formal and extensive networks of women with breast cancer available and willing to provide such a service. All participants commented time and time again about the value of such contacts. Having knowledge about how to reach other women with breast cancer early in their journey would be amazingly helpful.

A final way that biomedical discourses about making sense problematized women's own discourses is related both to women's ability to decipher and make sense of medical and scientific knowledge and their openness to other ways of knowing about breast cancer. Without exception, the participants in this study engaged with alternative/complementary discourses. Some women incorporated these practices as a routine part of their self-care, while others experimented with only a few and then chose whether or not to continue. It is clear that when we hear women's voices the biomedical is only a part.

Discourse: Acquiescence and Accommodation

Parameters of the Discourse

Acquiescence is defined in the Collins English Dictionary (1985, p. 13) as "complying with or assenting to something without protest", and that definition describes exactly what this discourse is about. Women went along with and accommodated to the health care system and the expertise or opinions of health care providers without protest. A definite part of this discourse is about being the good patient and being the good woman, but without negative feelings attached. Only one participant commented on the idea that it might be risky to speak out. For most, acquiescence seemed like the right thing to do at the time, and certainly the vulnerability felt during the time of diagnosis and early treatment might have played a role.

What is also striking about this discourse is that it seemed to be unacknowledged both by women themselves and certainly by health care providers, and thus may not be seen as a strength. This discourse was more evident early in the participants' journeys with breast cancer and seemed to change over time.

Elements of the Discourse

The Good Woman, Good Patient

Participants did not necessarily use the words "good woman, good patient", but in looking through the data, time and time again this seemed to me to be an important but unspoken discourse, one that is reflected on in retrospect or in relation to other women's experiences.

Maureen provides a compelling account of her first illness experience with cancer. She had been diagnosed with abdominal cancer and "sent home to die". On one occasion she recalled

> I remember an awful time in Vancouver - no before that ... in the summer I think. My bellybutton ruptured and I was spurting fluid out all over the place. We got hold of [surgeon] and we rushed in. He met us at the door of the OR and I was on the table in no time. And he said to W [husband] - when I get in there I'm going to take a good look around because she is not behaving normally with adenocarcinoma [diagnosis made on basis of tests not surgery]. ... so after the surgery ... surgeon says it's a mesothelioma - oh I say is that good news. No he says - actually it's bad news but it is different than what we've been going with all this time. They were talking back and forth - Kelowna and Vancouver - and they decided on a session of really powerful chemo - did you notice I said they decided? So off we trotted to Vancouver and also to consult in Vancouver with a surgeon. So more tests ... but no couldn't do anything more because he thought it was in the liver. So they did heavy duty chemo - put me out cold for a few days - awful, just awful. We went back a month later and the oncologist there said - well do you feel any better? And I said - no actually I don't. He said - I really don't see the point in continuing this - and I said well I sure don't either. So we together decided not to continue the chemo. (MW, 1998).

Mary is another participant who clearly talked about being the good patient and the good woman.

> They had given me the drugs [anti nausea drugs for chemo] but they don't tell you - you can vary the times of them. I followed strictly the rules that they had told me take the first one at eight in the morning. Well I didn't get chemotherapy until nearly noon - the effects of that had worn off. You need to take them much closer to the time. The way the unit was running - you might have a nine am appointment but not get in until eleven or later (MH, 1998).

> [talking about postponing things for herself] Pregnant by the time I finished school - found a job. He was a wonderful man ... we were married for eighteen years ... and it was a struggle for all of that time. He wanted me to be an at home mom which I loved and I did until the oldest was about fifteen and then I started to do part time work. And it came as a total blow when he asked for a divorce.

> The oldest one was graduating and the youngest was in grade nine. He asked for a divorce - he had met someone else and I had known this because we had had two years of him coming and going and not sure who he wanted to be with and it was a real struggle (MH, 1998).

Dorothy had her surgery so quickly that she did not have time to talk with anyone about what to expect. Her surgeon had strong opinions about the kind of surgery she should have and she acquiesced.

> no it was quick - within two weeks I had the surgery. D [surgeon] was adamant about that. ... I guess he felt this had to be done. And within two weeks I had the mastectomy. He advised one...[talking about attending the support group after surgery] D [surgeon] - he felt support groups were important (DN, 1998).

Again, it is important to note that participants acquiesced and accommodated in their roles as women and patients without negative feelings. One of the unspoken pieces of this discourse may be that there are times in illness when accommodation is in the woman's best interest

Willingness to Accept Expertise of Health Care Providers, And Accommodation to the System

This was a strong piece of this discourse and was evident in two ways: accommodating to the system, as Faith illustrates, and the acceptance of the opinions of health care providers.

Faith was able to accept the consequences of hospital overcrowding even though it impacted considerably on her care. She did so with good humor and a recognition of the difficulties health care providers face

> ... care was a little bit not so good because I was in pediatrics - it was an overflow time so I was in an area that was not related to anything to do with me at all. I was in pediatrics with screaming children around the hall and the nurses were quite - uh - they were curious -quite curious because it was this new [procedure] ... and I was in a four bed ward - I had asked for a semi - but ... the nurses were curious - they didn't know what to do with me (FP, 1999).

Many participants in the study talked about accepting the opinions of health care providers, which often resulted in delays in diagnosis. Seldom were participants critical about these delays, at least at the time. In our conversations together we often talked about the frequency with which this happens still, and how better practices might alleviate some of the problems. But this conversation was often long after the time, and women would wonder in retrospect about their compliance.

At least eight participants experienced delays in their diagnosis -- in the case of Ellen it was serious indeed. She had been having regular mammograms and two years prior to her diagnosis was told by the radiologist that they had seen a calcification on the mammogram. Her own doctor told her not to worry about it. When Ellen and her husband moved houses there were different mirrors in the bathroom and she noticed significant changes in one breast. Ellen went for another mammogram and two weeks later had a bilateral mastectomy. The lump was eight centimeters.

Sharon had also been to see her family doctor regularly and had shown her an abnormality in her breast. Her doctor said she would keep an eye on it and she didn't do anything -- "and from what I understand that's a pretty clear indicator" (SC, 1998). Another participant, Elizabeth, also experienced a significant delay in diagnosis. In her case her surgeon had missed the lump totally during the biopsy but had not revealed this to Elizabeth.

> Actually what happened was I was asked to get a mammogram after a physical ... and as a result of the mammogram they took a biopsy and after the biopsy was done everyone was very happy and assured me that there was nothing there. However I kept going for mammograms and every time I would go there would be this advice that I should have this removed ... so they would see the same lump ... and the radiologist would say get it checked and I would say why - it's unchanged. So finally [five years later] I kept getting this recall and I thought well I really should talk with them so I phoned up to where the radiologist was And I spoke to him and told him about my pathologist report. And he said what you don't understand is that when they did that biopsy they missed the lump entirely. And that was the first I had heard of that. So I then proceeded to have

> another biopsy which did come back positive. ... I never confronted the surgeon - I just ran from him to another. But I was feeling very much like there was something very wrong here. And I thought well I'll see what happens and after I had the results of the biopsy of the lymph nodes and there was no involvement I decided well - it hadn't endangered me obviously - although I was at risk - [conversation regarding the financial and emotional costs of pursuing action] ... so I did not follow up on it - although sometimes I think I should follow up because that's not a good way to practice medicine...so I think if the results of the biopsy had been different I might have made a different decision (EC, 1999).

The above discourses are only a few examples of participants' stories regarding acquiescence to medical authority. Some participants also talked about how they still see much more of this than they can believe in their work with recently diagnosed women.

> It's amazing to me the number of young girls that do come in - in their thirties, early forties and of course we always say - how did you find your lump? Oh I had it for years but my doctor told me it was nothing. - you're too young for breast cancer
>
> (JS, 1998).

Many participants, at least in the early stages of their journey, commented on accepting the opinion of the medical staff because "they know best". As Ellen said

> I take everything from medicine - what they offer me. I listen very well if my doctor tells me something what to do and what not to do and also like Dr C [oncologist] - like when she says it's okay for the tamoxifen that is fine with me. ... I believe her and I think I have done the right thing in trusting them [question from interviewer - and you have faith in them] oh yes - yes definitely [and in regards to her surgery] ... I told him you do whatever you think is good for me. I was not making a choice. On my operation he has to find - he knows best how much to take - so I told him you do whatever you think is right (ES, 1999).

Jill talked about her experiences supporting women after their surgery and about how many of the women she sees are of the generation that regarded doctors as omnipotent.

> Most of the women here just accept the doctor they are referred to and then found out afterwards that it has been terrible. I have had a few who have had to go up and have plastic surgery after the mess they were left with here. So I would say that most of the women that I've been around - at the cancer society - are still in the doctor knows best and if they tell me to do something I'm not going to question him. So if a doctor refers to another doctor they will accept that without any questions asked. And I think you don't see that with young people - they would question I think - I hope. (JL, 1999).

Excusing Health care Providers

The last element of this discourse of acquiescence and accommodation relates to participants' willingness to excuse medical mistakes and sometimes rude behavior on the part of health care providers.

Jill recounts her experience of having her incision rupture after she had been home a few days. She had her husband wrap a sterile dressing around it, it was open to the bone, and rush her into emergency.

> At emergency the nurses kept looking and saying - oh my god. The doctor suctioned the blood clots and sutured me closed. I took high doses of antibiotics. I was still fine. It's a good thing I had been a nurse. I found out later the tube had been in the wrong place and hadn't drained. I had been uncomfortable but not in pain but of course I didn't know what to expect. Later I phoned doctor - [surgeon] . Oh well he says that's one of those things that does happen. I'm not really surprised. Said he didn't want to see me. He was very nice - explained things well - a wonderful surgeon and a good bedside manner (JL, 1998).

Several participants had similar experiences of having their incisions rupture, but Leena's experience was particularly revealing of the way women acquiesce and seem willing to forgive rude behavior.

> Got my stitches out Friday and this happened Friday night. ... I got up to make supper and there was this gush of sticky stuff. And when I looked at it, it scared me half to death I phoned right away - got him [surgeon] and that's when he told me - put a sterile bandage on it and it should be fine ... and he hung up before I could say another thing (LC, 1998).

Leena went on to tell me the rest of the story. It was the following Monday morning and I was with her for our first interview. She was waiting for the call from the surgeon. After the Friday-evening call, when she had been told to put a sterile bandage on, she had shown her husband the wound. He was also scared and so they went to the walk-in clinic. The "doctor there said she could see my ribs and she warned me about infection" (LC, 1998). So they went home, changed the bandage twice a day, and then on Sunday night they noticed it had started to get red and so they went into emergency. The doctor there "really didn't want to touch it so he told me to take antibiotics and see my doctor in the morning". Leena goes on to say:

> when he hung up on me Friday night - I was shocked - he's going to hear about it. I'm really scared and he tells me to put a sterile bandage on it! And hangs up so I can't say another thing. I hate to be a troublemaker but I was shocked. I like him as a person but I was shocked. In the first place he told me he was worried because of my having had the radiation [following first experience of breast cancer] - that it might not heal. And when I told him it had split about two and a half inches - that's a pretty fair sized split. And he didn't say anything - just put a bandage on it. Anyway I didn't expect to give you this kind of a story. (LC, 1998).

At this point in the interview the phone rang and Leena was asked to meet the surgeon in emergency. We had our next interview in March of 1999 at which time Leena completed the story.

> It took a long time to heal - like really. It didn't really heal until December23rd and I thought all I want for Christmas is my new left boob. And I made it - it still hurt but it wasn't leaking. In emergency that morning he was very apologetic and when my husband came he was very apologetic to my husband. He said - are you

> speaking to me? My husband was very gracious - he isn't much of a trouble maker (LC, 1999).

Ellen, who talked with me about how visiting her oncologist always made her feel depressed, illustrates a final piece of discourse relevant to acquiescence. When Ellen tried to tell her oncologist the symptoms she was experiencing the oncologist would dismiss her but Ellen would find a way of putting the incident into perspective, often with the help of her family doctor.

> And then I was so angry when she said - I don't want to bother about this - don't want to bother about that. - only wants to know about my cancer parts while my whole body belongs - you know. But then I talked with Doctor - [family doctor] about it and he said - well she is a first class doctor - she is the best and she doesn't have to be nice to you - as long as she is good. Dr [family doctor] has been very good while she [oncologist] was being so negative - but maybe she wasn't - maybe she was using - what do you call it- reverse psychology? When she was telling me I was bad - oh I'm going to show you. I don't take that. maybe she knew what - knew me and how to handle me better than I did (ES, 1999).

Again, this is only a sample of participant's discourses around the idea of acquiescence and accommodation.

Does Biomedical Discourse Seem to Problematize Participants' Discourse of Acquiescence and Accommodation?

Within this discourse, women give voice to their experiences in an attempt to fit in with biomedical discourse and practices. They position these over their own experiences, but do so without rancor or significant negative feelings. Participants seemed to accept the fact that specialists were very busy and did not have time for them.

Discourse: Being in Relation With Self, With Own Body, and With Others

Parameters of Discourse

There are three distinct pieces of the discourse Being in Relation: being in relation with self, being in relation with own body, and, lastly, being in relation with others. Women's voices were extensively oriented to relationships; thus a tremendous amount of data was generated within this discourse.

Elements of the Discourse

Being in Relation With Self

As was evident in the discourse of making sense, participants in this study frequently commented on not being in relation with self, that is, being disconnected from self and focused on others in their lives. In fact, as I discussed in the discourse Making Sense, many participants felt that their breast cancer was in part due to the stress of caring for others to the exclusion of self.

Another aspect of being in relation with self was connected with a woman's ability to express negative feelings. Some were able to do so in certain circumstances but many others were not, at least in the moment, and in particular if the negativity related to health care professionals. Ellen experienced totally inadequate, unsafe and unconcerned nursing care at a time of extreme vulnerability. She was very upset but never did tell anyone at the hospital about it. That one incident was an impetus for her to be in the study, and she recounted the story to me in detail. She also wrote about it and it is a compelling story (Appendix V). She did not express this anger to the nurses but did vent much of it on her husband.

> I would fight - verbal arguments from year's back - what he had done on the farm to me. So much anger and the poor guy had to listen. I had hidden things that were there. I became sensitive - more sensitive but I never cried. I had already cried too much in Germany. The war was harder on me than this - what's the sense of crying?
>
> (ES, 1998)

In contrast, Barb was quite unable to express her feelings, and it heightened the pain of her experience with breast cancer. In commenting on her diagnostic phase she says "through all of this I was a wreck, all inside but a wreck. I was blowing up inside but keeping it there" (BW 2000). A part of most women's experiences with breast cancer is getting in touch with those feelings, which Barb did accomplish as her journey with breast cancer continued.

Being In Relation With Body

This element of women's discourses relates to two primary areas, that of knowing their own body and the effects of treatments and, secondly, the meaning that their breasts have/had for them.

The meaning that women attribute to breast removal, re-construction, and/or prostheses illustrates great differences within women's discourses. However, the way in which participants experienced the effects of treatments was a more cohesive discourse.

For some women in this study having their breast removed was devastating, while for others as soon as they knew it was cancer they wanted their breasts gone. Pam commented that she "thought it was the worst thing in the world that could happen to me. You know, it was just awful" (PM, 1998). Jane was relieved to have a partial mastectomy rather than losing her full breast. She commented, "and the fact that I'm alone and sooner or later I'm going to have to start dating again and I didn't want to have a whole breast gone" (JB, 1998). Faith was another participant who talked openly about missing her breast and remembering how sad she would feel when she saw other women who had not had a mastectomy. In contrast, Dorothy commented that "all I wanted was to get this thing out of me. That was my only feeling" (DN, 1998).

Another aspect of this discourse related to the question of whether or not to have re-constructive surgery. Again, women were very different with regard to their thoughts and feelings about this. For quite a few participants it was the discomfort of the prosthesis that had them exploring re-constructive surgery. They commented that the prosthesis was hot, heavy, painful to wear, and, in some cases, slipped around. Dorothy describes it like this. "It was too hot and heavy, mine was like a can of soup. It hurts your shoulder and neck. And it doesn't feel natural ... your skin doesn't breathe under it" (DN, 1998). On the other hand, several participants were equally vocal about how surprised they were at how natural it was and how it felt like a normal part of their body. Leena says "I'm amazed at how good the prosthesis is. I couldn't believe it - it feels so much like yourself that you almost forget that it's not. It's soft and it takes on your body temperature" (LC, 1999).

Quite a few participants did have breast re-construction, although the nature of the surgery varied from the simpler saline implant to the more complex transflap surgery. All were pleased with the decision and the results. There were also several participants who commented strongly that they would never have re-constructive surgery, often because of the feeling that they did not want any more surgery, did not like hospitals, and couldn't imagine volunteering for any more medical care.

Another portion of this discourse, and again one with many differences among women, is related to the use of tamoxifen. There were clearly two positions held by women on the topic of tamoxifen. They either felt relief that they were offered tamoxifen rather than chemotherapy and they felt secure while on it, or they felt that tamoxifen was a poison and to be avoided at all costs. Several women took themselves off the tamoxifen against their oncologist's wishes. Lynette feels strongly that tamoxifen is over-prescribed and that women are not given full information about the potential effects on their body.

> I think tamoxifen is a poison, a very strong drug that is given out ... like was said to me - if you had been ER positive you would have been put on tamoxifen for the rest of your life. And that would have been it. Like it was really insignificant. None of the incredibly dangerous side effects would have even been outlined. And I have heard individual horror stories about tamoxifen - now the consensus seems to be five years not the rest of you life but ... but well like J [sister] had an incredible blood clot behind her knee - she was in ICU and on all these drugs and then they put her back on and she got another one in her other leg. Other stories about ovarian cancer. I don't think it's a drug to play lightly with and I think physicians need to be much more careful regarding known risk factors, family risk factors. It's become accepted practice like HRT [hormone replacement therapy] (LM, 2000).

Other participants were equally concerned about tamoxifen, but more in relation to how it made them feel.

> ...the tamoxifen was making me feel awful - this was not necessarily the experience of other women but - I was hesitant in the beginning but I took them every day - trying to think - this is good for me. But I was experiencing muscle spasms in bed at night and my blood pressure was blown and I was anxious. I thought in my mind - if I could replace it with something else I believed in - ... and since I've been off it's like I'm back in my own body (SC, 1999).
>
> ... I've had a lot of trouble with the tamoxifen. I had a TIA [transient ischemic attack] in august this year and I asked my doctor - was this from the tamoxifen and she said no - there was no reason for me to have a stroke. I've eaten well. Been active all my life - you know, everything. But I said I want to get off the tamoxifen and they said no. It didn't cause the stroke and you stay on it. I don't feel good taking it and it's likely not doing me much good because I don't like taking it (PM, 1998).

And just as there were differences among women's discourses about the meaning of their breasts, other participants in the study either accepted the tamoxifen as necessary treatment or actively talked about tamoxifen making them feel safe. In some cases women did not want to stop at the recommended five-year period.

> ... and I don't know why but I just had a feeling when they gave me the tamoxifen that I had the right thing (MM, 1998).
>
> Dr - said I could have the tamoxifen if I wanted to even though I really didn't fit the protocol - my tumor was so small. I opted to take it - it would make me feel better 'up here'. I read about it and talked with lots of people about it - got very different opinions (JL, 1998).
>
> I was so relieved to get tamoxifen instead of chemo - the chemo I really didn't want - I've seen such terrible things. So when she said tamoxifen I said - yeh, okay I can do that (LC, 1999).

The effect that treatment had on the bodies of women in this study was a cohesive and significant piece this discourse. The effect that treatment has on women is of course dependent to some degree on the nature and length of the treatment. Participants, even those who had complications, seemed to recover fairly well from surgery, and this was not a source of much body talk. Radiation treatments had effects such as redness, burning, and dryness of the skin, as well as fatigue, which lasted longer than women expected. Many women commented negatively on the experience of being exposed during the radiation treatments, and a few were able to influence practice in this regard. Most however suffered in silence. Mary felt strongly about her experience.

> You don't realize that your radiologist might be a guy - a young guy. It's a bit of a shock especially your first few times when they're marking you. You're on display - you're lying there like this - arm up. There are other people there too. I'm shy and I was embarrassed too but it's hard - you're so exposed. ...it was cold - it's not cruel thoughtlessness - it's just thoughtlessness. They don't know what it feels like. You have to walk in someone's shoes. You have to feel what that feels like - to be exposed. ... you are a person, the breast is your breast (MH, 1998).

> The actual treatment was hard. It was a huge room with a table a long way from the door. You had to strip to the waist at the door and then walk to the table. There would be at least three young men standing around the table. I was so uncomfortable (JL, 1998).

The bodily effects of chemotherapy were the most bothersome and difficult to deal with. For both women who did and did not receive chemotherapy, the loss of their hair was a concern. Judy recalls standing in her kitchen crying and telling her husband how much she didn't want chemotherapy. "I don't want my hair to fall out. You know I was really concerned about it. I don't think I'm vain but I guess I am" (JS, 1998). Women who did have chemotherapy and did experience their hair falling out all commented on that being a very difficult thing. They also had some recommendations like "Get a wig before you actually lose your hair". Mary, who experienced a year of chemotherapy about two years ago and who is undergoing a second regime because of a recurrence of her breast cancer, took the initiative and shaved her head when her hair started to fall out.

> I had bought a wig but yes losing my hair was hard - anyone who says it isn't ... I had very full hair - my hair was always nice. Colored so it was brown - very strong hair. I like long hair so I had lots. So I had it cut short in preparation. But where it starts to come out I think is right in the center of your crown - handfuls started to come out and it was on everything. So when I started to have a circle in my crown - I could see that in the mirror I couldn't stand it - just couldn't stand it. So I pulled everything out - pulled as much as I could out - everything that would come and then I got the razor and shaved it off. Actually it felt good. I spent a couple of hours in the bathroom. I cut it short and then shaved everything off. And that felt good. And I had a turban. I had warned B [partner]. It was what I wanted to do. I had thought it would fall out enough and that would be fine but shaving it was much better. I tried to wear the wig but I didn't like it. I very rarely wore the wig - of course it was summer time. Scarves, turbans, silk hats, baseball caps - I didn't like going outside without something on my head. I think it's offensive - to me it's offensive to other people. I didn't want to be in their face (MH, 1998).

In addition to the loss of their hair, participants also spoke about the debilitating effects of the chemotherapy. Among the more common bodily effects were nausea, vomiting, extreme fatigue, bad tastes, mouth sores, and lack of appetite. All of the participants who had chemotherapy commented on the difficulty of watching it go in to them and knowing it was a poison.

> It was a really funny feeling having chemo go into you. It's a poison and I could feel it going in and I would get so cold. I really got cold in there. You could actually feel this coldness going through your body- it really bothered me. You can't get rid of it and you need it in there and you want it in there - but that was the hardest. I think if I had had to go for another {referring to her last treatment of the first regime) I don't know if I would have been able to do it (MH, 1998).

All participants also talked about lymphedema and, whether they experienced it personally or not, it was a topic of great concern. There were only a few women who did not manifest some degree of swelling, discomfort, or limitation in use of the arm on the side of their breast cancer, and they were greatly relieved to be spared this side effect of breast cancer treatment. Most women took extra care, had followed instructions regarding exercise and rest after surgery, and had, over time, chosen a particular path in order to live with this chronic condition. Some used their arm as usual even though they experienced swelling. Some had tried drainage sleeves, but these were considered quite unsatisfactory because the arm would swell again so quickly.

One participant was experiencing severe long-term side effects of the chemotherapy and radiation treatments that she had had about sixteen years ago. For a long time she believed she had developed asthma, and she had been treated over the years for that condition. During a conversation with a physician at a conference, she was told she was suffering from pulmonary fibrosis, a long-term effect of chemotherapy and radiation. It is incurable, and Lynette has since been forced to go on long-term disability leave from work. She uses oxygen for any extra exertion such as, for example, taking the garbage out. She also experiences chronic shortness of breath and is easily fatigued.

Being In Relation With Others

Although there were several participants who talked with me about how they isolated themselves from others during the course of their diagnosis and treatment, most of the women in the study were in many relationships, and for them this was a crucial component of their ability to go through their journey with breast cancer. I have categorized this segment of the discourse as including relationships related to receiving and giving support and relationships with health care providers. In addition to these lengthy and important pieces, there were other aspects of the discourse that stood out in listening to women's voices.

A universal theme for participants was the issue of who to tell, how to tell, and what to tell about their diagnosis of breast cancer. Most women in the study were very open about their breast cancer and many were talking with others as soon as there was a suspicion. There were others however, who kept their diagnosis to themselves. Elizabeth did not want her mother in law to know because she was a negative person, and Elizabeth felt she would find it hard to remain positive if she was receiving negative messages.

Another difference for women was the kind of family or significant relationships they were in at the time. Some participants had sisters who also had cancer, some were in strong committed relationships and were able to count on those people in their lives, some were in less supportive relationships and in fact experienced a loss of important relationships during their journey with breast cancer. Still others had small children and the question of what and how to tell them was a concern. Lynette recalled thinking about this immediately after diagnosis.

> But we talked about what we would tell the kids and my husband didn't have a clue and I said - you know I think we should use the word cancer and answer what their questions are. If we pussy foot around it's going to get around in the community and I just think we're better off being up front. So when the kids came home we sat them down and said - that mom has this condition - mom has breast cancer but - and I had no information about breast cancer - I didn't know the first thing about it - and I was still in shock. But then I said to them - we'll answer any questions you have and we'll keep you up to date. What do you know about breast cancer? And my daughter said 'everybody dies'. And so we said to her - look there are no guarantees either way but I'm going to do everything I can to make myself better and I'll get whatever treatment I need to get the cancer out of me and I have to have surgery on my breast and I'll probably have follow up treatment. And then we asked B who's five and very bright the question - and he said - mom did you get breast cancer because you breast fed me? And I just pulled him to me and said no - no B - in no way - it wasn't like that but I'm glad you said it. ... but were we glad we had told them because when the kids went to school on Monday other kids said to them - your mom has breast cancer and she is going to die. And my daughter said no she is not. ... it was April first and I showed them the milk carton - where it says cancer can be beaten - silly really
>
> (LM, 1998).

Receiving and Giving Support

The notion of support, both receiving and giving it, was a conspicuous feature in the texts of women's data. Support came primarily from nuclear and extended families, friends, and other women with breast cancer, both informally and in formal support groups. Interestingly, much of the conversation related to this discourse centered around the support offered by friends and other women with breast cancer. Participants did talk about the value of partner support but for several of the women in the study such support was conspicuously absent. In fact, several women talked about the lack of support and acceptance they received from their partners and a resulting deterioration in the relationship. Many participants also talked about the ways in which they tried to carry on normally so that family life would not be disrupted. This was especially true for women whose children were still living at home. There were also several participants who were living alone at the time of diagnosis with no immediate family near by. A story of strong, unconditional and ongoing partner support was rarely told by the participants in this study.

The importance of relationships with good friends however, was a prominent feature of virtually every participant's story, and some women acknowledged that it was this support that sustained them through their journey with breast cancer. What follows is a sample of women's voices confirming the importance of the support of friends.

> One of the things that got me through this was the support of so many people (LM, 1998).

> There was a Christmas party at Jo Rich [local community hall]. I was invited and I really wanted to go. I put a big jacket on and went because I didn't want to be alone I was in shock [day of discharge from hospital following bilateral mastectomy] but being with other people was good. They are good neighbor's and good friends - it was almost like Christmas for me. ... they were just great - my women friends. Women are natural healers - it's so much better to be around women at that time than men (ES, 1998).

> I decided to stay in Kelowna because I would have had to go to Vancouver [for the bone marrow transplant] ... because by that time I needed my friends very desperately ... I had the love of my friends all through - relationships intensified. The friends that helped me the most were my writing friends and they're all Canadians - we don't share a culture but got the same ideas. ... so I'm really happy I have all those people - despair would have been with me without them. ... they would phone me, walk in because we were snowed in, one brought me the dragon. And I told you about my friend who is a native healer and she came and made me laugh - she brought me sweet grass and the shell - and all these things they just carried me (ES, 1999)

All women in the study attested to the usefulness of support groups. Jessica talked about how she was unable to take up the offer of support from other women with breast cancer but felt it would have been useful.

> No I didn't go to a support group and that was stupid on my part. When I went on my initial visit to the Cross one of these ladies came around and talked with me and of course I was in tears and I didn't really want to talk to anybody. I found it really hard at that time to talk to people I didn't know. Then I went home and somebody phoned me to see if I wanted a visitor and I didn't. And that was stupid of me - I would have been better off if I had. It wasn't easy. I just didn't want to talk with anybody I didn't know. So I actually think myself - you know - if they did it when you were a little further into your treatment. It's such a shock, you know, you're going through so much (JD, 1998).

Most other participants involved themselves in one or more support groups. Some of these were designed for women with breast cancer and run by women, while others were run by professionals and volunteers and were for people with different kinds of cancer. Some women talked about the initial difficulty they experienced in getting there and sometimes about how hard it was to be there when other women in the group were experiencing recurrences or symptoms that they were worried about.

> ... she told me about the support group and so I thought well I'll go. I was a little apprehensive ... so I phoned g and she said it was good. so I went down and it

> was a big room full that night. ... and then on that particular night - trust me to pick that night - there were two or three women who had had cancer - well I just found a lump in my other breast, and then the next one - well two or three around the table ... and I'm thinking oh my god - no. All that confidence that I had slowly built up - that I was going to be okay (JS, 1998).

Judy goes on in her conversation with me to comment on how the support groups fill a need that family and friends really can't over the long term. This sentiment was raised by other participants.

> ... anyway I went back the next month. I still needed to talk about it. Your life has just been turned upside down, your security in your health has been shattered and you need to talk about it. But it's like if I bring this up one more time in front of my husband and friends - I feel like they're rolling their eyes. They're not but you feel like it. Get a life, move on - how much can we talk about this? And I really had nothing left to say to them but you want to throw it out again, go over it. It helps. She looks good. She is back doing all the things she ever did - what's your problem? But inside - you're not the same. And that's why I went back because I needed to still talk to these other people. And that really helped a lot - especially the girls who are five, six, ten year survivors - oh yeh - I'm going to be all right (JS, 1998).

> There are many people who don't want to talk about it and it's not just the older generation - definitely they don't want to talk about it. Some of my friends are even that way. But most are pretty good because I was straight they were pretty straight as well. And all of them certainly took it to heart and went and got mammograms ... we didn't talk about it a whole lot. People on the whole don't want to talk about difficult negative things that go through peoples lives - even when you're close. That's where a support group comes in - your friends are good and they will give you moral and emotional support but they don't really want to go into the - you know they might talk about this has changed your sense of self - something that is female - but they're not necessarily going to talk about the medical aspect of it. [comment from interviewer that some women have

> described losing friends] ... yes I can see that. Friends want you to be all right - you do feel a little detached from others at the time and that's where it's so good to find a group - where people have gone through it or are going through it. We call it a not so exclusive club unfortunately cause there is just too many people - but just women sharing similar experiences (FP, 1998).
>
> At times I had trouble going to the support group because I was feeling sorry for myself I guess and so going to the support group meant a real effort. Now I'm strong about going because I know how much they've helped me ... (MH, 1998).

All of the women in this study are actively engaged in giving back or providing support for other women with breast cancer. Two women actually started a support group in their local community and were actively involved over many years. Leena assumed responsibility for initiating a general support group for people with any kind of cancer. Her impetus was the death of her daughter from ovarian cancer. It had been her daughter's wish to begin a group but she had not been able to because of her illness. Leena felt this was something she could do in her daughter's memory. Women who remained active participants in local support groups often took on advocacy roles within the group. For example, several participants are on the breast cancer visitor list which means that they make themselves available for visiting women who have been recently diagnosed with breast cancer.

> ... and then they were looking for volunteers for the visiting program and I thought - oh - that's a way I can help. So I got involved with that and thoroughly enjoyed that. ... in some ways it's almost selfish because I get so much out of it. So it helps me - face it and deal with it and say you're going to be fine and I'm telling myself at the same time. You know it gives and it takes. You want to help them get through the fright - the feeling that you're so alone (JS, 1998).

Other participants provided more informal support by being available for women who wanted to call them, helping friends out if they were suspicious or had received a diagnosis of breast cancer. There are also participants who have developed a definite degree of expertise in biomedical discourse and practices and are available to advocate on behalf of other women in a variety of ways.

Giving and receiving support were powerful discourses among the women in this study. An interesting and sad point made by a fair number of participants related to the wish that they receive more respect from health care professionals for the work that they do on behalf of other women. Many stories were recounted to me about specialist doctors, surgical nurses, and Cancer Society representatives devaluing women's support initiatives In fact, program reductions were on the agenda of the local Cancer Society, and the support programs were to be eliminated until strong opposition prevented this, at least for now!

Relationships With Health Care Professionals

This was an interesting and illuminating discourse and one that illustrated the emotional and instrumental energy that women in this study devoted to attempting to develop positive, meaningful, and useful relationships with the people that were caring for them. Women took responsibility for relationship building and often tried a variety of approaches in order to attain this goal. As one might expect, nurses were not the primary source of this attention. With a few notable exceptions, nurses were not singled out in this discourse to the degree that family doctors, surgeons, and oncologists were. This is likely a result of the way the system functions as much as anything else. However, there were times when women spoke about nursing care and, as with most other discourses, there were significant differences in the experiences that women had. Several participants had particularly negative experiences with nurses. Ellen was left alone in bed the night of bilateral mastectomy surgery. She was without a call bell and she had intravenous equipment attached to both arms. She had not had a nurse in the room for several hours and she had to go to the bathroom. Eventually she got herself out of bed and made her way to the bathroom alone. She called the nursing care a disgrace. This experience has haunted Ellen and was one of her reasons for becoming a participant in this study. Barb also had an experience with a nurse that was less than satisfactory. Barb was kept overnight in hospital because of a severe reaction to the anesthetic. She was in bed with an intravenous (IV) running. "While I was there an instructor came in with a student to remove the IV. While removing it she bounced the tape off my incision" (BW, 2000). This of course caused her a great deal of pain. The instructor said she would bring Barb some pain medication but she never did.

In contrast, some participants described the nursing care as good, but there was virtually no discussion by participants of the nurses in the hospital being particularly helpful in any way.

> The nursing care was good - I was kind of a novelty and I thought - well they don't get many breast cancer women in here. Maybe it's the personal level from the nurses - how did you find your lump? ... they're all thinking in the backs of their minds - there but for the grace of god go I. ... and they were good but basically I don't think they have enough time to you know - even talk with you (JS, 1998).

Other participants talked about the nurses in the chemotherapy unit being helpful and one participant that experienced home care nursing was very positive about her experience.

> Once home care got on the scene things just turned around - like incredibly. Amazing - she [home care nurse] would go to the phone, phone the doctor and say - look M needs this and we need to institute - and it would happen. I went on morphine and my life changed - like night and day - just incredible (MW, 1998).

Relationships with physicians were a topic of great concern to participants. Elements of this discourse relate to resistance, which is discussed as a separate discourse, and to personal agency which is discussed in Chapter Seven. Women experienced very different sorts of relationships with their physicians. In a general sense these were seen as either positive or negative. In some cases relationships deteriorated and women changed doctors. In other cases relationships became more positive as time went on. This happened for Ellen. She describes her initial relationship with the oncologist as very negative. She felt as if her doctor dismissed her concerns, "she only wanted to know about my cancer parts ... told me not to bother her with other symptoms" (ES, 1998).

A woman's relationship with her family doctor is crucial because this person is in many ways the gatekeeper to the system. So if a woman was heard and her bodily knowledge was a respected source of information, she was more likely to get access or referrals to the care she needed. Barb is one participant who experienced significantly negative relationships with her surgeon but was able to count on her family doctor.

> My surgeon came in - said that things had gone well and gave me a lecture about my demand for the cancer marker test and my request for a referral to an oncologist. ... I was expecting the results that week. But the question of our relationship - why he was teeing off on me became a bigger thing to me than the results. I worried and I thought about that all the time. And I wondered if it was my being gay and that not being okay for him. It was all I could think of. ... I did talk with the surgeon - he didn't know we had a problem. I think he likes to have a clear answer and my case wasn't clear. ... so I basically fired my surgeon and oncologist - my own GP was supportive through all of this. I asked him if he would be my team leader and he said yes. I've been thankful for him. Doctor S has been there for me all through (BW, 2000).

Many participants spoke about feeling dismissed by their doctors. In fact, this was a strong theme in women's discourses and the source of much anxiety and anger among the women. For a significant number of participants, having their bodily knowledge dismissed by their doctors led to resistance discourses.

> I think that because I've been through it I have a better understanding than any doctor who hasn't been through it. ... I don't think that a male doctor can have any idea what he is talking about - really chauvinistic I know - but how could he possibly understand? It's out of his understanding - and especially an older doctor. And yet my family doctor is a woman but it bothers me that she doesn't have a specialty in breast cancer. I wish she knew more. ... basically she has dismissed me - it is either her opinion that you do not have cancer any more - cancer has gone out of your body so stop worrying. ... and if I go to her and tell her about this pain here - she dismisses me (MH, 1999)

Mary goes on to talk about how women often discuss their relationships with doctors at the support group meetings. She acknowledges that these are not meant to be doctor-bashing sessions but that women's experiences are sometimes so negative that they must vent.

> I've often thought - if any of the doctors were ever sitting in on the discussion - they would be shocked to hear some of the discussion. ... same names and same issues come up over and over again. That's the shocking thing - how do your rate your doctor - the fact that he only got one lymph node from me. ... he dismissed it totally. He absolutely dismissed it when I brought it up a couple of times (MH, 1999).

Many other women had wonderful stories of support from their doctors and a feeling of working in partnership with them. Several participants felt part of the treatment team from the beginning. They felt well enough informed to participate in making decisions about their care and were encouraged to do so.

> The oncologist that I had in Kelowna was very good but he thought with the strong family history we should immediately go with the mastectomy but he did suggest that I go to the Vancouver Cancer Clinic for a second opinion. Actually more than a second opinion - a group opinion. They put you in a setting where your particular case is studied by a surgeon, an oncologist - I think there were five on the committee. ... I had a meeting with the oncologist and she gave me the results of the meeting ... and then we decided on lumpectomy followed by radiation (FP, 1998).

Other stories were recounted of doctors coming in to sit with women who were very upset, doctors spending extra time talking about treatment protocols, and doctors who were able to make participants feel special. Unfortunately this was far from a universal experience, and for most of the women in this study relationships with doctors were sources of unease.

Does Biomedical Discourse Seem To Problematize the Discourse of Being in Relation?

The consistency of stories about feeling dismissed by doctors when women reported concerns or symptoms indicates either an unawareness of or an unwillingness to legitimize women's own bodily knowledge. This is clearly in conflict with women's own belief that they know their own body the best and that it is their responsibility to monitor bodily changes and to report them.

The importance that participants placed on engaging with health care providers and being in relation so that they felt able to partner in their care seemed to be overlooked by many doctors and a source of much anxiety and anger on the part of the women in this study. Both of these areas served as impetus for overt resistance to biomedical discourse on the part of some women and also the source of critical incidents or impetus to change for some.

Discourse: Generating and Sustaining Hope for Self

Parameters of the Discourse

Women in this study made it clear that fostering and keeping a sense of hope throughout their journey with breast cancer was essential in order for them to construct an illness story that they could live with. They also made it clear that friends, family, or health care providers that robbed them of hope or challenged their hard-won confidence in recovery made their lives very difficult. Given these comments, all participants also acknowledged that they understood the need to strike a balance between realistic scientific data and the more esoteric or elusive concept of hope.

Women in this study seemed to be sensitive to some doctors' difficulty in working positively with patients who may not do well. In fact, some participants made comments about doctors being educated to look for straightforward answers to diseases and being able to cure. When one or the other of these was not possible some participants saw doctors losing interest or withdrawing from the relationship. A fair number of stories were told to me about one particular oncologist who basically washed his hands of any patient who did not respond to treatment. This is perhaps an extreme example of robbing patients of hope, but most women had stories of more subtle examples of the same.

Elements of the Discourse Generating and Sustaining Hope

There are two major elements to this discourse. The first relates to the idea of giving false hope in the diagnostic phase. The second and more complex element is how women generate and maintain hope for themselves. Within this piece of the discourse women shared stories about resources and challenges they faced in keeping hope alive.

False Hope

This was a remarkably pervasive and passionate discourse. Women understood that doctors were attempting to be reassuring when they downplayed the seriousness of a potential diagnosis of breast cancer, but because so few women in this study ever actually expected to get breast cancer, they took the doctor's words of reassurance at face value. Once the scientific evidence was in and distilled and the diagnosis was made, the predominant emotions were shock, disbelief, and a total lack of preparedness.

> She [family doctor] was quite certain that it was nothing ... so when he [surgeon] phoned me ... I was totally shocked ... and I just felt like someone had hit me in the stomach. ... I wasn't expecting to hear this because no-one thought it was anything (JD, 1998).

> But the doctors are so sure that it's not - like they give you this false hope ... hope is important and they don't want you wallowing but ... it's not good (MH, 1998).

> You have nothing to worry about, everything is going to be just fine. It's not going to be a problem. I don't expect to find anything bad [doctor]. And I don't know if that's a good thing to say. So I went in feeling okay - this is just the same as the right one [previous biopsy]. When I was in the recovery room he walked in and said - I don't know how to tell you this but it was cancer. And it's just the coldest feeling ... I went into denial for a long time (JB, 1998)

Generating Hope for Self

The need to generate and maintain hope for recovery was a universal discourse among all women in the study regardless of severity of illness. This piece of the discourse was really about two things: the resources women were able to access in their quest for hope, and the challenges they faced in this work.

Most participants found that meeting with other women with breast cancer who looked well and who had 'survived' was a resource in their search for hope. Survival was a contentious word among the women in the study. They used the term, but many commented on how much they disliked it. However, no one could think of a better word.

> ... when I requested a visitor in the hospital - in comes this lovely lady. And of course you're looking at the nurses in their drab uniforms and the doctors in their baggy green pants - baggy and no make-up. Yeh, they're doing their thing and in comes this gorgeous woman, middle aged, sweet, pleasant and a breast cancer survivor. She brought me this gift package with a temporary prosthesis - something to stick in your bra until the staples are out. And she told me her story - that she had had one breast removed and three years later had cancer in her other one - and had that one removed. This had all happened five years ago and I thought - there is life after breast cancer. She was just so neat. And that did more for me than anyone telling me anything else. To see someone who had been through it and had gotten on with her life and she looked wonderful (JS, 1998).
>
> The bright part in the whole thing was when S [from the visitor program] came into my room. I was really sick - she could see that. But she looked so lovely and so all together and she told me that she had breast cancer and that was the first hope I had (DN, 1998).

As I stated previously, women found the visitor program extremely useful in kindling hope, but quite a few also commented on the need for a good match between visitor and newly diagnosed woman. So participants spoke about the desirability of the visitor having had similar breast cancer surgery and being at a similar place in her life.

Some participants who had children at home at the time of diagnosis were vocal about the relationship between generating hope for themselves and being there long enough to see their children grow up. Lynette had small children at the time of her diagnosis and remembers clearly sixteen years later how their presence in her life mingled with her need to generate hope for herself.

> I used to tell myself - I may not have a lot of time [at this point doctors were being pessimistic]. ... where I want the time most is to see my kids grow up. That was my number one concern. And I hope that happens but in the meantime I've got to make my kids independent and that was always part of it. I realized

> that I had to make them strong and self reliant. That was a conscious thing (LM, 1998).

The absence of positive lymph nodes was universally seen as a sign of hope, as were other biomedical signs such as particular type of breast cancer and clear margins on biopsy. Related to these diagnostic parameters was the reprieve of not having to have chemotherapy and the hopefulness associated with missing this aspect of treatment.

Certainly one participant stands out in her ability to reframe a grim diagnosis and prognosis. Ellen requested her charts and the first sentence she read was "this poor unfortunate woman" [written by her oncologist]. She recalls being terribly upset and thinking "Oh, my gosh, is it really that bad?" (ES, 1998) Ellen talked for well over an hour of the effect this statement had on her at first and then of how she gradually rejected the label "unfortunate" and claimed for herself the label "fortunate". She counted her blessings: she was still alive, she had a beautiful home filled with her paintings and the sun, she was feeling stronger and less depressed as time passed, and she had the love of her friends. It is interesting how well she could articulate the loss and then the regeneration of hope for herself. It is important to note that she did this by herself and in an atmosphere of gloom and pessimistic messages from her oncologist. Indeed, many women in this study performed much of the work of generating hope by themselves, sometimes in the midst of considerable challenges.

The challenges that women faced in generating and maintaining hope had several components, but perhaps the most disturbing is that, by far, the biggest obstacles to this work came from their doctors. Being with other women who were experiencing recurrences could sap hope for a time, as could being told horror stories. Some participants spoke about the tendency of some people to recount stories about someone they knew where things had turned out badly. This was not helpful for women trying to generate hope for themselves. As Judy remembers:

> ... because when you go through it everybody - and they don't mean to do it - but everybody wants to tell you a horror story. My mother's best friend just died of breast cancer - it was terrible, I tried so hard - don't be one of those people you know - be positive (JS, 1998).

Also a woman's own general mood could negatively affect her ability to feel hopeful. Some participants talked about feeling depressed at some point in the journey, sometimes related to reactions from health care providers and sometimes because they had been struggling with feelings of depression for some time.

So in what ways did doctors pose challenges to the generation and maintenance of hope? Women speculated as to the reasons why specialists might communicate hopelessness to them, but the fact that they did was incredibly evident in women's discourses. Because it was such a dominant theme throughout women's discourses I will recount several examples.

> I went to the GP [general practitioner] for some intestinal problems ... I was diagnosed with a growth in my abdomen, they were unable to operate. ... the surgeon told us he couldn't operate and to go home and be prepared to die - a matter of weeks , a matter of months (MW, 1998).
>
> ... felt that most of the doctors I had talked to had made me feel on the wrong side of every stat going. ... How can I make this man support me ... he was so negative. He made me feel like I was going to die anytime or certainly in the next two years
>
> (LM, 1998).
>
> ... they wouldn't let you hope - no doctor would give me hope, no nurse was positive either. You have to have hope - this was one of the worst [things to deal with]. That was why H [local oncologist] was so terrible. ... he as much as said - you're dying, don't bother me (MM, 1999).
>
> ... we were desperate. They weren't doing anything for her. It was interesting to me - Doctor H was good to her as long as she [daughter with ovarian cancer] was responding to the treatment he was giving and as soon as she wasn't he just washed his hands of her and wouldn't see her or anything. Wouldn't see her (LC, 1998).
>
> ... it was pretty discouraging going to the oncologist. Every time I went there I got depressed ... it would take me four weeks to get over it (ES, 1998).

Given these discouraging messages of hopelessness, and in some cases abandonment, how did participants create hope for themselves? There were several ways that participants seemed to overcome these messages of hopelessness. A strategy that many women used was to step out of biomedical discourse and emerge themselves in alternative care philosophies. Maureen, whose first cancer was considered life threatening, explains this strategy well.

> ... but also because there were no choices. I had no decisions to make ... that was very difficult, very difficult. Because even if they had said - you can have surgery, you can have radiation - you know, we will try this. But they said there was no hope - no hope. And it wasn't until I found the group in Vancouver called Hope that I realized that there were things I could do even if it was only meditation. So they didn't offer me hope because they stayed in a medical framework. Even if they had said you could meditate once a day - or if you could have a friend come over and massage your body, or give you therapeutic touch. Anything - anything would have been wonderful. Once there is nothing to be done medically - you're cut off (MW, 1999).

> ... then I heard about a Hope Workshop in Grand Forks of all places one of the home care nurses must have told me about it. We went to it. I laid in the back of the car. ... when people went around the circle and told their stories I couldn't speak, I couldn't say anything. - but I listened to everyone else's stories. It was amazing to find out that other people were going through similar things and what they were doing for it - and it was totally mind boggling to find out that A and J [workshop leaders] had both overcome a death sentence and what they had done and how they were dealing with things and they were still living. They hadn't sort of covered their heads up with the blankets and it sort of opened up a whole new world to me. There were things that a person could do and it might not mean that we wouldn't die but we could live until we did die and not just sort of waiting. I was just so impressed (MW, 1998).

Most of the women in this study have re-framed their views on life in some way.

I seemed to feel a bit stronger - just chugging along. My legs were swollen, tension in my abdomen - I went in every other week and had fluid removed. ... every day I would wake up and think - oh, here I am, another day. One day and one day more. Then I started trying to have little goals - so and so's birthday would be coming up. Our friends were wonderful - they would always invite us to their parties. I always thought I'll just hang on long enough to ---. If I can just be here for ---. Maybe I can even be here for Christmas and it was like a carrot dangling ahead of you and I would write about in my journal. A goal - wouldn't it be wonderful if I could be here for such and such? (MW, 1998).

I feel that it's very important to acknowledge that I have had breast cancer but I also think it's important to acknowledge the fact that many, many other people have had breast cancer and are walking, living, breathing wonderful people that are doing their job and going on with their lives. And I also feel that (MW, 1999).

... and it sometimes scares me when I think that - you know, I might get a recurrence or I might - but I think I'm more interested in the journey or the daily taking care of ... even if I die tomorrow, like the daily is more rewarding than living in anguish. Yes and there are many people - maybe half the people who come through this group [general cancer support group] who are still in that fear mode. ... that's how I was with my divorce and it's just fear ... so I think people don't become strong if they allow the fear to become - so when you go to your doctor and they might fill you full of fear ... doctors can generate fear because they are not open to different ways --- I think that they feel very strongly that they have to put forward the protocol and their view. But I think that they don't very often convey the idea that you might have some control over your recovery (SC, 1999).

Does Biomedical Discourse Seem To Problematize Participants Discourse of Generating and Sustaining Hope?

Biomedical discourse is problematized by participants' voices in this discourse in significant ways. The initial inclination of doctors to down play the possibility of breast cancer before the scientific evidence was in left women totally unprepared for a diagnosis of malignancy. After an initial message of hopefulness, however, women felt messages of at best neutrality and, at the worst, hopelessness. This made the task of creating hope for themselves much more difficult than it needed to be.

Probably the most obvious way women's discourses contradict biomedical is in the way women view the notion of what can be done. Participants got the clear message that once treatment was over, or there was nothing more doctors could do medically, there was nothing more to be done. Participants rejected this belief and undertook the task of finding alternate ways of caring for themselves.

Discourse: Being In Limbo and Feeling Powerless

Parameters of the Discourse

Participants talked about the feeling of being in limbo, and in fact this was their term. There are various stages in the journey when being in limbo is a heightened or more overt discourse. What differentiated women's voices within this discourse was not the content per se but rather the intensity of feelings generated by being in limbo and the level of powerlessness felt by individual women.

Women's experiences of being in limbo are a consequence of many factors. The necessity to see many different health care providers in a variety of settings over the course of diagnosis and treatment, a woman's ability to access health care providers and attain clear information or not, and the perceived seriousness of the disease all impact on women's perceptions of being in limbo.

Elements of the Discourse

There seemed to be two clear elements to this discourse: the notion of being in limbo during the phase of diagnosis and treatment, and the long term acknowledgment that once a woman has breast cancer she lives with the possibility of recurrence for the rest of her life.

Diagnosis and Treatment Path

This piece of the discourse relates both to the uncertainty sometimes encountered in diagnosing breast cancer and to the time of limbo women experience while waiting for test results and a defined treatment path.

> When I came out of the anesthetic the doctor said - you have the strangest kind of cancer cell - wouldn't you know it because you're a nurse. The pathologist is going to send it somewhere else for diagnosis (JL, 1998).

> My own GP [family doctor] called with the news that the results were not clear. This was really scary as I couldn't see a surgeon until July 20th [a month away]. He was on vacation. I was in limbo all that time. ... [my surgeon] was going to have a conference with the clinic and one week later he had still not had it. I didn't have any answers and no reassurance as to why no answers or what I should be doing (BW, 2000).

> He only got one [lymph node] and that one was involved - it had cancer in it. So that leaves you in a really - the one he happened to get - was that the only one with cancer in it or was it a whole lot of them had cancer? We have no way of determining - staging - and then I had to wait again... (MH, 1998).

> And the worst was the waiting - everyone says the worst is the waiting to find out the test results and then once I knew what the course of action was we were okay. But the waiting was definitely tough and everyone I talk with says the same thing
>
> (FP, 1998).

Interestingly, some of the women in the study spoke about feeling anxious when treatment was completed, although in contrast others also spoke about not being sure they could have gone for one more chemotherapy treatment.

> ... on tamoxifen for four years and so have one more year to go and I have to really think about it. It's like a crutch and I'm a little nervous about going off (DN, 1998).

> But after my treatment I found it really interesting - you're staying in the lodge and every day you cross the street and you get on this machine and you feel like it's protecting you - it's big brother. You get your little zap for the day and you've lived another day. And when it came time to go home - instead of being absolutely ecstatic that I was leaving this place - I didn't want to leave because all of a sudden that protection is gone. I'm not getting treatments anymore. What happens now? And a breast cancer patient doesn't even have an aspirin to take. It's just like go home and take care of yourself. Well how did I get this in the first place? What did I do that was wrong that I can change? I don't know what to change and nobody can tell you what to change because nobody knows how it arises. That's the worst part (JB, 1998).

Jane's last comments about going home and taking care of herself after treatment is over leads us well into the last element of this discourse, that of living with a feeling of being in limbo and the potential for recurrence.

Potential for Recurrence

This piece of the discourse was again very pervasive among participants and can be incredibly intense during the beginning phases of the journey. However, the intensity does seem to fade as time passes as long as a woman does not experience another scare. Elizabeth and other participants describe just such a scare.

> I did have another scare - I don't know if I told you about that. I waited quite awhile before I had reconstructve surgery - a reduction on one side and a construction on this one - and it would be - I think about a year ago when they did the mammogram - it's about two years now since I had that surgery. They saw something and they were worried about it. Could be calcium scar tissue but they didn't know so I went back -to the same guy who had done the biopsy before - Mr. hard heart. But when they did the reduction surgery they took tissue out and it must have been about four weeks later I had a call on my answering

machine. - sort of late in the day and it was the plastic surgeon and he asked me to call him back - he would be in his office until 5pm or so. So I took a chance and caught him. And he told me the pathologist report from that tissue ... but he told me I have cancer in this breast and he says you're going to need a mastectomy this time but I will do the reconstruction for you - don't worry. This was over the phone and so - I remember it so well ... well I think I want to talk to doctor KS [Vancouver oncologist] and he sort of rattled on a bit more. I said - this isn't any reflection on you - I want you to understand that but I'm not going to make any decisions until I talk with an oncologist about this. ... and she [oncologist] phoned me back and it was just about exactly 24 hours. And she told me it was all right

(EC, 1999).

They had pronounced me well - no follow up. There is no question about it now that I should have had counseling of some sort ... I should have had more time to reflect - become this new person - grow to catch up with living again. I've always been looking over my shoulder even though they said they got it all I wasn't sure I really believed them. I was just delighted to be alive and have this wonderful miracle happen but always just sort of right there on the back of my shoulder ... (MW, 1998).

I'd like to feel that it's gone but I never - it's always in the back of my mind. There is always the chance of cancer turning up anywhere. I've never disregarded that fact but I've always felt it important to get on with life and not muddle around and fuss about it and worry ... (MW, 1999).

So at times it's hard to grasp that I'm okay - it's gone, it's okay. And I say be happy, be happy but then the doubts come back again. ... and I go from thinking about it every day to having days - there are days I just feel great ... (ES, 1999).

I'm still terrified when I go down to the cancer clinic - even now. ... it's ten years at least before you don't think about cancer every day ... I'm always

> thinking if I've got it and I'm going to die - I've got to clean out those files, get things in order
>
> (MM, 1999).

An aspect of this discourse is how being in limbo negatively affects the construction of a cogent illness story, and yet, paradoxically, learning to live with the uncertainty of recurrence is necessary before this will occur.

Does Biomedical Discourse Seem To Problematize Women's Discourses about Living in Limbo?

Biomedical discourse is quite silent about living with breast cancer after treatment is over, so the emotional and instrumental work that women do in order to find a place of comfort within the reality of being in limbo with regard to their future goes unacknowledged and unappreciated. Inadvertently, family, friends, and health care providers can block this work and make it even more difficult for women.

The next discourse, that of being self-vigilant and being an object of medical gaze, is closely related to the discourse of limbo. For many participants it was being discharged from medical vigilance that surfaced strong feelings about being in limbo.

Discourse: Being Self Vigilant/Object of Medical Gaze

Parameters of the Discourse

This discourse is another example of coherence and cohesiveness among participants' voices. Women felt a responsibility to be self-vigilant, although they often felt frustrated in these efforts, and there was a strong belief among participants that they knew their bodies best. Medical vigilance was universally seen as positive, although differences in surveillance protocols worried women, as did the feeling that doctors were not taking vigilance seriously enough.

Elements of the Discourse

There were two aspects to this discourse that stood out in participants' data: self-vigilance before a diagnosis of breast cancer and the challenges posed by this, and the element of medical vigilance or medical gaze.

Pre-Diagnostic Vigilance

It must be kept in mind that this was a self-selected group of participants and that they shared many characteristics. As a group, however, they were remarkably alike in the regime of self-vigilance each had followed, even though breast cancer was not something they thought they would get. All participants were having mammograms, most regularly, many were performing breast self-examinations, and all were receiving regular care from a family physician. While not necessarily very knowledgeable about breast cancer (their description), they did have a good understanding about general health lifestyle practices and were responsible in this regard.

Being self-vigilant

Again women's voices were consistent here with regard to the necessity for them to monitor their own health, and in fact many participants spoke about this as their responsibility. Part of living in limbo with breast cancer relates strongly to this discourse. Because of the uncertainty regarding spread of the disease and what the future holds, women were always on the lookout for bodily changes and suspicious symptoms. So sore throats, headaches, shoulder or hip aches were cause for concern, as were any changes related to their breasts or underarms. The difficulty they sometimes faced was being taken seriously when they reported these changes. Mary illustrates this difficulty, as do many other participants.

> ...I had pain under my ribs ... and she kept saying there is nothing wrong with you. Your blood tests were coming back fine and so I asked her - did my blood tests show anything before I got the breast cancer and she says no - so okay blood tests didn't make me feel very good. I was worried about aches and pains and of course they always say that comes from radiation and chemo. It takes a long time to get out of your body. And I had a lot of that and I was tired, very tired. And that's another clue to me - maybe it's coming back. ... but it always concerns you when you have a pain you can't - and I've had quite a bit of it. But she dismissed me - I asked - when do I come back? You don't need to come back - you're fine - she was flippant
>
> (MH, 1998).

> [MH is telling the story of a woman in the support group] ... she had been uncertain about some pain in her chest but had put off telling the doctor because she didn't want to be told it was in her head. She later went in with some pain in the breast she had operated on last year and the doctor told her that the pain was because she was examining it too often. That she had bruised herself (MH, 1998).

> I went to the doctor last week with a sore hip - scared myself for a few days and then went to see about it. It's important to be vigilant (BW, 2000).

Medical Vigilance and Surveillance

The variety of surveillance protocols that different health care providers engaged in was a source of discomfort for women. And there were differences even among women with very similar kinds and stages of breast cancer. The cancer clinic and an oncologist followed some participants, while other women were referred back to their family doctors. Oncologists were seen as more knowledgeable about breast cancer, and consequently women felt more secure when this more highly specialized doctor was following them.

None of the women in this study expressed reluctance or dismay at participating in regular six-month or one-year examinations. At the same time that these appointments were anxiety-provoking, they were also reassuring. What did seem to stand out in listening to women's voices was the concern they felt when they did not think the vigilance protocol was thorough enough or when they believed they needed particular tests and these were denied. The experience of Mary exemplifies this issue of women believing that particular tests would be prudent and doctors downplaying the necessity for them.

> My radiologist in Vancouver was nice - he was very direct. He only said one thing to me that irritated me particularly. When I asked - what was the future - what was the follow-up. Okay, I go home after my radiation and then what do I do? Oh well, you will be followed - whatever the oncologist up there decides. What other tests can they do to make sure it hasn't come back someplace else? They're not going to do any tests. I asked about a bone scan - what would you

> want a bone scan for? If we find it has come back in your bones there is nothing we can do anyway - so what would you want to know that for anyway? I just looked at him. You have no idea. That was the end of the conversation (MH, 1998).

> This fear is a natural fear and people want you to ignore it - you're cured. Those are mixed messages. It will be your fault though if you don't report something. ... I guess I just want reassurance - why is that a bad thing? We all want reassurance. It's a frightening situation we've been through. Some go back for mammograms every six months or so - some are told not to come back for a year. ... the different follow-up protocols worry women... any intelligent person who has done any reading at all knows there are things you are meant to be watching for. You would be really stupid not to have it go through your mind - gee - I wonder what that means. I haven't been back to my family doctor ... because I felt dismissed - get on with your life. ... all she needs to do is ask and I could tell her (MH, 1999).

Does Biomedical Discourse Seem to Problematize Women's Own Discourses About Vigilance?

Mary is in the middle of being treated for a recurrence. Her experience illustrates much of the vigilance discourse we have just read about and is not an unusual story. Mary consistently attended regular appointments, reported her health status, and got the results of her blood tests. She had noticed a large and painful swelling under the arm on her surgical side. Her doctor kept telling her it was scar tissue. Her doctors did not hear her and as a result her concerns were not checked out immediately. Consequently, Mary was not diagnosed with her recurrence for well over five months. She is living the fear that every woman with breast cancer has. She knew her body and was responsible in reporting a large and unusual swelling under her arm, but she was unable to convince her doctor to investigate until it had grown to about three times the size.

What is it about biomedical discourse that silences women's voices and experiences to this extent? Women's voices are at great odds here with biomedical discourse but consistent with each other. Women feel that they know their bodies well and they have a right and responsibility to be vigilant and report unusual changes. They also believe that they have a right to be taken seriously with regard to this bodily knowledge. Current practice as illustrated in these participants' discourses would indicate that this is not happening.

Discourse: Resistance

Parameters of Discourse

This is a discourse that emerged clearly through many participants' voices. It was evident most often in the latter stages of treatment, rather than in the earlier phases of diagnosis and treatment. Women engaged in this discourse in direct challenge to biomedical discourse and sometimes in direct challenge to doctors themselves. Nurses were involved in challenging biomedical discourse on behalf of two participants. In one situation, Barb had requested a particular blood test prior to her biopsy at a nurse friend's suggestion. The nurse on duty in the pre-admission clinic made sure she got it and congratulated her on "sticking to her guns" (BW, 2000). The second incident involved a nurse, again in the pre admission clinic, noticing Dorothy's previous severe and dangerous reaction to the anesthetic she had been given. The nurse called the anesthetist to the clinic and made sure that a newer and more expensive anesthetic with fewer after effects was ordered. Dorothy says this about the incident:

> I got a different anesthetic and I was home in the morning. I didn't get it the last three times because it's expensive. And the only reason I got it this time was because of the admitting nurse. She said - I don't like this and I'm not going to admit you unless the anesthetist comes down here and we have a discussion. And from now on I'll fight for it. I fought like crazy for my son but never for myself. And I should have (DN, 1998).

Some participants also challenged public discourse that poses breast cancer as an opportunity. Lynette was particularly vocal on this theme. She had just read an article in a popular magazine.

> It was so contrived and staged and lots of these people had press agents and PR (public relations) people. It was a very superficial presentation. Everyone was so successful with their outcomes and that is not the reality for most women. It didn't present the true facts about breast cancer (LM, 1998).

It is important to note that when participants were discussing these incidents of resistance, they all made a point of describing to me in detail the ways they had tried to get their messages across in a non-confrontational manner.

Elements of the Discourse

There seemed to be three elements to this discourse: resistance regarding the cause of breast cancer, resisting rude behavior and challenging particular practices, and, lastly, changing doctors at some point in their journey with breast cancer.

Cause of Breast Cancer

Even women who did not resist biomedicine in any other way resisted this discourse with regard to the cause of breast cancer. All participants had a great deal to say about this topic. Only one participant knew she had risk factors prior to diagnosis (family history of breast cancer). She and the rest of the women in the study believed firmly that stress in their lives was likely the number one cause of breast cancer. Other participants also spoke about the fact that they did not have any of the so-called risk factors so dominant in both biomedical and public discourse. In fact many women were angered by the risk discourse, and some felt that focusing on personal lifestyle issues was a cop-out and diverted much needed attention away from environmental carcinogens, the overuse of estrogen, and stress that is so much part of women's lives. Here is just a sampling of women's voices on risk discourse.

> My risk factors were so low it was incredible. I mean I was married at seventeen, had my first baby at eighteen. I hadn't started my period until I was thirteen. Nobody in the family had breast cancer (MH, 1998).

> I think the worst thing I went through was the fact that I had always been very health conscious, very proud of my health. I had done a lot of running - for twenty years and very conscious of my diet ... low fat and for me this was the

> way to go. ... and because my body had let me down I felt really cheated - like shit - what are you supposed to do? ... it just makes me furious when you hear the news and you hear them say - you lower your chances of getting breast cancer if you eat a healthy diet, if you exercise ... I just go bull shit. If you're a woman you're at risk for breast cancer ... but it annoys me, it's like a cop out - this is what is causing it so we don't need to investigate anything else - we're doing our job. You women will have to get your act together ... it's like saying it's your fault - that's exactly what it's saying (JS, 1998).

Resisting Rude Behavior and Challenging Practices

Much of the resistance discourse involved challenging practices. Most of the challenges were in relation to health care practices or the way health care providers behaved. Two examples illustrate challenges of another sort, however. Ellen became angry about the lack of parking at the cancer clinic.

> That parking and it's close to the building and it's not for the patients and most of the time it's empty. And I don't understand why they do have an empty area and we patients have to walk so far. I'm going to go to the administrator and ask him that
>
> (ES, 1999).

A fair number of participants do volunteer work for the Cancer Society. There was much discussion around particular policies in the local office and some considerable displeasure with how women volunteers may be treated. Maureen recounts a story of trying to find a meeting place for the group she was starting.

> I phoned the Cancer Society office to see about meeting in their offices. The secretary said - we can't just have anyone using our offices - we can't just have anyone. I said we're not just anyone. We're the reason you have a job and we would like to use some space - it's not used in the evening. It's just sitting there and there is no reason why we can't use it (MW, 1998).

Other examples of resistant women's voices relate to challenging the behavior or practices of medical specialists.

> The hurry in the beginning - you see I really do object to. The one thing I really find fault with the medical aspect of breast cancer is the rush and the hurry. Because if the cancer has been in my body for ten years it's not going to matter if I take two weeks or even a month to take time to research and study and find out what I want to do. And I do object to the fact that they want to rush everybody into treatment - of what they feel is important. I think that is wrong (MW, 1999).

> … I was down in x-ray for the mammogram [for localization of the lump prior to the biopsy] … I was still squished when I heard a voice behind me. I said - do you mind coming around, I can't see you. So he came around to the front. … I interviewed him. He told me exactly what he was going to do. … I was asking questions the whole time. I don't know if he would have explained everything if I hadn't asked and that's the thing - they forget and assume you know (JL, 1998).

> When I was in Vancouver I asked for all my records … and he was annoyed that I had asked for them I guess (MH, 1998).

> I gave him hell, nicely, I thought - about not being prepared [for the surgery] and I questioned him about the how the scar looked, the shape and the lack of sensation. He said it was probably permanent and it was evident that he didn't care (BW, 2000).

> … at this point I decided that these people didn't know what they were doing and it was up to me now so I basically fired my surgeon and my oncologist (BW, 2000).

A fair number of participants managed to change doctors', something that is not easy in this community. This was done for a variety of reasons but most often because of a perceived lack of appropriate care, inappropriate delays in diagnosis, or, in Mary's case, extremely rude behavior on the part of the doctor.

Coming Out the Other Side and Developing Personal Capacity

Parameters of the Discourse

This discourse is related to the manner in which women found a way of living their journey with breast cancer in a way that had meaning for them. It is a discourse that highlights the strengths and capacities of women as they live the journey and illustrates that, although women rely on families, friends, and health care professionals, they must rely primarily on themselves.

It is in this final discourse where you see women reflecting on the journey and their role or part in it and also on the very hard work they engaged in. Most of all it is through this discourse that women come to a sense of how to take care of themselves and redefine themselves in light of having breast cancer. This discourse also illuminates how women learn to live with an uncertain future in a way that has personal meaning and contributes to their ability to construct a cogent illness story.

Elements of the Discourse

There are three elements to this discourse: engaging in self-care, recognizing past capacity and personal strengths, and, lastly, coming to a sense of how they are different now.

Engaging In Self-Care

Participants all engaged in some form of self-care and they identified their particular practices in this manner. Women were very different in the kind of self-care practices they tried, but all evaluated and monitored their body and mind reactions as they attempted new or different things. A fair number of participants involved themselves in formal self-care groups, where they learned skills such as meditation and relaxation, while others explored non-medical practices through reading or talking with other women. The health care providers actually involved in the care of participants were not a source of information or encouragement with regards to self-care. Study participants all spoke about the compelling need to do something for themselves and said that as soon as they embarked on this path they felt better about themselves and more involved in their illness experience.

Most women in the study explored herbs and vitamins, tried a variety of relaxation techniques, and made conscious decisions to find time for themselves. While they were undergoing treatment this was imperative because of the fatigue they experienced. So women talked about stopping an activity if they were tired, finding time for support groups, reading, traveling, and being with special people.

Visualization was a technique utilized by many women. Ellen recounts a rather unusual visualization that she used when receiving chemotherapy.

> I visualized a Chinese dragon. When I was burning up with the chemo I would imagine I was lying on his belly. I would fill him with cold water from the ocean and he would cool me down. Then he would slurp off all the cancer cells. He was a good dragon but I didn't want to tell anyone about him because people think of dragons as bad
>
> (ES, 1998)

Later she tells me about a friend giving her a beautiful dragon and a tape of the song, *Puff the Magic Dragon*, which Ellen would play over and over. Barb also explored a variety of self-care strategies.

> I went to an alternative medicine talk. The presenter had had breast cancer three times before. The presenter and her partner were there big time for me and my partner and that really meant a lot. ... I read Simonton [book] and that was a really useful and important book in my getting well. He talked a lot about stress and the link with cancer. I had experienced a lot of stress in my life. I was able to use meditation to control the pain after surgery..I only took one pain medication and I still use meditation (BW, 2000).

Knowledge of Past Capacity

Participants often talked about things that they had been through in their lives and about how the knowledge that they had managed to survive those times helped their confidence in living with the reality of breast cancer. Mary's husband asked for a divorce and she was forced to return to work in order to support herself. Getting through a divorce was mentioned by several participants as giving them a sense of capacity.

> I had to go out and find work - he would pay child support...but he wouldn't support me. And then what do you do after all those years at home. But I did. I found a job. I wanted to make my own way ... started part time and then it worked into full time ... I worked really hard. I bought my first house by myself and my first car ...
>
> (MH, 1998).

Previous experience with serious illness such as experienced by Maureen gave her a sense of capacity and, as she called it, an edge.

> My first experience of cancer had an impact - that was such a horrendous - not horrendous - such an overwhelming diagnosis and prognosis. And I had a lot of time to grow up and I think the fact that I faced death - looked death in the face - and it was a definite reality. It gave me a perspective when I was diagnosed with breast cancer. It didn't necessarily mean death to me at that time. I wanted it out and removed but it didn't necessarily mean the end of my life. So yes, I think it did give me that edge (MW, 1999).

Although there were some participants who did not talk about past capacities in the way I have illustrated, all women were able to speak about their personal strengths and the ways in which they could rely on themselves.

How Am I Different?

This is an important piece of this discourse as it illuminates the ways in which women create meaning for themselves in living the journey with breast cancer and in creating an illness narrative they can live with, even with the reality of an uncertain future. All participants talked about taking better care of themselves and learning to live in the moment.

Taking better care of self was a dominant piece of this discourse. This involved a variety of self-care practices, as I have already noted, but it also involved putting the self first more often and creating the kind of life a woman wants for herself. Interestingly, for many participants in this study part of the new life was giving back to the community in some way, and for some it was political advocacy work on a national scale.

Barb was one participant who talked about how other women had helped her and the fact that she now felt a great need to give back. She also talked about ending a long-standing relationship once she realized that she might live. "I knew that I wanted some joy in my life". She goes on to say:

> I was with her when she died [alternative therapy presenter and a friend with breast cancer]. She was an angel in my life. Being there when she died was a gift. It was peaceful and a profound experience. I try to do for other's some of what she did for me. Having cancer has been a pivotal thing in my life - not then but as time goes by. It was a tap on the shoulder that I finally heard (BW, 2000).

Other participants also expressed ways in which breast cancer has changed them.

> The way I have sort of come to operate is - sometimes I think people fear that if they hitch their recovery to a certain thing and it doesn't work then they have failed. So they don't hitch it to anything because they are afraid to set themselves up - you know to fail. Any of the things I do - I'm growing and not there by any means - aren't guarantees and I don't use them as that. it's just the way it is and the way I feel now and I feel that I'm moving along in my understanding. And if I die tomorrow and I'm scared to get a recurrence for me but what choice have I got? You just have to move on daily. I mean you don't have any assurances. You can't live as if you're dying
>
> (SC, 1999).

> I'm thinking that maybe my breast cancer was a wake up call for me to be paying attention to something about myself and my body, but more my inner self that the body - so I think I'm trying to pay more attention tome and how I react to things and what I do with my feelings. ... I was always thinking about other people all the time. It's a very difficult thing to learn (MW, 1999).

Does Biomedical Discourse Seem to Problematize Women's Discourse on Developing Personal Capacity?

Women's work regarding their own-self-care and the personal strengths and capacities that women bring to the experience of living with breast cancer go unnoticed and unacknowledged by biomedical discourse and practice. Thus women's health care providers are unable to work with women in strengthening their sense of personal capacity.

Conclusion

This chapter has illuminated women's discourses about their experiences of living with breast cancer and, along with Chapter Five, contributes to the creation of participants' illness stories. Women's discourses were constructed in a way that highlights the complexity of women's work in making sense of breast cancer and navigating within and among the discourses that frame the breast cancer experience. Explicating the discourses of the participants in this study has illustrated the ways in which they were able or not able to make their voices heard.

CHAPTER SEVEN

REFLECTING ON WOMEN'S ILLNESS STORIES WITH A FEMINIST POSTMODERN LENS

Introduction

In the previous two chapters I constructed a composite illness story about living with breast cancer derived from the participants in this study. I have illustrated the infinite possibilities for difference and similarity among participants within the story of their journeys and discourses about living with breast cancer.

Participants' voices in the construction of their breast cancer stories have of necessity been filtered through my own voice. I have made choices about the criteria for participant selection, the manner in which a composite women generated story was constructed, which voices to include and exclude in particular pieces of the construction, and which accounts would be privileged over others.

I am also embedded in the discourses I write about, and a partner in the research process. Women's accounts of their experiences are historically situated, context dependent, and open to change, as is my present discourse. I have attempted to be reflexive throughout the writing and to present myself as located in particular ways, so that the reader can interpret my writing with some sense of knowing my beliefs and values about research with women, and how I situate myself in the world (Hertz, 1997). Additionally, participants had the opportunity to reflect on and participate in individual and group dialogue around the particular way I have constructed their breast cancer stories. That conversation is included in Chapter Eight.

In this chapter I present my personal discourse about what I have learned as we (the participants and myself) reflected on and spoke about their experiences of living with breast cancer. Consistent with postmodern theory, this analysis represents a provisional, contextually derived, and partial account of the data, and is not intended to represent absolute truth about living with breast cancer but, rather, one outlook or way of viewing these experiences.

The reader may have noted that women's stories are relatively silent about nurses and nursing care. This was evident to me throughout the process of doing the research, and certainly in the analysis phase. Two participants had strong words about the negative nature of the nursing care they received. Others, however, commented only peripherally about the chemo nurses being great or the nurses not seeming to know much. Thus, nurses and nursing work were almost invisible in participants' stories. I will return to this issue in Chapter Eight.

I began this research with the aim of exploring the construction of the breast cancer experience with the seventeen participants in the study. I wanted to uncover and illuminate the ways in which women interpret biomedical discourse and position themselves within biomedical and other discourses. This analysis has been partially developed in Chapters Five and Six. I also wanted to understand how women's own discourses, sense of agency, power, and identity are impacted as they traverse their personal journeys with breast cancer, the topic for this chapter.

In the previous chapter I constructed women-centered discourses around living with breast cancer, and illuminated some of the ways in which women's discourses differed from biomedical discourse and from each other. In this chapter I examine the effects that biomedical discourse has on health care practices, on health care provider interactions and relationships, and on women's illness experiences.

In a further effort to locate myself theoretically, I will begin this chapter with a discussion of my current understanding of feminist postmodern thought. I return to a discussion of discourse, discursive practices, and Foucault's concepts of power/knowledge, as they relate to a feminist postmodern analysis of the data generated in this research. I will then theorize about women positioning themselves and being positioned through discourse, women's resistance to particular discourses, and the development of personal agency.

Current Understandings about Feminist Postmodern Thought

As one would imagine, my own understandings of postmodernism have shifted, altered, and come in and out of focus with some regularity. While acknowledging the difficulty of ever gaining a clear, lucid, and unchanged sense of postmodern theory

(Kvale, 1995; Giroux, 1991), I nevertheless have chosen to theorize about the illness stories constructed with the voices of participants using a postmodern lens.

Allen and Hardin (1998) explain how a postmodern analysis of discourse enables a shifting of focus from the experience of individual women to an examination of the social and institutional discourses that position women in particular ways. This perspective marks the difference between a hermeneutic notion of themes and the postmodern notion of discourse. Allen and Hardin (1998) go on to note that by exploring beyond a woman's individual experience we can also gain an understanding of the ways in which particular discourses become institutionalized and reified within a certain social historical context, and how women may be positioned by these discourses without being aware of the constructed nature of them. Thus, specific subject positions may become routine and automatic. An examination of the effect of biomedical discourse on the positioning of women with breast cancer makes a place for illuminating women's agency, or their ability to take up, reject, or reconstruct particular subject positions that are more compatible with the discourses they create as they live their breast cancer story.

As I discussed in earlier chapters of the dissertation, I have felt a personal paradigmatic fit with feminist postmodern thought, and believe that this lens affords me the opportunity of exploring the questions I set out at the beginning of the research. Like Cheek (1998), I believe that one must be open about the fact that theoretical perspectives are never neutral. When a researcher chooses a certain lens with which to frame the research, particular questions can be asked and others are excluded. Additionally, the theory chosen actively shapes and constructs the analysis, and defines the parameters of the ensuing discussion. Thus, postmodernism as a lens renders the analysis of the data from this research in specific ways (Cheek, 1998).

What is Postmodernism?

In its most general sense, postmodernism is a theoretical position that rejects the notion of a single truth in favor of many truths or ways of viewing phenomena. Agger paraphrases Lyotard in saying that "one cannot tell large stories about the world but only small stories from the heterogeneous subject positions of individuals and plural social groups." (Agger, 1991, p 116) Previous chapters have told some of these small stories, constructed from the words of a heterogeneous group of seventeen women who participated in this research.

Postmodernism asserts that knowledge is constructed in, and contextualized by, social historical factors. Thus, the idea that it is possible to represent a singular reality, speak for others, or attain universal understandings is challenged by postmodern thought (Cheek, 1998, 2000). Multiple voices, truths, and views about reality are recognized. Best and Kellner (1991, p. 4) offer a clear definition of postmodernism as a theoretical understanding that rejects "modern assumptions of social coherence and notions of causality, in favor of multiplicity, plurality, fragmentation and indeterminacy".

In the area of health care and, in this case, women living with the disease and illness of breast cancer, postmodern theory offers an opportunity to problematize or question taken-for-granted health care practices, and the belief that health care providers are the experts on women's bodies (Tang & Anderson, 1999; Cheek, 2000; Cheek & Porter, 1997). In fact, women's discourses clearly challenge the idea that doctors are the experts about their bodies. Within their discourses, women position themselves as being their own bodily experts and as having relevant knowledge about their health care needs.

Postmodernism also explores the relationships among discourse, discursive practices, regimes of truth, power/knowledge, and positioning, thus facilitating an examination of the link between these concepts and their articulation through institutions and bureaucracies. (Cheek & Rudge, 1994; Allen & Hardin, 1998). In illuminating the invisible and taken-for-granted aspects of discourse and practice, a way may be opened for other possibilities and action.

Foucault: Discourse and Discursive Practices

Foucault (1980) challenges the enlightenment idea that knowledge is value-free, objective, and progressively developed through rigorous science. Rather, he argues that knowledge is inevitably linked to power, and he explores the "power/knowledge link through the concept of discourse" (Cheek, 2000, p. 22). Discourses are produced with particular interests in mind, and with regard to certain rules and norms. Language, the vehicle of discourse, does not mirror reality; rather, we "enact our roles and relationships in language" (Allen & Hardin, 1998, p. 4). The language of medicine may position women with breast cancer as dependent and grateful for medical care, but, as we saw in our examination of women's discourses, this position can be re-framed, and women can and do position themselves in many different discourses.

Postmodernism asserts that there is no fixed natural meaning or truth; rather, there are many competing discourses that make truth claims. Some discourses are privileged over others, and thus are seen to carry greater authority. Biomedical discourse has an established institutional base in our society, and there are differential knowledge/power relations inherent in institutions such as medicine and in places of work such as hospitals and clinics. Thus medicine as a profession, with doctors as practitioners of medicine and holders of medical knowledge, has assumed dominance over other types of knowledge. If we accept this view, the discourse of medicine may be considered an example of Foucault's (1980) notion of regimes of truth. A regime of truth attains the status of the only truth; all other ways of knowing are measured, in some way, against this discourse. Holders or owners of this particular form of knowledge have power to include or exclude other knowledge. Manias & Street, utilizing the work of McLaren (1994), say it this way:

> Hence, regimes of truth cannot be understood in absolute terms that exist outside the knowledge and power relations of discourses but, rather, they must be understood in relational terms. Therefore, a particular view of truth depends on the history, cultural context and power relations that operate in society (Manias & Street 2000, p. 53).

Various discourses, then, offer a particular way of looking at the world, and may compete with other discourses for status and power. An analysis of different discourses allows an examination of the way medicine, for example, creates knowledge, thereby constituting and sustaining biomedical discourse. A postmodern perspective allows an analysis of the links between knowledge, power, and resultant discourses and helps us see the ways in which these are inextricably linked (Cheek & Rudge, 1994; Weedon, 1999; 1987). McLaren ties these ideas together well and is worth quoting.

> Since discourses which work through language lead to social and institutional practices, a knowledge of the discourses that inform our subjectivities can lead to the construction of new forms of subjectivities, social relations and

> institutional arrangements more hospitable to equality and social justice (McLaren. 1988, p. 6).

An examination of women's discourses and their positioning within and among other discourses can enhance our understandings about the different ways that biomedical discourse can position women and the different ways that health care professionals can position themselves within the discourse.

Power/Knowledge

The dominance of biomedical discourse in the health care field is linked clearly with Foucault's (1977) conception of power. This view of power differs from a traditional view, which regards power as a possession that one either has or does not have. In the traditional view, then, power can be seen as repressive and flowing from the top down. Foucault's perspective on power as capillary and existing everywhere shifts the emphasis from, who has the power to the question of the effects of power in certain situations. So the questions for me became: How are women with breast cancer affected by power relations, and what subject positions are available within existing discourses? Which subject positions might be seen as enabling and which might be seen as disabling from a woman's perspective? How do women with breast cancer reclaim power through their own discourses? If power is exercised and not possessed, then is there opportunity for resistance? (Cheek, 1998; 2000; Manias & Street, 2000; Tang & Anderson, 1999; Davies & Harre, 1990; Weedon, 1999; Allen & Hardin, 1998)

Additionally, Foucault saw power as not merely repressive but also as productive. Knowledge is a vital product of power, so what is deemed truth about breast cancer confers power. Using the work of Elizabeth Grosz (1994), Manias and Street explain the power/knowledge nexus in this way:

> the subject positions created within discourses govern and constitute individuals in particular ways depending on how these discourses disrupt and challenge power relations. In Foucault's (1977) analyses, power and knowledge are intimately connected and expressed as one: power/knowledge. Thus, for Foucault, knowledge is an important technique of power. Knowledge reinforces

> and supports existing regimes of truth. In addition, power generates and shifts with changes in knowledge (Manias and Street, 2000, p. 53).

Illuminating women's own discourses and knowledge about breast cancer generates a shift in knowledge and therefore confers power in different ways. So women working with other women and exposing the knowledge about breast cancer embedded in their discourses is a way of challenging the dominant power relations of biomedicine.

Biomedical discourse has an established institutional base in medicine and, in this social-historical time, the power to define truth about health and illness. Biomedical discourse also determines which subject positions are acceptable and which are not. Exploring dominant regimes of truth has the potential for opening up space for new discourses and subject positions and may expose the manner in which a discourse attains dominance and authority with regard to best practices in providing health care (Manias & Street, 2000).

Cheek (1998) explains how the relationship between discourses and power/knowledge has effectively given biomedical discourse the claim to truth status, which has had the effect of eliminating other discourses or forms of knowledge from health care. Cheek comments that the knowledge claimed by subaltern groups such as women is especially dismissed and deemed non-objective, unreliable, and of little importance. This positioning of women by biomedical discourse was especially evident in participant's discourses of bodily knowledge. If women-centered discourses were to gain recognition as a valued way of knowing about breast cancer, then this knowledge could be a productive source of power.

In addition to the concepts discussed above, Foucault explicates the idea of how a dominant discourse such as medicine institutionalizes surveillance and disciplinary strategies. In *The Birth of the Clinic* (1973), Foucault explores and illuminates concepts such as the gaze, examination, surveillance, and disciplinary regimes. He uses the metaphor of the panopticon to explain how society has conferred power to particular groups of experts to control and discipline other individuals in society and to define what is normal. The panopticon refers to a particular type of prison arrangement whereby all the cells faced inwards towards the center of a circle, with a guard tower in the center.

Thus, all the prisoners could be seen by the guard and by other prisoners at any time. Never knowing whether you were being scrutinized or not resulted in self-scrutiny and passive docility on the part of the prisoners and guards, who were themselves open to scrutiny by the prisoners and other guards. The metaphor of the panopticon also implies that relations were centered between guard and individual prisoner, rather than between prisoners. This idea has an interesting parallel with the manner in which some doctors' position themselves as central in their relationship with women and attempt to minimize their patient's contact with other women living with breast cancer.

Foucault relates this notion of the panopticon to health care practices such as the examination, which entail a ritualized and highly structured use of power where individuals are diagnosed, categorized, and subjected to particular forms of surveillance and treatment (Cheek & Rudge, 1994). A discursive postmodern lens enables me to illuminate the ways in which the examination, categorization, and surveillance carried out by medicine position women within diagnostic categories that may have a significant impact on their subsequent experiences. Recall the experience of Lynette. She was told at the time of her surgery that she was a "stage one breast cancer" (LM, 1998). The hospital lost her tissue sample and so estrogen receptor status could not be determined. As a result, her doctors recommended treatment with chemotherapy and radiation. Somewhere along the way in her journey, her oncologist categorized her a stage three and she was scrutinized as a more serious case. It was not until several years later, when Lynette was considering re-constructive surgery and her doctor recommended against it, that Lynette discovered the mistake that had been made. The doctors remained reluctant to alter the staging even though her lymph nodes were negative and the lump had been small.

This discussion has fore-grounded aspects of postmodernism and Foucault's work that will be useful in looking at the different discourses that compete for meaning in the care of women with breast cancer. This discussion should not, however, be read as minimizing the value and importance of biomedical discourse, but rather as a look at the enabling potential for various discourses and the power relations inherent in different discourses. A postmodern analysis offers the possibility of new and different discourses being accessible and makes a space for a plurality of voices and subject positions to be available (Cheek, 2000).

Positioning Through Discourse

In this section of the chapter, I move from a general theoretical discussion of the intricacies of discourse, power/knowledge, and the construction of subject positions to a more explicit conversation about positioning and being positioned within biomedical discourse for the participants in this study.

Allen and Hardin (1998) state that a postmodern lens encourages the researcher to analyze the discourses available and then to ask how subject positions are produced, resisted, and negotiated within the available discourses. They note that women can be positioned and also position themselves. However, because of the taken-for-granted status and power of medicine, for example, there might be differing levels of awareness for women regarding these ideas of positioning oneself and being positioned. Davies & Harre explain how a subject position is made available within discourse.

> Positioning ... is the discursive process whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced story lines. There can be interactive positioning in which what one person says positions another. And there can be reflexive positioning in which one positions oneself
>
> (Davies & Harre, 1998, p. 48).

They go on to note that the concepts of subject positions and positioning open a place for a thinking, choosing subject; we are able to locate ourselves in the positions we choose, and resist those that do not fit for us in some way at a specific time in our illness experience. As Allen and Hardin explain so well, the key factor to highlight about the concept of positioning is its relationship to agency.

> The relationship of individual agency to institutions, power relations and discourse is a key concern in justice oriented inquiry. ... We explore how individual 'agency', and discursively created 'subject positions' intersect, challenging a tendency to theorize individuals as either the inception of their

> experiences [thus having complete agency and 'free will' to act], or conversely, being discursive marionettes. Discourse analysis allows us to ask different questions that provide different understandings about how we both act as 'agents' and are simultaneously positioned as 'subjects' within discursive systems. The notion of 'subject positions' allows us to view 'persons' as being produced by institutions, yet concomitantly understand that subject positions are not static. We have the ability to reposition ourselves and act as agents who are continually reshaping our worlds not by stepping outside of them but maneuvering within and among discursive possibilities (Allen & Hardin, 1998, p. 10).

This is an important quote because it highlights the relationship between positioning and agency. Participants in this study were not only positioned in certain ways, they also expressed agency in resisting certain positions and constructing different positions for themselves. Participants' discourses also revealed some of the ways doctors were able to reposition themselves in relation with women.

Within society at any given time there are particular subject positions that are sanctioned. For example, being positioned in society as a pregnant woman brings with it clear understandings on the part of both men and women of the range of activities and behavior that are acceptable. Activities such as smoking and alcohol use would be unacceptable within this subject position while, in contrast to earlier times, vigorous exercise may be a sanctioned activity within contemporary public and biomedical discourse.

Similarly, for women living with breast cancer there are particular subject positions sanctioned by institutionalized medicine and biomedical discourse. The most discursively sanctioned subject position within biomedical discourse is that of patient-hood.

Medicalization and Being Positioned as Patient

Medicalization

Morgan asserts that in order to understand women's health experiences in today's society it is necessary to "understand the highly complex and dynamic sociopolitical structure of contemporary biomedical medicalization" (Morgan, 1998,p. 84). She constructs a theoretical model depicting the layers, complexity, and interdependency of medicalization in an attempt to illustrate the ways in which

> Women's agency, women's health care practices, and women's political struggles around health care can be seen as a serious political drama involving contesting authoritative knowledge-seekers and providers. It is a drama in which medial authorities often believe that they alone are entitled to manage women's bodies, hearts, and minds and to prioritize women's health needs. It is also a drama in which some women, individually and collectively, contest that entitlement and struggle politically against the de-valuing, the trivializing, the intimidating, and the silencing of women's voices, women's concerns, and women's health knowledge. Involving highly diverse modes of resistance, it is a drama of contestation over medicalization, over competing discourses, alternative paradigms and diverging understandings
>
> (Morgan, 1998, p. 84).

These may seem like strong words, but I believe that it is only by examining medicalization in all its complexity that we can understand the power/knowledge relations inherent in discourse and particular subject positions.

Morgan's (1998) model of medicalization was constructed in response to a feminist critique of the increasing intrusion of medicine into ever-new aspects of women's lives. The medicalization of menopause and childbirth would be contemporary examples. I am not suggesting that the disease of breast cancer is not a legitimate concern for medicine. I am, however, suggesting that illuminating and examining the concept of medicalization will, in turn, elucidate the positioning of women as patients and the possible consequences of such positioning on a woman's sense of agency.

There are four dialectically related components of Morgan's medicalization model that relate well to a postmodern analysis. The first component is that of conceptualization. Medical knowledge is conceptualized as the authoritative and only reliable and scientific form of knowledge about, for example, breast cancer. New knowledge in this paradigm is deemed truth if researched in the scientific tradition and found to be verifiable by carefully chosen peer review processes. Competing discourses are deemed non-scientific and therefore not valid.

The second component of Morgan's model describes the macro institutionalization of medicalization. Macro institutionalization refers to the interlocking social, economic, professional, and political forms of control and power that keep one paradigm or view of the world dominant. Thus, research priorities, what counts as medical knowledge, what technology gets priority development funds, and who is considered part of the speaking community are controlled by these interlocking systems and institutions. Medicine as a profession develops a virtual monopoly over medical knowledge and a role-structured dominance over other forms of knowledge. This is enacted through doctor-patient interactions in hospitals, offices, and cancer clinics.

Morgan (1998), along with many other feminist writers such as Lupton (1994; 1995) and Coney (1994), makes the interesting point that medicalization has become so powerful that as a society many of us have moved to a " culturally shared perception of the human body as a feared site of virtual pathology" (Morgan, 1998, p. 90). Women have been particularly vulnerable with regard to this aspect of medicalization and the taking-on of various forms of medical control in the name of prevention and risk management. Increased use of mammography at younger and younger ages, the use of a potent drug such as tamoxifen in healthy women, and the increasing incidence of bilateral prophylactic mastectomy surgeries are examples of the power of breast cancer risk discourse institutionalized through medicalization.

The third component of Morgan's medicalization model describes micro institutionalization through doctor patient relationships. As Morgan explains, our culture sees the doctor as the benevolent holder of expert knowledge, and the doctor-patient relationship as a site of expert provision of care for the individual. Morgan asserts, however, that it is important to acknowledge that doctor-patient relations are constructed with strong hierarchical positions. Such relationships can be sites of oppression or empowerment. The institutionalized power of the doctor to make decisions around what diagnostic technology will be made available to which patients under which circumstances is only one example of how the relationship can be constructed as oppressive or empowering. In this study there were clear examples of both kinds of relationships.

The fourth and final component of Morgan's medicalization model describes micro institutionalization through self-management. As Frankel (1983) warned us, once constituted as patient with the mutual acknowledgment of the doctor as expert, women move into legitimate range as object of medical gaze and surveillance. This discourse is most effectively produced and reproduced when internalized by women, who then actively seek out medicalization (Morgan, 1998; Coney, 1994).

This discussion of medicalization is intended to illuminate the complexity of the subject position of patient-hood. A diagnosis of breast cancer immediately catapults a woman into the culture of patient-hood, whereby expert health care providers become the primary source of information on the nature and type of breast cancer and the treatment required. Women must begin the process of dealing with a potentially life-threatening and certainly chronic illness. Immediate responsibilities must be put on hold, future goals and aspirations re-evaluated, and the role of patient assumed (Tang & Anderson, 1999). Women's discourses illuminated the speed with which their world changed and the way they were thrust into diagnostic and treatment protocols that were organized around health care professional and institutional interests. As Dorothy explained, "everything happened so fast that I never quite caught up with what was happening" (DN, 1998). Other participants experienced the opposite and had agonizing waits for everything. Barb recalled many broken promises about when test results would be available and when consultations with specialists would occur (BW, 2000).

Being Positioned as Patient

Tang and Anderson (1999) go on to assert that the dominance of biomedical knowledge positions it in hegemonic relationships with other ways of knowing and that the construction of patient-hood occurs within a hierarchy of power relations. Women, once they suspect or are suspected of a possible diagnosis of breast cancer, are immediately plunged into the world of medicine and the language of biomedicine. As Tang and Anderson (1999) so aptly note, "The issue therefore may not be expert knowledge per se, but rather, the hegemony of expert knowledge and the denial of the wisdom and agency of the patient in the process of healing" (p. 85). The idea of being positioned by biomedical discourse as patient, then, allows an examination of these power relations and the dominance of biomedical knowledge over women's own knowing about their body. Morgan, perhaps facetiously and perhaps not, has this to say about the ideal female patient.

> From a hierarchical, expert-dominated medicalization point of view, here is the ideal female patient: she is reasonably [but not too] intelligent, enthusiastic about but only sufficiently informed about medical institutions, procedures and technology to satisfy minimum legal consent conditions, cooperative with respect to the paternalistically motivated medically directed use of medical technology, convinced that institutionalized medicine and medical technology provide the best health care in a larger macro-institutional setting where medicine enjoys pride of place, highly compliant with respect to following medical orders, and cheerfully responsible with respect to medicalized self-management (Sherwin, 1998, p. 109).

In listening to the stories that women constructed about their experience of living with breast cancer, and in examining the discourses that framed many of the stories, there is an obvious theme of working to fit in with the position of patient and comply with the institutional and professional demands that accompany it. For example, as ordered over the phone by her surgeon, Leena re-bandaged her open wound and waited more than forty eight hours before having her wound re-stitched (LC, 1999). The hierarchical nature of the doctor-patient relationship, and the vulnerability of the position of patient, ensured that participants felt responsible for keeping the relationship positive and therefore not openly challenging orders from their doctor.

From the beginning of the time when participants were confronted with the possibility of breast cancer, they began to accommodate to the dominance of biomedical discourse. For some study participants, the subject position of patient was denied them until the health care expert determined that particular signs or symptoms required further investigation. Thus, the position of patient is not a straightforward one and involves obvious power relations, both in being conferred as well as in being denied. The lump that Ellen (ES, 1998) reported to her doctor and was deemed nothing to worry about, the rupturing of Leena's incision (LC, 1999) and the surgeon's denial of her need to be seen by him, are examples of being denied patient-hood even in the face of convincing evidence that something medical is not right.

Being positioned as patient occurs at the discretion of the doctor and heralds entry into the diagnostic and categorization process of assigning breast cancer type and stage. At this point women are dependent on their doctors for clear and concise information on their medical status. As Sherwin (1998) comments, however, there may be disparities with regard to a doctor's view about what women need to know about their breast cancer and a woman's choices in this regard. When women's discourses are fore-grounded as they were in Chapters Five and Six, we can see the position of patient-hood carries with it an implicit belief that there are experts who know what women with breast cancer should know and who will parcel it out as they see fit. The fact that so many women in this study proceeded through initial diagnostic tests and eventual surgery with what they considered insufficient knowledge alerts us to a problem regarding views about what constitutes adequate information. Sherwin (1998) reminds us that there are good reasons to be wary of the manner in which the appearance of choices can be used to mask medical control. She questions the reality of choice when the available options presented to patients are the ones sanctioned by biomedical discourse. It might be useful to comment here on the way that alternative/complementary discourses can also position themselves as expert and in opposition to anything biomedical. Ellen was the recipient of many messages from the naturopathic doctor that she consulted about the ravages of chemotherapy. He specifically recommended that she refuse chemotherapy and radiation treatment (ES, 1998).

Being positioned as patient fit better for some participants than for others and for the same participants at different times. All participants accepted being positioned as patient at the beginning of their journeys. Many would have wished for a smoother diagnostic journey and relationship with health care providers, but the need to find out what was wrong, the need for definitive treatment, and the tremendous vulnerability felt at this particular point in their journey meant that women felt dependent, and they relied on, and were grateful for, expert knowledge.

Being positioned as patient and recipient of expert health care continued to work for several participants. For example, Jessica enjoyed what she considered excellent care by professionals that worked as a team, were consistently involved in her care over many years, and made themselves accessible for her questions and concerns (JD, 1998). She found no need to venture outside the system of biomedicine and would say that it worked very well for her. The only time she doubted this care was when she moved and was being treated at a center with different oncologists seeing her every time, and where she did not feel they were treating her cancer properly. Similarly, Marjorie received treatment at a center with consistent oncologist coverage and satisfactory answers to her questions. She too felt well cared for, secure in her position as patient, and grateful for the expertise of professionals (MM, 1998).

On the other hand, there were many participants who at some point in their journey with breast cancer rejected the dependency and unequal power relations inherent in the position of patient. Often this occurred when things did not go well. Barb fired her oncologist when, after repeated attempts, she could not get any of the information she wanted and needed (BW, 2000). Others navigated through the system of biomedicine until they connected with a health care provider who was more able to work with them as having knowledge about their own body.

As can be seen from the foregoing discussion, the subject position of patient-hood is not itself unproblematic. Most of the women in this study remained positioned as patient, but in a context relevant and acceptable to them. Obvious power-over relations, denying women a place in biomedical discourse, and medical mistakes or delays that impacted on participants care were the most common reasons for contesting and reconstructing this subject position.

Being Positioned as an Object of Medical Gaze

In our contemporary North American society, and I would argue in many other parts of the world, healthy women are increasingly positioned as at-risk. This is certainly true for women with regard to breast cancer. Interestingly, the women in this study were active with regard to regular examinations and mammography, and felt positive about the availability and ease with which they could attend these forms of surveillance or screening. However, with the exception of one participant, they did not see themselves as being at risk. Thus, surveillance protocols were undertaken as part of their responsibility for their own health.

Once diagnosed with breast cancer, being positioned as the object of medical gaze and participating in various protocols with regard to their cancer were regarded as necessary by participants and, in some cases, a privilege. Participants accepted and were glad to be positioned in this way. Faith commented that "they know every inch of me" (FP, 1998), and that gave her a safe feeling.

One area of difficulty that many women in this study experienced in living this subject position was that it was in the context of the doctor-patient relationship where decisions were made about the kind and amount of surveillance a particular woman would get. That meant that some women were positioned as requiring more or less surveillance, not necessarily related to stage of breast cancer. This caused great anxiety and discomfort among some participants, and was often the impetus to some form of resistance. For example, women who completed their radiation and were then discharged from their oncologist's care back to their family doctors often felt less safe that those who continued to be followed by an oncologist.

Being Positioned as Unknowing

The hegemony of biomedical discourse and its ability to lay claim to truth positions other forms of knowledge in an inferior position to medical knowledge. As I have discussed elsewhere in this dissertation, biomedical discourse exists within both institutionalized and professional power relations, and lays claim to an objective, neutral body of knowledge that is scientifically verifiable (Turner, 1995; Tang & Anderson, 1999; Cheek, 2000). Seldom is it acknowledged that this claim to objective science actually masks powerful interests and power relations.

Women's discourses are replete with examples of being positioned as unknowing with regard to their own bodies and therefore as powerless in accessing the health care they needed. All participants resisted this position, although most did so by taking on responsibility for getting the information and access to what they felt they required, either through their other relationships with doctors or by working with other health care providers. They all believed that they knew their bodies best, and some had compelling examples of being correct even when discounted by their doctors. Most participants also saw it as their responsibility to know their own bodies and report information to their doctors, even though they received conflicting messages regarding what to report.

Being positioned as unknowing by their doctors meant that participants often experienced great difficulties in having their concerns heard. More often they felt their bodily knowledge was not valued and not important. Even when women's bodily knowledge was finally confirmed by biomedical knowledge, no verbal acknowledgment was ever made about the value of women monitoring their own health. The surgeon caring for Leena hung up on her when she called him to report the rupturing of her incision (LC, 1998). This had potentially dire consequences -- a wound open to the bone and three days before the weekend was over and Leena could be seen in emergency by the surgeon. In fact, it was months before the incision healed, and she did experience a serious infection. Mary experienced a delay of months in diagnosing a recurrence of her breast cancer because her doctor did not take her reports of a growing lump under her arm seriously (MH, 1999). These are only a few of the examples evident throughout women's discourses, but they illustrate clearly the manner in which dominant discourse can position others as unknowing.

Part of the subject position unknowing included being positioned as nuisance for some participants in the study. This feeling of being a nuisance, or being told you were a nuisance, either implicitly or explicitly, was a common element of women's discourses about their relationships with health care providers. Just as doctors have the power and authority to diagnose and categorize illness, they have the power and authority to deny access to surveillance and diagnostic technology. In this way women could be positioned as nuisance. Barb insisted on particular blood tests before her surgery, after being told by a nurse that they would provide important information in deciding follow-up treatment. Barb asked for and had the tests, but her surgeon berated her for asking for "unnecessary tests that he had not ordered" (BW, 2000). Many participants were told to stop worrying about their breast cancer, it was gone and they should just get back to normal. In fact, one participant was told she was examining her breasts too often and that was the cause of her symptoms.

Positioning Around Self-Monitoring

There are mixed messages within this position, but there is no doubt that participants felt responsible for engaging in good health care practices and for monitoring their own health. At the same time, they were recipients of messages regarding risk factors for breast cancer that they felt implied blame and a lack of proper health care practices on their part. So, long before a woman was diagnosed with breast cancer and designated patient, she would be aware of messages related to self-responsibility. Allen and Hardin (1998, p. 9) remark that, as a society, "we have learned to watch ourselves, not descriptively but judgmentally", and to position ourselves in discourses about what we should do, should not do, and/or should have done. This positioning was evident for all participants with regard to taking responsibility for their own health and adopting new health care practices.

This was not an unproblematic position, however. Despite a public and professional message regarding a woman's responsibility for her own health, women often experienced difficulty in being taken seriously by their doctors when they tried to report symptoms, monitor their health, or engage in discussion about their self-developed health care practices. The fact that there is internal dissonance within this subject position was not lost on the participants. Biomedical discourse positions women as responsible for monitoring their own health, but at the same time often disregards their attempts to report potentially serious symptoms.

The foregoing discussion has centered on a postmodern analysis of women's experiences in living with breast cancer within the context of a medicalized health care system. I have illuminated some of the ways in which women may both be positioned and position themselves through discourse. As Davies and Harre (1990), and others, remind me, a particular strength of a postmodern lens is its ability to elucidate the constitutive nature of discourses in making certain subject positions available and, at the same time, its recognition that women are capable of exercising agency and choice in relation to positions taken or resisted.

Agency

There is a complex interplay of subject positions for both providers and recipients of health care within discourses at any one time. Subject positions are not necessarily unwavering and stable; rather, people move in and out of particular positions depending on many factors. Having agency describes this ability to take on, resist, and/or create different subject positions in constructing women's own illness journeys (Allen, 1997).

Factors Influencing Agency

There are many factors that may influence the way in which women navigate or maneuver in various discourses and, in so doing, actively construct their own illness story. One factor that seemed to influence participants in this study was their past experiences of being positioned.

Maureen had been positioned squarely within the culture of patient-hood with her first experience of cancer (MW, 1998). When her breast cancer was diagnosed, she and her family knew that they wanted a more active role in decision making. Knowledge of her past experience and the feeling that taking on the position of patient had not worked well for her enabled Maureen to create different subject positions for herself. For example, Maureen, with the support of her husband and family, positioned herself as partner in care with her doctors and as a knowledgeable person about her own body and in regard to biomedical discourse. She researched her particular type and stage of breast cancer and the research on radiation following lumpectomy. She learned that there were conflicting opinions within different discourses and within biomedical discourse itself about the necessity for follow-up radiation with her particular type of breast cancer, and she made the decision to refuse radiation treatment. She and her husband communicated the decision and the rationale for the decision to her treatment team. They agreed to disagree and continued in relation with each other. Although biomedical discourse may locate itself as a unitary discourse, it is evident that, in fact, biomedicine is a multitude of discourses, and there may be strong differences of opinion among medical practitioners about particular aspects of diagnosis and treatment.

Another key factor in the exercise of agency for women in this study seemed to be related to gaining knowledge about other discourses. This was true particularly with regard to women having access to other women's discourses about breast cancer. So the more available and out in the open alternative discourses were, the more readily participants were able to navigate within and among them. Being able to access different discourses helped women choose among subject positions and/or construct ones that worked for them. Sharon (SC, 1998), with her clear sense of knowing her own body better than anyone else, has explored many different discourses. From these different ways of knowing about breast cancer she has constructed a healing path for herself that blends medical and other ways of knowing.

A third factor that seemed to influence participants' sense of agency was knowledge of past capacity. Women talked about being there before and, therefore, not feeling so vulnerable this next time around. Often this sense of having been there before imparted women with a sense of the availability of alternative discourses, and the support of other women and family in the taking on of different subject positions. Ellen (ES, 1999) provides an interesting example of this notion of being there before. She was born in Europe and, as a fifteen-year-old, was incarcerated in a treatment facility for tuberculosis. She was there for an extended period of time under severe and abusive conditions. Ellen reflected back on that period in her life during some of the times in her breast cancer journey when she felt most depressed and hopeless. In conversation with me, she recalled thinking that since she had made it through that awful time of incarceration in Germany then she could make it through this experience. Ellen did not feel supported in her relationship with her oncologist, and in fact told me that she was depressed for weeks after a visit to the clinic. Her way of coming to a place where she could resist being positioned as a "poor unfortunate woman" (ES, 1998) was to reposition herself as defiant and capable of authoring her own story about living with breast cancer. She used to repeat to herself (as she had done in Germany), you won't get me, and you can't get me if I don't let you. She then proceeded to explore a wide variety of healing discourses and to re-connect with women friends and local support groups. She designed a treatment and healing regime for herself and felt a renewed sense of optimism and hope through this work.

A fourth factor that seemed of great influence in participants developing a sense of personal agency was being treated badly by health care providers. Unfortunately, these were not isolated incidents and they relate very much to the interactions and relationships' women had with their doctors. One speaker can position another by adopting a discourse with certain interpretations of how the other is to act and, if the relationship is to be continued, the other participant must conform (Allen & Hardin, 1998). Within biomedical discourse, the doctor is positioned as expert and the patient as dependent on the doctor's knowledge and expertise. Women in this study did not contest that belief. What became difficult for many participants was the manner in which the interaction or relationship was constructed and the denial of participants own knowledge about breast cancer, their bodies, and other discourses of healing.

Some of the women found their relationships with their doctors to be empowering and satisfying. They came away with the information and reassurance they needed, they felt cared for in a personal way, and they felt secure with the care they received. For instance, Ellen (ES, 1998) has a relationship with her (new) family doctor that has been supportive throughout her three years with cancer. It was this family doctor who was able to instill Ellen with a sense of hope and help alleviate the despair and depression that seemed to follow her interactions with other specialists. The change to this new family doctor was made in unusual circumstances and exemplifies an extraordinary degree of personal agency. Ellen had tried to see this doctor earlier but his practice was full. In the course of taking care of a friend who was dying from cancer, Ellen learned that her family doctor was the one that she had wanted. At the time of her friend's death, Ellen phoned the doctor and told him that she knew he had an opening in his practice because one of his patients had just died. She was accepted as a patient and was forever grateful for his concern on her behalf and for the sense of optimism about her prognosis that he was able to impart to her.

Many other participants needed to exercise their agency in exiting or getting out of relationships that they found oppressive, and in some cases demeaning. These relationships almost always served as the impetus to changing doctors.

Mary (MH, 1999) had probably the most horrifying story about being treated in a rude and dismissive manner by her surgeon. She phoned me at home one Saturday morning saying that she needed to talk with me about what had happened in her surgeon's office the day before. Mary had been trying to get the attention of her doctors for some time, as she had a growth under her arm that had been growing rapidly. Eventually, she was scheduled for further tests that did show a recurrence of her cancer. We had a long talk during which Mary told me how her surgeon had dismissed her concerns and told her that he would decide "if, what and when" he would do anything (MH, 1999). I had to work hard at listening to her story and reflecting what I was hearing, rather than letting my own opinions show. At the end of the telling, Mary looked at me and said, "I can't go back to him, I can't have him operating on me". We then proceeded to explore alternatives. We came up with several, one of which was to see if her oncologist would help her find another surgeon. We both thought this unlikely, and so thought of a couple of other options. Monday was a busy day for Mary. She received a phone message from her oncologist saying that what she wanted was impossible and that perhaps she had over reacted in relation to the visit with her surgeon. Her oncologist also said , "you know we work as a team so I couldn't possibly refer you to anyone else" (MH, 1999). Mary then went to option number two, which was to contact her family doctor with the explicit request for names of surgeons in Vancouver who do breast cancer surgery. By the end of the day, Mary had her new surgeon's name, was scheduled for preliminary tests, and had an appointment to see the new surgeon in two weeks time.

It was Mary's choice not to confront the surgeon with her anger at his behavior at that time. Rather, she chose to tell him that she wanted to have her surgery in Vancouver because she had family support there. She did, however, want the conversation recorded. Mary has been in active treatment since that episode and we have not pursued any further discussion about what she would like me to do about the tape.

This example illustrates a disempowering and oppressive doctor-patient relationship. In listening and re-listening to the tape recording of our conversation, I was able to see the range of positions that Mary herself took in response to the interaction. The surgeon clearly positioned Mary as difficult because she was not accepting his wait-and-see attitude. The surgeon didn't seem to have a course of action, at least one that he was willing to communicate to Mary. Mary wanted to know the plan, and she also wanted this potential recurrence of her cancer to be treated with some urgency. In the moment of the interaction, Mary was unable to reposition herself, and she left his office feeling angry and scared. During the early part of our conversation she frequently took on responsibility for the interaction going badly. "Maybe I wasn't as up as I usually am, I don't think I smiled when he came in". She eventually repositioned herself. "I was being polite and he wasn't. He didn't need to talk to me that way". With that repositioning came the realization that he had in fact treated her very badly and that she had lost confidence in his ability or desire to treat her properly. Through her own reflection on the encounter and our reflective conversation, she was able to engage in a significant act of resistance by finding a new surgeon and informing her former surgeon that she would be going to Vancouver for treatment.

It would seem that by examining the various ways that biomedical discourse positions both doctors and patients we can learn more about oppressive and empowering relationships. If we accept the view that both doctors and patients are positioned within discourses, then we can see how each might be enacting different subject positions. The doctor is positioned (and may position him/herself) as expert and in charge of information flow and treatment plan, while many women wish to position themselves as partners in care. It is easy to see how relationships can become difficult if participants are enacting different subject positions without even being aware of it (Allen & Hardin, 1998).

Emerging Discourses of Agency

For a fair number of women in this study, a personal sense of agency developed over time and in reaction to pivotal events. Some women described how they had felt they were swimming up-stream in their own story, against the currents and tides and never knowing what was around the next bend. These intense feelings of despair, unrest, or hopelessness served as the impetus to taking action or taking charge in their own care. For many, this intense need to do something for themselves was not voiced to health care providers but communicated via journals, poetry, short stories, or going back to one's art or music (Appendix V and VI). Acts of resistance were frequently unspoken until participants began reflecting on their experiences with breast cancer in dialogue with myself and family or friends. As we dialogued over two years, I also witnessed acts of resistance in action. For the most part, participants would not have characterized the changing of their doctor, for example, as an act of resistance, but rather as something they needed to do for their own good.

At the heart of resistance and developing agency seemed to be a rejection of the power and dominance of a medicalized system that positions women as dependent and ignorant with regard to their own bodies. Women wanted to work in partnership with their doctors and be respected as knowledgeable about biomedical and other discourses, in particular their own bodily knowledge.

Claiming Agency

Sherwin (1998) has written a wonderful essay about contested bodies and contested knowledge. Within the context of medicalization, she describes a model of resistance and agency whereby subjectivity and epistemic power are (re)claimed by women.

(Re) Claiming Subjectivity

Women have always claimed knowledge about themselves, told stories about their own health and healing practices, and enacted healing roles in the family and community. The dominance of biomedicine has eroded many of those traditional ways of being and knowing for women. With the rise of biomedicine, women's own body of knowledge has been de-valued, and women's ability to understand scientific medicine has been questioned. This was evident in participants' discourses. Comments from doctors like "Oh, you wouldn't understand that" were common, and resisted by participants.

Reclaiming women-centered discourses, and taking hold of biomedical as well as other discourses, is essential to women's enactment of personal agency. Women in this study illustrated such reclaiming. Women-generated discourses illuminated through this research are powerful in their rendering of what it is like to be a woman and a patient with breast cancer in this community. They are also powerful in the way they illustrate capacity to comprehend biomedical discourse and incorporate various discourses into their treatment and healing path. Women in this study have illustrated immense capacity to critically analyze and take up or reject different subject positions within discourses and chart their own journey. They have also illuminated the power relations inherent in different discourses and ways of resisting power-over relations. Leena, Ellen and Barb are examples of three participants who were able to let their doctors know what they needed and what the doctors needed to do in order to ensure that the care they received was satisfactory.

(Re) Claiming Epistemic Power

"Claiming subjectivity and agency is critically dependent on having access to relevant knowledge as the basis for one's choice in circumstances in which genuine choice is a real possibility" (Sherwin, 1998, p. 113). As we saw in the discussion of women's discourses, this was not an easy task for the participants in this study. Some doctors worked with patients to de-mystify biomedical knowledge and ensure that women could be genuine participants in their care. Many, however, did not, and women were left on their own to search out, translate, and incorporate biomedical information about their particular breast cancer and treatment. Getting their own medical charts, researching scientific journals, reading medical texts, and talking with other women were some of the ways women accomplished this.

In addition to claiming biomedical knowledge, women in this study were active agents in reclaiming their own bodily knowledge. Rejection of this knowledge by their physicians was often an impetus to resistance and the development of agency.

For the most part, I have been talking about developing a personal sense of agency. Participants claimed a degree of expertise in biomedical and other discourses; they resisted positions that left them vulnerable, while not rejecting all medical treatment for their breast cancer; they incorporated other discourses into their personal healing plan; and they negotiated with health care providers for the kind of relationship they needed, or they exited the relationship.

A surprising number of the women in this study also demonstrated agency on behalf of the community of women with breast cancer. Many moved from relying themselves on the various support-groups available to leading and facilitating these groups. Every woman in this study advocates on behalf of other women with breast cancer in some way, and some have made it more than full-time work. Activities that participants remain involved in include advocacy on behalf of women with surgeons and nurses, one-on-one and group support, and leadership positions with local, provincial and national organizations.

It is important to note that agency for these participants did not involve a rejection of biomedical discourse at all. Rather, women navigated through different discourses with varying degrees of allegiance to each. For some, biomedical discourse was most prominent in the construction of their illness story. For many other participants, biomedical discourse, their own bodily knowledge, and aspects of other discourses were integrated into their illness story and healing path.

Conclusion

In Chapters Five and Six I fore-grounded participants voices and their construction of a cogent illness story that provided them with a sense of personal meaning and a way to live with their breast cancer. These chapters illustrated the ways that women made their voices heard, inside and outside of health care encounters. As well, these chapters constructed women-centered discourses and described some of the ways women's discourses are similar to and different from each other. Chapter Seven has illuminated some of the ways women make sense of, engage with, and position themselves within and among existing discourses. Women-centered discourses highlight the time and effort invested in mastering biomedical discourse, so that they can engage with health care professionals and understand the nature and type of breast cancer they have. We have also seen how women take on and incorporate biomedical discourse as their own in conjunction with a variety of other discourses.

In this chapter, I have brought to the foreground my own voice about the research outcomes. A feminist postmodern lens has enabled me to reflect on the ways in which medicalization and the dominance of biomedical discourse position women with breast cancer in particular ways. I have also been able to elucidate the ways in which women resist and reposition themselves in relationships, and the ways participants exercise personal and collective agency. Such an approach focuses attention on the strengths and capacities of women in the context of their world and provides insights into health care provider relationships and practices.

CHAPTER EIGHT
REFLECTING BACK AND THE PATH FORWARD

Introduction

From a feminist postmodern perspective providing a conclusion to the dissertation is not really possible but this chapter does provide opportunity for reflection on the research outcomes as presented in previous chapters, the process itself, and some of the ways that feminist postmodern research may be authenticated. Additionally, I reflect on the path forward and respond to the final study question, What are alternative possibilities for understanding and action?

When I embarked on this research I was interested in understanding the various ways that women with breast cancer engage with biomedical and other discourses and the form and substance of women-centered and women-constructed discourses. I have enhanced my understandings of these questions immensely. What I did not anticipate or at least give words to at the beginning of the study was that the dominance of biomedical discourse would have such a profound effect on every aspect of a woman's experience of being diagnosed and treated with breast cancer. The understandings gained through this research have helped me to articulate the differences between the journey a woman lives in and through as she navigates living with breast cancer and the biomedical trajectory that concerns health care professionals. Women's discourses, including their overarching journey discourse, are constructed by participants as integrative, with the purpose of melding together their personal journey with breast cancer and the biomedical trajectory that frames much of their care. Understanding and acknowledging the difference between a woman's personal journey with breast cancer and the biomedical trajectory that frames health care provides some critique of our current practices. These critical understandings helps us see ways in which health care providers and our ways of practicing could be more congruent with and supportive of women's experiences and could then be of assistance to us in the development of transformative knowledge for practice.

Reflexivity: Reflecting Back

I am conscious as I write this dissertation of the ways that I have illuminated a researcher-participant relationship over time. For the past two years we have been engaged in interactive interviewing sessions among many other activities, and, as Herz (1997) reminds me, participants react to and engage with me not only as researcher but as a woman. As Herz (1997, p. xi) notes, "in plain talk, they size us up in order to situate us". Throughout the research process I have consciously presented myself as open and forthcoming with regard to the various ways that participants saw our relationship. In looking through the journal that I kept over the time of this research I see many different relationships. Some participants seem to place me fairly firmly in the role of researcher, and so would call me to tell me something they might have forgotten during the interview or to keep me up to date with their medical condition. There were other participants who responded to my requests for interviews but did not initiate contact with me, and our relationship was more formal. Others would call me to let me know they would be away for a period of time and when they would return or to ask how I was doing. Still other participants would be in touch on a regular basis for a variety of reasons. Often it would be to tell me of an interesting conference coming up, a new book they had read, or a documentary on television that they thought I might enjoy.

Because the research extended over two years, and because I was not always on schedule with regard to particular time frames I had set for myself (and often had communicated to participants), I was frequently in touch either by letter or by phone to apprise everyone of the latest revised schedule. At these times I would catch up with their latest medical and personal news. Over the course of the research, I was in touch with all but one participant in these ways approximately four or five times. In addition to these formal and informal contacts, I attempted to be in touch with all participants once I had a substantial draft of chapters one through seven written. I was able to speak with thirteen participants and nine were able to attend our group meeting, where I presented a summary of the dissertation and we talked about how the research process had been for them. Their comments were incorporated in the final writing. Several participants were overseas and I will meet with them individually when they return. I have been in touch with all the others and have arrangements organized that suit each individual. Most have also requested that we meet again as a group when I have completed the university process, and we have agreed to do that.

The final group meeting was held in the evening to accommodate those who work outside the home, and, because it was late fall and dark early, I drove several women to the meeting. I had a draft of the dissertation available (one copy) and copies of the summary for everyone. They agreed that copying the entire dissertation was unnecessary and they made arrangements to share the one copy among themselves. I opened the meeting with a discussion of the process of research to date, in particular the process I had followed to analyze their data and the university protocol that I would be involved in over the next few months. We then talked our way through the summary I had written (Appendix IV). Several participants who were unable to attend the meeting indicated that they didn't need the summary and would wait until the entire dissertation was available.

I found it interesting that all present at the meeting were very intent on reading what I had written, and engaged me in dialogue about each of the discourses. They wanted me to write into the dissertation that these discourses fit for them and expressed their experience in a way they could not have imagined before reading and talking about the various discourses and, especially, the analysis process. Several participants also wanted further discussion around the discourse of Acquiescence and Accommodation. Mary wondered if I was meaning that women "gave in or gave up with regard to having their own say with doctors" (MH, 2000). I responded by talking more about how I saw this discourse as being necessary at various times in their journey and especially in the beginning when they were first diagnosed and attempting to make treatment decisions. I also talked about how I was presenting this discourse as a strength of women but one that was usually unacknowledged by both women themselves and health care providers. This conversation opened further dialogue about the variety of discourses in play at any one time and the way women could be alike or different in the discourses operative at any particular moment in their living with breast cancer.

We also had substantial dialogue about the concept of agency, and again I found interesting the manner in which those present at the meeting unanimously stated their liking for this word and the way I was using it. Several participants talked about not liking the words being in control or taking control of their own care. In their opinion, the word control emphasized a taking over from someone else and also might in some circumstances imply conflict between themselves and health care providers. In their view, the word agency implied an intent and ability to work alongside others in their care and a respect for their own knowledge about their breast cancer and their bodies.

When I asked them how the research process had been for them, there was much talk about the amount of work I had done and their felt privilege in being part of the research. Participants commented on the fact that I was in a position to communicate their experience to others and said that it would be important that I do so. We talked about publishing in professional journals and the lay press, but more important for them was the commitment I made to communicate findings from the research to health care professionals in our local community. They also expressed their satisfaction at being able to help other women by sharing their own experiences and their renewed commitment to making a difference in the care of women living with breast cancer. A substantial number of participants in the study are committed to further action and advocacy work and see our research group (myself and interested participants) and this study as one stepping stone for this enterprise.

I left participants with a comment sheet (Appendix IV) for further thoughts regarding the research process, and am still receiving a few. Several women told me that the comments expressed at the meeting were reflective of their thoughts and experiences of being in the research and they didn't need an anonymous venue through which to express anything else. DN returned hers by e-mail and responded to the query about being in the research process by commenting: "I found it freeing – that someone would actually want to hear my story – and do something with it. Many have heard the story. This is the first time that I felt that it would actually be helping others". Other participants also commented on enjoying being in the study and felt confident that women would benefit from the research. Many participants stated clearly that they wanted to ensure the study would have some effect on the care women with breast cancer received and one participant commented: "selfishly I would like to ensure that the study is powerful enough that health care professionals will pay attention to breast cancer professionals. We have been there – we know what it feels like" (DN, 2000). Dorothy reiterates other participants' observations with these two statements:

> I attended a breast cancer forum. There I suddenly understood that I was sharing my breast cancer with many women – and – given the right circumstances I could help women live through the dark days of initial diagnosis of breast cancer. I would be able to give them hope and understanding. So I became an advocate, as I had been an advocate for the physically handicapped in my former life.
>
> I would like to see the ideas in this research carried forward. I would not like to think that this research sits on shelves, gathering dust. More must be done for and with those first diagnosed with breast cancer, as well as the giving of constant support for those undergoing treatment and then onto living with cancer (DN, 2000).

Where do we go from here was a frequently voiced comment by almost all of the women in the study.

As I re-read my personal journal I am conscious of my gratitude to these women who have so much going on in their lives and yet are willing to share their time and energy with me, as well as their inner thoughts and feelings. They live with such grace and fortitude, and in many places I comment on my feelings of awe at their resilience and commitment to others. When I have presented some of this work at conferences, I am often asked if I find it difficult to be involved with such sadness and tragedy. There are many places I write about my fears for the next check-up or ominous sign a participant has told me about; my tears as we share a story of recurrence, further treatment, or unexpected slow healing; and my own questions around what I might be like or do if I were faced with what these women live with every day. There are also places where I write about the laughs we shared and my learning about graceful living and the important things in life.

I have been committed to researching with integrity and honoring the commitments that I have made with regard to the action piece of this research. This will be elaborated on further in the last section of this chapter.

Authenticating the Research

A feminist postmodern study "accepts the presence of it's own fallibility as well as its contingent relation to progressive social change" (Kincholoe & McLaren, 1994, p.151). In light of this understanding, the following discussion is not intended to portray a magical method of validating the findings of this research. Indeed, the creative search for criteria that constitute rigorous research has been varied and multifaceted (Reason & Rowan, 1981; Lincoln & Guba, 1985; Sandelowski, 1993; Lather, 1986a; 1986b; 1993).

From a positivist or post positivist perspective, the term validity is used to refer to the truth and accuracy of a particular research study, where a single truth can be discovered. Postmodernism rejects the notion of one truth, thus the criteria for validity alters. In looking at synonyms for the word validity, I was struck with the simplicity of meaning. There are a variety of synonyms for the word validity, words such as convincing, logical, substantive, sound, legitimate, and relevant (McLeod, 1986). I asked several participants what they thought of the soundness or relevancy of the way I presented the study findings and indicated that this question was important in talking about the rigor of the research. They were able to speak to the relevance of the study to their experience of living with breast cancer and to the fact that the way I had presented their words was legitimate and convincing.

In a more general sense, the academic search for alternatives to positivist versions of validity has resulted in reformulating two important questions about rigor in qualitative research. The first is called the crisis of representation, the representation of other in our texts, and the second, the crisis of legitimization, the authority we claim for our texts (Lincoln & Denzin, 1994). In challenging the authority of a text, that is, a text represented as true, accurate, and complete; and in challenging the notion that following a rigid set of rules about knowledge production ensures validity (an epistemological validity), feminist postmodern research evokes the crisis of legitimation (Lincoln & Denzin, 1994; Parsons, 1995). Regarding the crisis of representation, researchers must ask themselves questions that do not necessarily have any good answers. "Is there any such thing as authorative speaking that presents a more legitimate or expert version of reality than any other?" (Parson's, 1995, p. 26) Lather (1991, p. 84) attempts to respond to this issue by being specific about what reflexivity means to her. She asks the following questions to which I respond:

1. "Did I encourage ambivalence and multiplicity?" When I described participants' discourses, I ensured that many perspectives were represented and that I was clear whether it was most or some of the participants who had told me a particular thing. During conversations with participants I let ambivalence and uncertainty lie in the spaces of our speaking and I tried to encourage many different perspectives.

2. "Did I encourage thinking aloud, imagining possibilities?" Throughout the time I spent with participants, whether in formal interviews or informal conversations, I was very conscious of my own embeddeness in biomedical discourse and also my discomfort with some of what I saw occurring between participants and health care providers. I was very conscious of these situations, particularly when women were being treated in a way that I thought was inappropriate or unkind. I tried to use reflective comments like, "I hear you saying so and so", and also comments that encouraged thinking of alternatives. For example, in listening to Mary's story of her encounter with her surgeon, I asked her what she could see as viable options given what she had told me.

3. "Have voices gone unheard, differences not explained?" The voices of the women participating in this study have been represented throughout, but it is important to acknowledge that this was a self-selected group and, as such, there are women not represented within the study. In particular, non-English speaking women, women of different cultures or ethnic backgrounds, and very young women with breast cancer were not represented in the study population. Additionally, although I worked hard to ensure participants voices were represented in the findings of the research I analyzed the data and it is possible that there are other voices that might have been represented differently had another researcher analyzed the data.

4. "Have I made resistant discourses and various subject positions readily available?" I made a conscious decision to hear participant's words and stories and not to

impose pre-determined research questions into our time together. In that way, the women in this study were free to talk about and express whatever was most important to them at the time. The participants in this study illustrated difference within their own discourses, subject positions assigned to them, assumed or rejected. Additionally, they illustrated differences with regard to the manner and degree to which their own personal illness story, journey, and discourses fit with or were dissonant from biomedical discourse.

5. "Did I create a text that was multi-voiced without being paralyzed?" I believe that the strength or validity of this text rests on its ability to present multiple discourses that link together in a meaningful whole. The challenge has been to narrate a text that is true to women's experience of living with breast cancer and that is coherent and accessible. In so far as the participants in this study are concerned, I have accomplished that.

In addition to the above discussion on authentic research, I draw on the work of Lather (1986a; 1986b; 1991; Kincheloe & McLaren, 1994). These authors put forward the following components as useful in assessing the authenticity of feminist postmodern praxis research:

1. Triangulation. The use of multiple data sources, methods, and theoretical perspectives is useful in establishing the trustworthiness of the study. In this research I employed the use of one-on-one dialogue, personal reflections, and group dialogue. As well, several theoretical perspectives informed the research process; thus a place was made for "counter-patterns as well as convergences" of data (Lather,1986a, p.270). That is, we, the participants and I, talked about the similarities and the differences apparent in the stories and discourses I wrote about, and participants were able to see the ways in which their experience was like or not like other participants.

2. Construct Validity, This criterion involves the process of being open to participants' experiences and emerging data, being cognizant of the theoretical underpinnings of the study and being aware of emerging theoretical relationships in the data, without imposing one over the other. In truth, while I was in the process of interviewing and being in relation with participants this was not a difficulty for me. I was caught up in the individual experiences of each woman I was with and was trusting that

the data I would need to fulfill the requirements that I had set out in the beginning of the research would emerge. It was not until I attempted to impose an analysis process on the data that I struggled with the relationship between the questions I had started with and the words of the participants. I had to intentionally return to women's data without my questions in mind before I felt that I was being true to their words. As an example, I had expected more gender issues to be apparent in women's stories. In fact, a feminist analysis or explanation for some of the issues that women were encountering was part of only a few participants' stories. At the same time, I was aware that by letting the research process play out without consciously thinking about what I would find to write about, I was more open to the dialogical process of drawing forth descriptions of experiences, thoughts, and feelings, while simultaneously engaging in, confronting, and questioning those experiences, thoughts, and feelings.

3. Face Validity. This criterion refers to the research participant's recognition of the data and emerging analysis as truly representing their experience. I have spoken elsewhere of the many and different ways that participants have been involved in the emerging research construction and their responses to the research construction.

4. Catalytic Validity. This criterion refers to the necessity of praxis-oriented research to have an emancipatory outcome". "Catalytic validity represents the degree to which the research process re-orients, focuses and energizes the participants toward knowing reality in order to transform it, a process Friere (1970) called conscientatization" (Lather, 1986a, p. 73). Individually, participants in this study have evidenced emancipatory behavior and enhanced awareness of the dominance of one discourse and the silencing of others, including that of women with breast cancer. This has been captured in the chapters on their journeys and women-constructed discourses. As well, many participants are committed to further advocacy work based on some of the findings of this study. Many other authors have reiterated the need for a pragmatic validity or an evaluation of the usefulness of the research in effecting social change (Kvale, 1997; Mies, 1983).

Reflecting Forward

A feminist postmodern praxis orientation to this research has alerted me to two penetrating questions, the answers to which frame the remainder of this chapter. The first question is: How do we develop critical insights into particular discourses as we simultaneously live in and are constructed by them? And the second is: How do we turn those critical insights into emancipatory action?

Developing Critical Insights Through the Process of Researching

In my literature review I told a multivoiced and multifaceted story about living with breast cancer, and in so doing uncovered for myself the true extent of the differences among, for example, biomedical and women's discourses. It was clear to the participants in this study and to myself that the only way, or at least the dominant way, that health care professionals know about breast cancer is via the biomedical and it is this discourse that carries power and authority in our society. Women learned early on in their journey one crucial insight: There was only one viable way of being a participant in their own care and that was to learn and incorporate biomedical discourse into their own. What came as more of a surprise and caused more difficulty for participants was the realization that there is more than one biomedical discourse. Participants initially accepted the myth of certain science and one truth, and they believed that clear and unequivocal answers would be forthcoming once diagnostic tests were completed. They also believed that definitive treatment protocols would be agreed upon by the community of health care professionals looking after them. Both of these beliefs proved to be false for at least some of the women in the study. The myth of one truth and the power and authority of biomedical discourse made it difficult for women to access or investigate a range of possibilities, as there is little room in biomedical discourse for differing opinions. It should be pointed out that some participants experienced much the same philosophy when attempting to access particular alternative/complementary discourses.

The power of any discourse lies in its ability to shape meanings, subjectivities, and actions. Both biomedical and women's own discourses shaped meanings around, for example, the truth value of biomedical discourse. As we saw in the discussion of women's discourses in Chapter Six, participants in this study believed in and accepted biomedical knowledge about the disease of breast cancer as superior to that put forward by other discourses. However, with regard to their illness experience and knowledge about their own bodies, women felt that their personal knowledge was superior. Similarly, women developed critical insights around the ways in which biomedical discourse creates meanings about hope. Finding these meanings inadequate, participants engaged in a great deal of self-work in creating their own meanings about hope. This is an example of where women's discourses became fore-grounded over biomedical. The construction of a passive object of biomedical expertise was also for the most part rejected by participants. An active and involved participant was the subject position created by women, and we saw this with all participants in their expressed need to take care of and create healing practices for themselves.

There were many other critical insights gained by women as the research progressed. Feminist postmodern praxis-oriented research is oriented to illuminating the strengths and capacities of participants. It is also oriented to answering questions of importance to the discipline. Women in this study became aware of strengths they had not acknowledged before and abilities to effect significant changes in their care. They also became committed to effecting change at the practice level, and have many ideas for how to go about this. In this and other ways, participants have developed transformative knowledge, that is, knowledge about and for change in health care practices (Stanley, 1990), and a sense of their own power and capacity to author their own story about living with breast cancer (Weiler, 1987). A major part of developing these insights was the coming to know about power/knowledge relations. These are not the words participants would necessarily use, although some did, but all women in the study talked about the necessity to understand biomedical discourse. This was not limited to understanding what their particular health care providers were telling them, but involved the need to investigate their type of breast cancer, recommended treatments, other women's experiences, and, for many participants, reviewing the latest research via internet and/or medical research journals. Armed with knowledge, both biomedical and other, women felt more able to express agency in their journey with breast cancer.

"To know anything is to know it in terms of one or more discourses" (Davis & Harre, 1990, p.44). This quote summarizes well the critical insights that developed over time as women were treated and learned to live with breast cancer. Learning biomedical discourse thoroughly, voicing and learning to trust their own discourses, and integrating a variety of discourses into a meaningful whole that made sense for them was a process that developed over time and in different ways for each participant. There has been much nursing and other health care related literature concerned with the vexing questions of how to teach patients with cancer what they need to know, when they need to know it, and how to provide support to women and families as their journey with breast cancer unfolds (Baillie, Bassett-Smith & Broughton, 2000; Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson & Mueller, 1997; Hack, Degner & Dyck, 1994; Hoskins, & Haber, 2000; Galloway, Graydon, Harrison, Evans-Boyden, Palmer-Wickham, Burlein-Hall, Rich-van der Bij, West, & Blair, 1997; Lugton,1997; Hilton, 1994; Adler, 1996). It may be that understanding more about women's discourses and the manner in which they incorporate many different discourses into their learning about breast cancer would be helpful in the quest of health care professionals to meet the needs of this group of clients. Certainly, the more open a discourse is to change, the more attractive the discourse seemed to the participants in this study.

Reshaping the Context of Health Care for Women Living With Breast Cancer and the Development of Transformative Knowledge

A valued aspect of a feminist postmodern perspective to research is the surfacing or illuminating of taken-for-granted aspects of health care and the concomitant task to challenge some of these practices or beliefs. For example, participants in this study challenged the notion of one truth and highlighted their own personal ways of knowing about their bodies and their breast cancer (Carper, 1978). They also developed sociopolitical knowledge as they gained agency and developed strategies for challenging and altering particular practices (White, 1995).

Cheek (2000) reminds us that a postmodern lens alerts us to the dominance of a particular discourse but that identifying a particular discourse as dominant does not mean that it must be replaced or displaced. Rather, it is important to recognize it for what it is.

One useful question to ask about dominant discourse is: Who is this discourse good for? The construction of the subject position, patient, by biomedical discourse, for example, might be seen as serving the needs of health care providers and not in the best interests of women with breast cancer. On the other hand, some pieces of this subject position might be useful for particular women at certain times in their journey with breast cancer. A second question to ask is: as determined by whom and on what basis? Participants in this study illustrated great skill in sorting through these questions and integrating pieces of a variety of discourses that comprised the best for them at that particular moment in their journey with breast cancer, thus creating their own subjectivities, meanings, and actions.

As we have seen from the foregoing discussion, women in this study developed and used transformative knowledge, essential to their ability to exercise agency. Transformative knowledge describes a way of knowing that enhances women's awareness of the similarities, differences, and contradictions of their own discourses and biomedical discourses. This way of knowing also increases awareness of the many ways they may be positioned by biomedical discourse and potential sites of resistance, both personal and collective. By going beyond women's individual experiences of living with breast cancer and examining professional and institutionalized discourses, a space was opened for the development of transformative knowledge (Allen & Hardin, 1997). It is in the journeying with breast cancer, the creation of a cogent illness story, and the critical self reflection that participants engaged in that our understandings were altered and action could be taken.

Transformative Knowledge and Responding to Women's Discourses

Doctor Patient Relationships

Women's descriptions of their journey with breast cancer and the discourses surfaced throughout this research illuminated many issues in doctor patient relationships. Perhaps the most prominent from the perspective of the women in this study was their need to participate in their care as partners with health care professionals. Women believed that they had expert knowledge about their own body, their illness experience and healing modalities. Many also had good working knowledge about the medical aspects of diagnosis and treatment for breast cancer. Very seldom, if at all, was this knowledge and expertise acknowledged and sought after by their doctors. Compounding this lack of acknowledgement of participants own body of knowledge was the difficulty that most women experienced in getting appropriate and timely information from their doctors.

It would seem from the data generated in this study that some doctors are unaware of the magnitude of women's desire to be partners in care and are unclear as to what this means in practice. Additionally, a doctors singular focus on the medical aspects of diagnosis and treatment precludes paying attention to the differences between a medical path or trajectory and the illness journey that women live as they are diagnosed and treated for breast cancer. If women's discourses and their illness journeys were better understood by doctors, would partnership relationships be more prevalent? Would doctors put different emphases on the meaning and substance of being in relation with women with breast cancer? Could nurses play a more definitive role in developing and maintaining relationships where knowledge about women's illness journey and discourses are a valued part of caring for women with breast cancer and where women are recognized as experts knowers?

There is beginning recognition among some doctors that their relationships with patients are not meeting the standards they either set for themselves or their patients set for them. The issue of communication between doctors and women with breast cancer has been aired at many different public forums, most recently at the yearly Breast Cancer Conferences held in Vancouver and sponsored in part by the British Columbia Cancer Center. The National Forum on Breast Cancer held in Canada in 1993 identified the need for further education in communication skills for doctors treating patients with cancer, particularly oncologists and surgeons (National forum on Breast Cancer, 1993). Since that time there has been some effort to address the broad issue of effective doctor – patient communication and the more specific issue of developing partnership relationships. Nurses have been involved in some of the workshops and conferences designed to put into action the recommendations related to communication first put forward by the National Forum on Breast Cancer (1993). Hartrick (2001) recounts an experience she had of attending such a forum. The topic was improving relationships between women with breast cancer and their health care providers. The presenter put two slides up for view; the first was of microscopic breast cancer, and the second was of a lovely smiling woman. Differentiating the disease from the woman with breast cancer cut to the heart of the matter for Hartrick and is an issue that women in this study talked about extensively. Hartrick highlights the differences between a curative disease model of care (dominated by biomedical discourse) and a broader understanding of health as a resource for living, and the ability to exercise choice in one's life (WHO, 1986).

Relationships with health care providers, principally doctors, permeated women's discourses and were the source of much agony and distress for many participants in the study. Hartrick (2001) provides an illuminating look at what she calls relational practice and a useful perspective on doctor patient relationships, although I would say her work is equally useful for any health care provider to consider. She asks us to consider three hindering assumptions that she believes flourish in care originating from a disease treatment perspective. These three assumptions are:

1. Relationships with clients are seen as a means to an end. That is, the doctor engages with women with breast cancer in order to achieve a particular outcome, for example, consent to be treated with a certain drug. The relationship is not seen as important in and of itself. In contrast, relational practice views the relationship with women as inherently health promoting and as a worthy goal itself.

2. Relationships can be seen as helpful while engaging with women with breast cancer but are not essential. Relational practice, however, views the relationship as foundational to practice. Whether a practitioner views relationship as important or not, they are in relation with the people they care for. It is impossible not to be in relation, and the participants in this study illustrated this clearly.

3. Communication skills are foundational to developing relationships. Hartrick notes that skills are useful strategies, but being in relation involves much more than the application of particular skills. Being connected and knowing about the person you are relating with are essential components to relational practice.

Evident throughout women's discourses were examples of positive and negative relationships with health care providers. Sometimes negative relationships were the impetus to resistance on the part of women and eventuated in achieving what was needed at the time. Whatever the outcome, a great deal of negative time and energy was spent by ill women in dealing with these incidents. Conversations with doctors who practice with women living with breast cancer about the importance of relating with women and being connected with them in a way that honors their ways of knowing and their discourses would be one strategy undertaken as a result of this research. Certainly we (participants and I) believe that doctors have women's best interests at heart at least most of the time and that they would like to be better at relationships. Given these beliefs, seminars and workshops where women with breast cancer and the doctors caring for them come together with people skilled in relational practice would be another strategy that could be undertaken in order to enhance relationships between doctors and women living with breast cancer.

Nurse Patient Relationships

The absence of discussion regarding care provided by nurses in participants' discourses was startling. Two women had distressing experiences with nurses, while the other women in the study either did not mention nurses at all or, as an afterthought, commented on the nurses in chemo being great. One participant had received a great deal of home nursing care during her first experience of cancer (abdominal cancer), and she was vocal about how helpful they had been and how everything had changed for the better once they were on the scene.

In reflecting about why nurses were so absent in the care of these participants, I began thinking about the dominance of biomedical discourse and its emphasis on treatment and cure of disease. I also reflected on the absence of women's voices, or for that matter any alternative voices other than the biomedical. What that means is that the only way health care providers know about breast cancer is through biomedical discourse. Women's journey and illness experience with breast cancer is muted or absent. It would seem that knowledge about the biomedical disease trajectory rather than a woman's journey with breast cancer might be informing nursing practice as well as the practice of medicine. Certainly nurses, as health care professionals providing nursing care, were not seen by participants as contributing to the healing experiences of women, even though we claim peoples' experiences of health and healing as our domain of practice (Hills, Lindsey, Chisamore, Bassett-Smith, Abbott; Fourier-Chalmers, 1994).

It is not possible to provide definitive answers as to why nursing care was so obscured in women's discourses, but it is possible to raise some questions about the absence of nursing in the care of these participants. Viewing this issue through a postmodern lens, I am guided to think about positioning and reflect on the potential ways that nurses might both position themselves and be positioned in our health care system. I know that nurses are under tremendous pressure and that they have been exposed to the fallout of many of the fiscal restraint policies implemented over the past few years. Nurses everywhere are talking about never having enough time to be with people, being overworked, and finding less and less satisfaction in nursing. Do nurses communicate this to their patients?

Nurses have been and are still positioned as fulfilling the role that other health care professionals deem appropriate for them. Certainly in large bureaucratic organizations like hospitals and cancer clinics there are strong hierarchical relations in place that may constrain nurses from practicing in autonomous ways. For example, in our community it is the surgeons who control access of information to the woman with breast cancer, and nurses are not given an autonomous role in working with women who are pre or postoperatively under their care. Similarly, in the cancer clinic it is the oncologists who control the teaching and information flow to women attending the clinic. Could nurses develop effective relations with women with breast cancer and be instrumental in working alongside them in integrating biomedical discourses with their own story of breast cancer – a partner in women's journey and able to work between both biomedical and women's own discourses?

The fragmented way that women experience diagnosis and treatment for breast cancer also works against nurses fulfilling a healing role for women with breast cancer. Nurses would seldom see the same woman for more than one shift and in fact, may only see a woman during admission or for fifteen or twenty minutes during their shift. Breast cancer surgery is often a day care procedure and, even for the most extensive of mastectomies, a one or at the most a two-day stay in hospital is the norm. There is little time or opportunity to develop relationships and understand an individual woman's experience in this short time.

It is my inclination to focus on the system and professional territory issues that I see may preclude nurses from practicing in the way they have been educated. However, I wonder also about other reasons for the absence of nurses in women's discourses. Are nurses so disillusioned with their work that they have lost interest in exploring with women the ways that they might be of assistance? Do nurses feel especially vulnerable because the disease is breast cancer, and isolate themselves from women because of that? Are nurses simply unaware of the differences between a disease model of care and a health and healing model, a biomedical disease trajectory and an illness journey?

There is much to reflect on regarding nursing practice and the care of women with breast cancer. In the interests of reflecting on the path forward I will conclude this section with the following questions:

1. What might make women's experiences with the health care system more acceptable?
2. How might nursing practice and nurses contribute to that?
3. What would need to change for nurses to be able to contribute to the care of women with breast cancer?
4. How might these changes happen?

Institutional Practices

I have highlighted relational practice for both doctors and nurses in the preceding discussion about responding to women's discourses and reshaping the context of health care, and we have seen the impact that the system has on all aspects of a woman's care. As a research group, we have often talked about how our health care system works, or in many cases does not work. This has been a topic of great interest recently, as our community feels the impact of fiscal restraint, health care professional dissatisfaction, and fragmented delayed care. I have had the opportunity to hear several conference presentations on the concept of Breast Health Centers, a one-location diagnostic and treatment facility staffed by medical, radiological, and nursing experts in breast cancer. There are several such centers across Canada, the United States, and the United Kingdom. These centers serve as models for professional collegiality and partnerships, seamless and less fragmented care. Our research group is interested in pursuing further information about some of these models and potential for adoption in our community.

In the short term, what can be accomplished in reshaping the way health care is offered to women with breast cancer? We have already started a task force in our local hospital in an attempt to bring together various professionals and women experiencing their care. The radiologists have learned that localizing a woman's breast lump first thing in the morning might be good for their schedule but it is unacceptable for a woman to lie on a stretcher for up to eight hours waiting an operating room time. This was a practice that had gone unnoticed until brought to the attention of the task force. Likewise, being in the day care surgery room filled with both men and women and receiving a diagnosis of breast cancer is unsettling. We have many other areas to address, but there is a commitment to continue with this work. A future goal is to nurture this group along at a better pace and to include a wider representation of stakeholders.

I have been on the Education Committee for the Cancer Center for the Southern Interior for the past several years. This is a committee with a mandate to improve care for the clients of the center as well as the education of health care professionals and the public. We have been planning a series of seminars for people working in the center around the issues of education and relation building. Again, our research group is interested in expanding on all these efforts and in seeing that the results from this study are communicated along with the development of action and evaluation plans to be implemented.

Articulating the Relevance of the Study

This research is unique in its emphasis on illuminating women's discourses about living with breast cancer and in its emphasis on the professional, social, historical, and institutional discourses that shape experiences for women. Focusing on women's agency and the development of transformative knowledge is also a unique aspect of this research. Articulating women's experiences and the manner in which they are positioned and resist unsatisfactory positions contributes to theory development about the experience of living with breast cancer. Additionally, the surfacing of women's discourses and, especially, the integrative nature of their discourses and the variations among biomedical disease trajectories and a woman's illness journey contributes to theory development.

Highlighting a woman's journey with breast cancer and her own discourses also makes these available to health care professionals and may provide them with an understanding about women's experiences and an insider's view that they did not have access to before. This research has also illuminated aspects of medical and nursing culture that may act against women with breast cancer receiving the best professional care possible. A discussion of the way our system functions, sometimes to the detriment of women as illustrated in their journey discourse, has been useful in illustrating various ways that practices and systems might be changed. Perhaps most importantly for the women who participated in this study, the reader has seen how women gain a sense of personal agency and transformative knowledge, and health care providers can gain some sense of ways to facilitate these processes.

Implications for Research, Theory and Practice

Further praxis-oriented research is warranted based on the results of this study. It would be particularly interesting to conduct research that explored health care professionals' (surgeons, oncologists, family physicians, and nurses) experiences of working with women with breast cancer. Following on from that could be a participatory action research project with a group of health care professionals who work exclusively with this population in an effort to improve practices. Additionally, research with under-served and diverse populations is clearly important. We have very little information about the experiences of being diagnosed and treated for breast cancer in our community for non English speaking women, women from other cultures or life styles, or very poor women.

There are many implications for education from the findings of this research. The participants in this study were clear in regards to their dissatisfaction with certain practices, the delays and uncertainty surrounding the diagnosis phase of their journey, and the relationships they had or did not have with many health care providers. Education around the content and shape of women's discourses and the places where health care providers seem to fail them the most would be immensely useful to both women and well-meaning and caring health care professionals. Additionally, education around the concepts of agency and positioning would help care providers enhance and encourage positive interactions and the integration of biomedical discourses with women's own discourses and illness journeys. Clearly, these educational endeavors are necessary for all health care professionals involved in the care of women with breast cancer. This would involve the more formal attempts to influence educational programs for nurses, doctors, specialists, etc., but also the need to provide ongoing on-site educational opportunities for people engaged in practice.

Dissemination of the Research

The participants and myself have talked a fair bit about the need to publicize the results of this research. All participants understand the "doctoral dissertation process" at the university and concur with my need to publish in academic journals. All would also agree that professional journals are a good venue for reaching health care professionals. More important to them, however, is the obligation to discuss this research with people practicing in health care institutions, doctors' offices, etc., and to engage this group in dialogue about their practices and women's experiences of receiving care. Additionally, we have talked about the usefulness of publishing in the lay press in an attempt to reach women who are newly diagnosed or who do not have easy access to other women with breast cancer.

A powerful way to disseminate research findings is to speak at conferences, forums, and education and research gatherings. I have already done a fair bit of this and intend to continue. I had an important insight when I was asked last summer to speak at a National Operating Room Nurses conference. I wondered what I could possibly tell them. I know little about the operating room, and certainly women's experiences of being in the operating room was not a big piece of this research. I decided to focus on women's discourses and their illness journey and was gratified to discover that what the participants in this study had to say about living with breast cancer had much impact on the nurses in the audience. There is no doubt in my mind that they will never again see breast cancer surgery as an isolated technical piece of the treatment for breast cancer.

Concluding Thoughts

This research originated from my belief in the critical importance of surfacing women's voices about their living with breast cancer. The feminist postmodern praxis orientation to the study has illuminated the ways in which women construct their own integrative discourses, experience and move among subject positions, exhibit agency both personally and collectively, and as well, develop and utilize transformative knowledge. An examination of women's discourses has focussed our attention on the strengths and capacities of the participants, their illness journey and differences with a biomedical disease trajectory, and provides insights into health care practices and relationships. With these insights health care providers may envision ways of practicing that support and strengthen women's construction of a cogent illness journey and ability to participate in their care in ways meaningful to each individual woman living with breast cancer.

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APPENDIX I – LETTER OF INTRODUCTION

My name is Joan Bassett-Smith. I am a Registered Nurse, currently enrolled in doctoral studies at the University of Victoria. I teach nursing at Okanagan University College and volunteer with the Canadian Cancer Society for the Southern Interior. I am undertaking a research project to explore women's experiences of living with breast cancer. I am interested in how and in what ways our 'talk' about breast cancer affects the ways that nurses and doctors treat women with breast cancer and the ways that women think about their breast cancer.

To accomplish this I need assistance from women who live with breast cancer and who are willing to:

Participate in a minimum of two interviews with the researcher. These interviews would be tape- recorded and you would have access to either the full text of our interviews or a summary that I would prepare for you.

Share with myself your thoughts and feelings about having breast cancer and about your participation in this study.

Participate in group discussions with other women participating in this study. We would talk about what we are learning from the study, what is working well for you and in what ways things might be different.

Your time commitment would extend over approximately a six - nine month period and would involve approximately ten to twelve hours of your time. All appointments, interviews and group discussions would be at a place and time of your choosing.

I would be pleased to explore this study further with you, explain the methods I will employ to ensure your rights, and answer any questions or concerns you may have.

If you are interested in further information, please call me at:

(h) 769 –5513
(w) 762 5445 (7400)

Joan Bassett-Smith

APPENDIX II –CONSENT FORMS

Consent to Participate in a Research Study

Title

Women With Breast cancer and Their Living In and Through Discourses: A Feminist Postmodern Study.

Investigator

Joan Bassett-Smith, R.N.; M.A. Nursing; PhD(c)

Nursing Professor, Okanagan University College

Kelowna, B. C.

Phone: (250) 762-5445 (7400)

Student: University of Victoria

Faculty of Health and Social Development

Supervisor: Dr. L. Sheilds

Intent of Research

The intent of this study is to explore women's experience of living with breast cancer with the intent of illuminating more clearly how women interpret and make meaning of the various ways that we speak about breast cancer. I am interested in learning about the ways that women themselves talk about living with breast cancer and how their experience might be made better. In this study, women with breast cancer and the researcher, will participate in a collaborative process of dialogue and reflection aimed at transformations in our understandings about living with breast cancer and about nursing and medical practices.

Participant Involvement in Study

Participants will be asked to engage in two taped and transcribed interviews with myself (the researcher) and, if willing, join with other participants in two group meetings where we would share some of our understandings about living with breast cancer. This will involve approximately six to ten hours of their time and extend over a seven to nine-month period. All interviews and group discussions would be at the participants' convenience.

Statement of Understanding

I hereby give consent for my participation in the study entitled: Women With Breast Cancer and Their Living In and Through Discourses.

I understand that my participation in this study means the following: I will participate in two interviews with the researcher, and group discussions with the researcher and other participants. I understand that interviews and group discussions will be taped and transcribed and that the transcriber will sign a confidentiality agreement. Additionally, my identity will be concealed by use of pseudonyms and data will be kept in a secure location to which only the researcher will have access.

I understand that I have the right to withdraw from the study at any time and that I will have the opportunity to read full transcripts, or a summary provided by the researcher. I further understand that I can turn the tape recorder off at any time, halt the interview or ask that specific information not be used. If I wish, tapes will be returned to me.

I understand that this research is being conducted as part of a degree in nursing and that there will be a university nursing professor that will be discussing this research with the researcher.

I understand that a dissertation will be written from this research and that it will be held in the University of Victoria Library of Congress. Other publications will be produced from this research but there will be no identifying of individuals. I will have the opportunity to read the dissertation if I wish.

My signature indicates that I am willing to participate in this research and that I have had all my questions answered.

Signature: Participant

Signature: Researcher

Consent to Participate in Group Discussion

Title

Women With Breast Cancer and Their Living in and Through Discourses: A Feminist Postmodern Study

Investigator

Joan Bassett-Smith R.N.; M.A. Nursing; PhD(c)

Nursing Professor, Okanagan University College

Kelowna, B.C.

Phone: (250) 762-5445 (7400)

Student: University of Victoria

Faculty of Health and Social Development

Supervisor: Dr. L. Sheilds. Phone: (250) 721-6467

Intent of Group Discussion

In addition to participation in individual interviews with the researcher, participants are asked to participate in two discussions with other participants. These group discussions would be held at a time convenient for all and at a location approved by the group. The purpose of these group discussions would be to talk about our collective understandings of the experience of living with breast cancer and as well, what we are learning about the issues and possibilities in relation to both living with cancer, and participating in the study. Participants would be encouraged to share only what they feel they want to about their personal story and/or their participation in the research. my focus for the first group meeting would be to generate a sense of comfort and collegiality among participants, to present some of what I have learned and the questions that have been raised for me so far. In the second meeting, I would want to build on our collective understandings and discussions generated from the first meeting. Additionally, I would invite participants to share what we have learned about breast cancer, the different voices we have heard and how the experience of living with breast cancer could be made better.

Voluntary Nature of Participation

Your participation in this research project is completely voluntary and you may choose to withdraw from the study at any time. You may also turn the tape recorder off at any time during discussions.

Confidentiality and Anonymity

Due to the nature of group discussions, participants will come to know one another. Group participants will discuss and agree to maintain confidentiality regarding other participants and all matters discussed in the group. The researcher will tape the group proceedings and provide group members with a synthesis of the discussion. Participants will have the opportunity to provide feedback and request that portions be removed or altered. The researcher will not use identifying data in any formal or informal reports of the group discussions and will abide by the wishes of the group regarding the way in which the group material will be used.

Statement of Understanding

I hereby give my consent for participation in two group discussions associated with the research study entitled: Women With Breast Cancer and Their Living in and Through Discourses: A Feminist Postmodern Study. I understand that my participation means the following. I will participate in two group discussions with other participants in the study. I will share only what I feel comfortable about with regard to my experience of living with breast cancer and being a participant in the study. I understand that group members will come to know each other and that we will all maintain confidentiality about each other and our discussions. I understand that the researcher will tape the discussions and provide the group members with a synthesis of the discussions that we will have the opportunity to review and revise. I understand that the researcher will maintain our confidentiality in all formal and informal reports produced from these discussions. I understand that participation in these groups is voluntary and that I can withdraw from the discussions at any time. my signature indicates that I am willing to participate in these group discussions and that I have had all my questions answered.

Signature: Participant

Signature: Researcher

APPENDIX III –SAMPLE INTERVIEW QUESTIONS

General Research Question

For women living with beast cancer, how are discourses and health care practices implicated in relations of power and how do these discourses and practices inter-relate and inform each other in their care? What are alternative possibilities in creating new discourses and practices for women living with breast cancer?

Specific Research Questions

1. In what ways do women with breast cancer make sense of, engage with and position themselves within and among existing discourses?
2. How do women make their voices heard, and what might women constructed discourses be like?
3. What are the conditions that facilitate/constrain their positioning within discourses and in creating new discourses?
4. What alternative possibilities for understanding and action?

Examples of Questions Relating to Voice, Power/Knowledge, Agency and Praxis

1. How do women come to understand the many ways there are of 'knowing about' breast cancer?
2. What do these different understandings mean to them and how these different ways of 'knowing' influence their experience?
3. Does more than one way of knowing influence the way they live with breast cancer?
4. Do women feel able to exercise their will, make choices and participate in their care?

5. If so, in what ways are they able – in what ways are they unable?
6. What would make their living with breast cancer better for them?
7. How are women's experiences alike – different?
8. What strengths and capacities do women identify?
9. How could things be different?
10. How did things come to be this way?

APPENDIX IV –SUMMARY OF DISSERTATION

Draft Outline of PhD Dissertation Titled: Women With Breast Cancer and their Living In and Through Discourses: A Feminist Postmodern Study

Joan Bassett-Smith- 769-5513

October 8, 2000

I have prepared the following summary of my dissertation in order to provide all the participants in the study the opportunity to become familiar with the way I have conceptualized and presented the data generated over the past two years. This is a draft only and will be reviewed by my committee over the next months. There will be re-organization and re-writing involved so the final chapter organization might look somewhat different. The way I have conceptualized your work would not change except with regard to the feedback you give me. I am wanting to include your thoughts and ideas about how I have presented your data before I submit to my committee and ask that you be in touch at any time if you have further thoughts or questions.

I began this research with the intent of surfacing women's own voices and stories about living with breast cancer. I believe that health care providers have much to learn from women who actually experience our care but our own professional literature is silent about women's experiences, thoughts and feelings as they are diagnosed, treated and then live with breast cancer.

I have used the concept of discourse to look at the ways in which health care providers speak about breast cancer and the ways in which women speak about it. If we examine the ways these discourses are the same and the ways they are different and even contradict one another, we can learn more about what women need from health care providers.

Chapter One

In this chapter I set the background and context for the study. I provide statistics about breast cancer, some information about myself and interest in the topic and then describe the way in which biomedical discourse (medicine) defines what counts as knowledge about breast cancer. I then examine briefly, what oppositional discourses look like and the ways in which they are marginalized by biomedical discourses.

Chapter Two.

I review the literature on breast cancer in this chapter. In my early reading of the literature about breast cancer I was struck with the sterile feel of the nursing and medical literature I was reading. Women's voices and experiences were simply not evident. I wondered how we could possibly provide women centered care if we didn't know anything about their experience. I then moved to reading 'non-professional' literature. It was when I started reading books, poetry and journals written by women living with breast cancer that I realized how much more there was to learn. I also reviewed literature written by feminists and alternative/complementary practitioners, both of whom critique medical discourse for the control it exerts over women. A review of these bodies of literature is captured in this chapter.

Chapter Three

In order to study the questions that I wanted to answer with this research, I needed to design a methodology that allowed me to surface the voices of women and then analyze that data in a way that put biomedical and women's own discourses together. The specific research questions that have guided this study were:

1. In what ways do women with breast cancer make sense of, engage with and position themselves within and among existing discourses?
2. How do women make their voices heard, and what might women constructed discourses be like?
3. What are the conditions that facilitate/ constrain their positioning within discourses and in creating new discourses?
4. What are alternative possibilities for understanding and action?

The methodology I designed to answer these questions is described fully in this chapter along with the manner in which I paid attention to your ethical rights.

Chapter Four

The previous three chapters were written before I began the research and will be revised in some ways to fit more exactly with what I did. This chapter begins the story I have created with your data. I talk here about ethical issues and the ways that I attended to these and I introduce each of you. You will be provided with the vignette I created and have the opportunity to alter it in any way you choose. Think about what you would like the members of my committee to know about you and what would be important for them to know with regard to the composite illness narrative constructed with your words.

Chapter Five

Chapter Five and Six fit together and describe what I have called your illness narrative or story. You each told me your own story about living with breast cancer. From those individual stories I constructed a composite story; one that illustrates how women's experiences are similar and ways that they are different. My hope is that when you read, or we talk about these two chapters you will feel a sense of 'fit'. Yes, that sounds right - or no it isn't quite right. I really appreciate this feedback from you.

Chapter Five tells the story of your journey with breast cancer. It is written as you told it to me and I reconstructed from the composite data. What is significant about this story is that in the telling we see the complexity and fragmentation inherent in the way the system works and the impact for women. There is much for health care providers to learn.

Chapter Six

This chapter pulls together the discourses that I heard you speak. Again I construct them from your data and I look forward to your feedback about the 'fit' for you. The discourses I identified are not ordered in any way and are not separate entities. They co-exist, overlap and intermingle. For the sake of clarity I needed to categorize them. Within the discussion of these discourses I take care to illustrate the similarities and differences within women's discourses. What follows is a very brief summary (this is a 60 page chapter) of each of the participant centered discourses I identified. I have not included examples of your words in this summary but they are abundant in the full chapter.

1. Making Sense of Breast Cancer

This discourse describes and explains the tremendous amount of work that women do in order to gather the information they need to make sense of what is happening to them. Parts of this discourse involve resources; what access do you have to information and how easy was it for you to get information. Other pieces of the discourse involve thc need for you to learn biomedical discourse, the times in the journey when the need to know was more intense and the many ways women came to know about breast cancer.

You were all very active in this work of coming to know about breast cancer. A last piece of this discourse was related to resistance. Some of you met with blocks in your attempts to learn all you could. I finish the discussion of each discourse with a look at the ways in which women's voices might be the same as, different from, or challenge biomedical discourse. This last piece points out some of the ways health care providers might do things differently.

2. Discourse of Acquiescence and Accommodation

This discourse talks about the ways in which women went along with and accommodated to the health care system and professional expertise. What seems important to me is that health care professionals and even women themselves do not seem to recognize this as the strength it is. It describes the 'good patient' role.

3. Discourse of Being in Relation

This discourse is comprised of discussion related to relationships with self, with own body and with health care providers. Many of you talked about not being in relation with self, but rather, being focused on others. You also illuminated clearly how well you knew your own body and you spoke about both positive and negative relationships with doctors and nurses. There is much for health care providers to learn from this discourse. It is clear that relationships with other women with breast cancer are very important and that a more partnership like relationship with doctors is desired.

4. Generating and Maintaining Hope

The need to have and maintain hope was a strong theme in the data. Along with that was many examples and descriptions of the ways in which hope can be fostered or conversely, taken away. It was clear from your talk with me that the responsibility for generating hope fell to you and was not in most cases part of your relationship with your doctor.

5. Being In Limbo

Limbo was a word used by many of you and it refers to the uncertainty and waiting associated with diagnosis and treatment and the knowledge that you live with breast cancer for life. Sometimes the waiting and the uncertainty were unavoidable but it is evident that sometimes, this feeling of being in limbo could be diminished.

6. Being Self Vigilant.

This was a discourse where women were very consistent. All of you have excellent health care practices and are responsible with regard to following through with medical check ups. Many of you, however, experienced great difficulty being heard by your doctors. In some cases this resulted in unacceptable delays in diagnosis and treatment.

7. Discourse of Resistance

Many of you felt the need to take more control over your own care and to challenge doctors or nurses when you did not feel heard. Examples of this were changing doctors or requesting tests that the doctor had not ordered. I am interested in your thoughts about what moved you to taking a more active role.

8. Developing Personal Capacity

This discourse describes how each of you have found a way of living with breast cancer that has meaning for you. Engaging in self care, gaining knowledge of your strengths and capacities and being able to talk about how you are different now, are examples of this discourse.

Chapter Seven

Having presented women centered discourses and a picture of your journey with breast cancer in the previous two chapters, Chapter Seven focuses on my own discourse about what you have taught me about living with breast cancer. Using a feminist postmodern lens alerts me to look for particular things in the data. Specifically, I challenge aspects of biomedical discourse that seem to cause difficulty for women who are being treated for breast cancer. I explain the link between discourse and practices earlier in the dissertation.

I first review postmodern thought and the concepts of discourse, power/knowledge and positioning. I then talk about medicalization and the creation of 'patienthood'. Within this context it is easy to foreground the ways in which power relations are institutionalized in medicine and the manner in which medicalization creates particular subject positions for women with breast cancer. An example would be the way medicine positions women as 'not knowing'. Thus your own knowledge about your body is not acknowledged.

From there, I move to a discussion of the ways in which all of you developed your own sense of personal agency, which I describe as an ability to make your own decisions and move within and among different discourses. All of you created your own healing path using various practices. These included medical treatment but also many others. The way that women work to create a healing path for themselves goes unrecognized by many health care providers. Because it is invisible to doctors and nurses, it seems like it is easy for them to get in the way of that work. This study has focused on the strengths of women living with breast cancer because I believe that knowing about women's strengths and capacities can help health care providers see better ways of practicing and being in relation with their 'patients'. I conclude the chapter with a discussion about (re)claiming women's knowledge about themselves.

Chapter Eight

I want to write you back in to the dissertation in this chapter by discussing the feedback you have given me with regard to being in the research and the way I have presented your data. I also would like you to reflect on the following questions:

1. How was it for you to be in the study?
2. As I bring closure to the research, are there any things you would like said?
3. I have talked in Chapter Seven about the notion of agency. If you had to describe one thing that moved you to taking charge, what would it be? So what happened as a result of that?
4. What suggestions do you have for me with regard to this research?

Our discussion at the meeting and your feedback to me about what you have read and the questions I have asked will provide the substance of this chapter.

In this final chapter I also summarize the research process and the way in which I conceptualized your data. I will likely return to the general and specific research questions I began the study with and summarize a response to these. The final piece is a discussion of the implications of this research for further research and for practice. This is another topic we could talk about in our time together or that you could talk with me about at another time.

APPENDIX V – ELLEN'S STORY

Ellen's Story (June, 14th, 1997)

This is a piece of work written by Ellen following discharge from hospital. In her words, she wrote this to put her mind at ease at what she had endured in hospital. Her poor nursing care was one of the reasons she joined as a participant in the research.

By now I ran through the rest of the narrow hallway. The tall girl in front of me operates her tall legs faster than me. She pushes and balances a wheel chair in front of her. I puff and huff by now. Once in a while I reach down to my right foot in a desperate attempt not to lose my foam rubber slipper.

I am cold, my legs are bare and the hospital gown nearly covers my nakedness. Now comes the end of the tunnel, that is how I call the connector from one hospital building to the other one. In two minutes flat she has crossed the connector. Good timing the government has saved a lot of money. Two patients are handled at once. Great.

Now she swings around the corner, one arm she lifts up, the fore-finger's point to the wall and I guess, that must be the next waiting room. She, by now I named her Brunhilda, does not stop for a second. Off she runs with the wheelchair to another destination. Out of breath I fall into the next chair. I freeze, I shake. My husband gives me his jacket to cover my naked legs. Careful, I reach down and pull the slippers into place. I held on to them with my toes for the last few minutes.

What time is it? I look at my husband. Only ten more minutes to go – he shows me his watch. Ten minutes. I am afraid.

A tall man walks up to my chair. Are you ES? He looks down at me. Please come out into the hallway with me. With slow motions – I do not feel my arms or legs. I follow him. Please open your mouth and stick out your tongue, he asks – polite as he bends down to examine me in the hallway around the corner of the waiting room.

Ya, that is the doctor who puts people under or out during an operation. I do believe I have got to get my blood pressure checked. I take the mini blade out to talk. Oh, no, there is no more time for that. That was done when you came in. but it says so in my instructions. I had the nerve to talk back. It is too late for that now and not necessary. He talks to me as if I am a child. Two minutes later I sit in my chair again, covered by my husbands jacket. I need your glasses please, a friendly nurse reaches out towards me. Can't I keep my glasses on? I am nearly blind without them. No, rules and regulations forbid the wearing of glasses. She is a nurse of consequence.

June, 15th, 1997

This hallway is wide. It is filled with fog. My eyes are not able to see clear lines. A nurse leads me toward the execution chamber. By now my fear has turned into reasoning. They won't shoot me because that is against the law. And they will knock me out to cut off my breasts, that is, I am sure of. I keep on to reason with myself. I am glad I am here and not in the war zone. There the hands cut off the breasts and that one girl they nailed to the gate.

Slow I walk, my foam rubber shoes slip again but I do not care. There through my clouded eyes, I see the long table. Don't fall, the nurse holds my arm tight. Up the stairs now, you go up now. She still holds my arm. Two steps I make out and careful, I feel my way up. I am ice cold, stretched out on the table. I wander back to the war zone.

That feels good. They cover me from my waist down with a warm blanket. Through the mist I see the nurses and a man in the background. Do you want to speak to a surgeon, a nurse asks in a friendly tone? Oh, that must be him, I squeeze my eyes toward him. I see him smile at me. It is more a grimace with a blurry smile. Stretch her arms wide out he tells the nurse and I freeze. Almighty, now I get crucified shoots in my mind.

The doctor who does me under works on my left arm. One needle in and out. Another one in and out. I cannot find a vein, he speaks with a clear voice. I try the feet. Needles in and out on the left foot and needles in and out on the right foot. Those bastards hurt.

Mrs S. nothing I can do with you. I do not find a vein. I give you a needle to put you to sleep and then I give you the anesthesia, he looks at me through the fog. My mind shuts down. My last thought dwindles. Where are the nails?

I piss as a horse would do. The water pours out of me. It feels as if a pressurized pipe has burst. That feels good. I squeeze some more drops in to the pee pot and relieved I pull myself up. My mind is dull. My arms do not want to do what I want them to do. Pull me up, I say. Slow, they follow my command.

The night nurse took the left railing down on my bed. The help button was attached to that site and now it was in between the railing and the bed. After I came to life again they gave me a lot of water to drink. Ice water. That is good for you, I was told. That was the reason for my great dilemma. Around 2pm my water starts to rise, up to my tongue. Panic in my blurry mind sets in. I've got to pee. I burst, I explode if nobody helps me to get up. I reach for the help button. I can hardly move, I do not find the button.

Matti, help me. I will not wet my bed. I do not want to have a wet bed. Matti, please come and help me. My diapers, no more diapers. The pressure makes my belly into a balloon. Now I gather all the blankets they gave me and work them to a log pile under me. Completely exhausted, I rest but I cannot let my water go. No, no, I do not pee my bed.

There is more to come about the way I got myself up to the bathroom.

APPENDIX VI - LEENA'S POEMS

A Cloud of Unknowing — written in 1985 after my lumpectomy and while waiting for radiation.

I was
    at peace …
The cancer
    was taken.
Why now
    this invasion?
This cloud
    of unknowing?
Three weeks
    seem forever
When you are
    planning
The lives
    of your students.
How will it
    disrupt them?
Already disrupted
    by losing a teacher.
The oft empty
    promise
You'll know
    by the weekend.
Disrupted …
    you must
Wait
    your turn
Then
    you understand
    quite well
The impatient student's
    push for attention
Ahead of his classmates.
But isn't it urgent
    to kill off stray cells?
How silly
    to think so …
I must learn
    to be patient …
Doctors are busy

and I am
on paper …
A file folder only
with pictures of nothing
My doctor has told me
'twas only the dead cells
That spilled
out the story.
They said I must have
radiation
So stray cells
won't migrate
Metasictize,
spreading
their hideous influence.
Oh God give me
patience
and gentle compassion
For others …
whose lives
are disrupted
With waiting
and wondering …

Cancer - Written for use as a starter for the Cancer Support Group.

Only a six letter word
But it can change
Your values
Your attitudes
Your plans …
Your dreams …
And your lifestyle.

It interrupts
Your life
and makes
you more aware
of Death,
It can make time
seem fleeting
or
Interminably long
It can sap your
Energy

or arouse anger
And a fighting spirit.
Only a word with six letters
CANCER.

The Cancer Society - published in the Cancer Society Journal

From the roots of deep compassion
Sprang the Cancer Caring Tree ...
Now it reaches out in branches
That support us daringly.

Terry Fox did not have money
But he used his precious time,
His one leg and love of running,
And we watched the millions climb.

All the green leaves growing yearly
From the dollars that are shared
Contribute annual rings of learning
A tribute to the folks who cared.

We CANSURMOUNT the many problems
When hands and heart reach out to hear
The special cares that need surmounting ...
How good to reach a listening ear.

When women who are prone to nuture
Feel mutilated many ways
We can now REACH FOR RECOVERY
And make the most of future days.

LIVING WITH CANCER can be lonely
So we join hearts and heads to share
All the new things we've been learning
About disease and love and care.

The research roots are always reaching
For new treatments, for the cause. ...
Is it environment, stress or diet?
What makes those T cells take a pause?

So the tree has roots and branches
And its annual growth to share,
Recording all the acts of kindness
Done with love when people care.