

MAKING THE CONNECTIONS:  
WOMEN TALK ABOUT BREAST SELF EXAMINATION

CENTRE FOR NEWFOUNDLAND STUDIES

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MAKING THE CONNECTIONS:  
WOMEN TALK ABOUT BREAST SELF EXAMINATION

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## Abstract

Breast cancer is a serious health concern for women. Early detection has been hailed as key to reducing the morbidity and mortality associated with this disease. Largely as a result of three large trials that failed to demonstrate a mortality reduction with breast self examination (BSE), the usefulness of this screening method has been seriously questioned. In 2001, the Canadian Task Force for Preventive Health Care concluded there was fair evidence to recommend physicians no longer routinely teach BSE to women. Through reports in the academic and lay literature, women have been advised that BSE may not only be ineffective, but harmful to them. The research problem is that there is a poor understanding of the meaning of BSE to women within a society that does not value it. Previous research on BSE was chiefly concerned with measuring women's knowledge, attitudes and beliefs related to BSE with the primary aim of increasing compliance. Yet, little was known about how women really felt about BSE. To investigate this phenomenon, women were engaged over time in a cycle of collective self-reflective inquiry to explore personal and social factors influencing their practice of BSE. This was achieved through a series of group discussions with two groups of women as they examined their everyday experiences related to BSE. Consistent with a participatory action approach, the women were considered co-researchers and were actively involved in the framing and analysis of the research problem. Thematic analysis allowed for the collaborative identification of the temporal map components that described the context of BSE for these women. These components were later organized by the women into a concept map, which provided a meaningful schematic representation of the meaning of BSE to them. Consistent with a feminist experiential approach, the standpoint of women was considered a valuable source of knowledge. Through this collective inquiry, the women developed a critical consciousness of the

commonality of their personal experiences in relation to BSE, and their relationship to the larger social environment. In this way, the women were able to more fully understand the complexity of personal and social factors influencing the meaning of BSE to them, which was empowering. At the beginning of the research process, the women's subject position was characterized by their feelings of vulnerability in relation to their perceptions of breast cancer as a lethal disease and their inferior status in the world in relation to men. BSE is an intensely personal issue for women. It brings to the fore a complex web of interrelated meanings and experiences such as those related to cancer (breast cancer in particular), being a woman (and having breasts), and the health care system (including their treatment by physicians). By situating BSE at the juncture between these phenomena, a greater understanding of its meaning to women can be achieved. Three dominant discourses are relevant to women's practice of BSE: (a) femininity, (b) medical and technological dominance, and (c) lifestyle and responsibility for breast cancer. To the extent that breast cancer is seen as a threat to a woman's self-worth, she will be reluctant to do it. To the extent that a woman is ambivalent about her relationship with her physician and medical technology, BSE may be seen as a threat to her ability to care for herself. To the extent that the prevention, diagnosis and treatment of breast cancer is not well understood, BSE brings to the foreground the uncertainties of the disease and the reluctance of women to be held accountable for its trajectory. This research study has shown that experiential knowledge held by women is important and should not be subjugated by increasing medical and technological dominance. Relying solely on scientific evidence to evaluate BSE provides an incomplete measure of its value. Future research into BSE and other issues affecting women's health should be carried out collaboratively with women so that their voices are heard.

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## Preface

This research explores the meaning of breast self examination (BSE) to women. This area of interest grew out of both my personal and professional experience.

My mother was diagnosed with breast cancer at the age of 46, with a tumour her doctor described as “the size of a grapefruit”. Her diagnostic work-up began after I observed Mom undress and noticed her deformed breast and inverted nipple. I was in nursing school at the time and knew these changes to be ominous signs of the disease. When asked, she could never clearly express whether or not she knew about the changes in her breast. In fact, she was reluctant to even speak about it. Her reticence to discuss this always intrigued me and caused me to ponder on its origin: a reluctance on her part to admit that she had not had the obvious abnormality assessed; a mental rejection or denial of its existence; or perhaps an alienation from her body so profound that she did not look at herself, and had, in fact, never seen it before. She was a brave and proud woman who did not speak freely about the loss of her breast and I always struggled with understanding how she did not discover (or attend to) a tumor as large as hers. As expected, Mom’s cancer had spread extensively to her lymph nodes and she was diagnosed with bone cancer six years later. After a year of excruciating pain related to metastatic involvement in the skull, spine, ribs, and pelvis, Mom died at the age of 53.

Three years later, I became employed with a provincial breast screening program. My responsibilities included promoting breast screening including mammography, clinical breast examination, and breast self examination to women and health professionals. In addition, I performed clinical breast examination on women aged 50-69 at the screening centre. I was convinced of the importance of a three-pronged approach to breast screening. I believed in the value of screening mammography for women 50-69 years of age. Based on evidence, I also felt

strongly about the need for clinical breast examination as an important method of breast cancer detection, especially for younger women, when mammography is not as effective, or to find particular types of cancers not easily detected by mammography. I had researched and felt convinced of the value and importance of breast self examination for women of all ages, and the inability of randomized control trials to evaluate or demonstrate its worth.

Despite the comprehensive approach to breast screening established in our province, a debate began in our program (and others in the country) around whether or not we should be teaching women to examine their breasts, or if clinical breast examination was effective at all. Over time, there was an increasing emphasis placed on screening mammography nationally, to the extent that funding for other components was threatened or reduced.

While believing in the effectiveness of mammography for women 50 to 69 years of age, I was nevertheless dismayed that the focus of breast screening was invariably on the high-tech, expensive and expert-driven mammography. I was extremely concerned the comprehensive approach to breast screening would be lost in our program and began to advocate for maintaining all components. My efforts to educate health professionals, policy makers and the general public about the need for a three-pronged approach to breast screening were not appreciated by all. I was formally reprimanded for speaking at a national professional workshop and denied funding to participate in an international conference as an invited speaker. At the same time as the debate raged within breast screening circles about whether all women should receive a clinical breast examination or be taught how to examine their own breasts, our program decided to extend its mammography screening to women aged 40-49 years (for whom population-based screening was not recommended by most studies). Feeling unable to effectively influence policy, I enrolled in doctoral studies and resigned from my employment with the breast screening program.

For many years I have been keenly interested in issues that affect women's lives and have worked in numerous community and government programs to advance women's health including those related to violence against women, HIV prevention, healthy sexuality, and addictions prevention, in addition to breast cancer. I have been involved in volunteer community services for many years with organizations related to cancer including the Canadian Cancer Society, the Canadian Breast Cancer Research Initiative, the Newfoundland Cancer Treatment and Research Foundation, the Canadian Breast Cancer Foundation, and the World Breast Cancer Organization.

## Chapter I

### Introduction

Breast cancer is a serious health concern for women. It is the most frequently diagnosed cancer and a major cause of premature death and morbidity in Canada and around the world. Breast self examination (BSE) has been recommended for decades as one of three screening methods for the early detection of breast cancer. Recently, the effectiveness of BSE has been called into question, mainly owing to the results of three large population-based or randomized trials that reported it did not reduce breast cancer mortality. Most damaging were the final results of the Shanghai Trial released in 2002, which led respected and influential organizations to change their recommendations concerning the promotion or practice of BSE. One example is the Canadian Task Force on Preventive Health Care that concluded there was fair evidence of no benefit and good evidence of harm associated with its practice. As a result, some programs and organizations concerned with women's health have stopped teaching women how to do BSE, or advised women that existing evidence does not support its practice, or even that it is associated with health risks such as unnecessary diagnostic work-up. In addition, the media has widely reported the results of the trials, commentary on the results, and the changing policies of organizations such as the Canadian Task Force on Preventive Health Care.

Women have become aware of, and confused by, the debate surrounding BSE. While BSE has never been an exact science, women have been reasonably confident that looking at, and touching their breasts, could lead to an earlier diagnosis of breast cancer (than not doing so) and that most breast cancers are found by women themselves. Now they were hearing that BSE might be a useless exercise. Historically, women were confused about how to do BSE, now they

were experiencing ambivalence at a much deeper level – whether or not to bother doing BSE at all.

The majority of evidence related to BSE has been gathered in large epidemiological studies that have evaluated the effectiveness of BSE education (or ways of increasing its effectiveness), or the demographic or cognitive factors associated with its practice. What has not been studied well, and what is not well known, is how women feel about BSE. The research problem is that there is poor understanding of the meaning of BSE to women within a society that does not value it.

What is needed to address this research problem is a more in-depth investigation of women's understanding of BSE. This requires a sustained engagement with women to grasp this issue in its full complexity. Such an exploration would benefit from an iterative process of data gathering that would encourage women to critically reflect on, perhaps for the first time, their everyday social practices and beliefs systems about BSE. Breast cancer affects the quality of life of a large number of women in our society and this research focuses on an issue pertinent to their everyday lives.

It is important that women have meaningful input into the research process by being actively engaged in the evolving framing and analysis of the problem. Such a participatory research design empowers the participants to probe more deeply, and more comprehensively, the issues of concern to them relevant to BSE. It is an approach that is not only respectful of women, but has the potential to improve the quality of their lives and contribute to their emancipation. This study aims to explore the meaning of BSE to women by encouraging them to critically reflect upon personal and social factors related to its practice. This inquiry is significant because it examines BSE in a manner not previously undertaken. It has the potential to extend

understanding, not just about BSE, but the context of women's lives and how systemic social phenomena may influence their health beliefs and practices.

## Chapter II

### Breast Cancer Screening

#### Introduction

The purpose of this chapter is to provide an overview of seminal and often-contradictory information related to breast cancer and breast screening including BSE, clinical breast examination, and mammography. It will begin with an examination of the epidemiology of cancer and breast cancer in particular. Conflicting information related to risk factors for breast cancer is highlighted to demonstrate the contradictory and changing messages to which women are exposed, which may cause confusion and bewilderment. An in-depth exploration of the three large BSE trials will follow, including a critique of their methodology and findings. A review of evidence related to the usefulness of clinical breast examination and mammography will also be presented, along with a discussion of the inconsistent application of evidence related to screening.

#### The burden of cancer

Cancer is a growing threat to the health of our world's people. Over 10 million people are newly diagnosed every year, and global incidence rates are predicted to increase by 50% within the next 20 years (Stewart & Kleihues, 2003). In Canada, it is the largest contributor to premature death at present (National Cancer Institute of Canada [NCIC], 2004), and will soon become the leading cause of death overall (Canadian Strategy for Cancer Control, 2002).

#### The epidemiology of breast cancer

Breast cancer is a disease almost exclusively affecting women. The global incidence rate of breast cancer is increasing, even in countries with historically low rates (Russo, 2002).

Approximately one million women develop breast cancer every year, making it the most common cancer (World Health Organization [WHO], 2003) and the most common cause of cancer-related death (Anderson et al., 2003) among women worldwide.

Breast cancer incidence has been increasing in Canada over the past 15 years. This year, it is projected that more than 21,200 women will be diagnosed with the disease (NCIC, 2004). And while breast cancer is considered to have a good prognosis overall, one quarter of all women with the disease will die from it. Compared with other types of cancers, breast cancer disproportionately affects the young. Twenty-one percent of Canadian cases are found in women less than 50 years of age, for whom mortality rates are highest and there are no clear screening guidelines. Due to a combination of prevalence, earlier age of onset, and relatively shorter survival times, breast cancer is among the top causes of potential years of life lost in Canada (NCIC).

#### Natural history

Breast cancer is a complex disease. It is usually slow growing and indolent and may take as long as eight years for a single neoplastic breast cell to become a 1 cm mass, during which time the woman is asymptomatic. Once diagnosed, however, the median survival time is about 3 years if left untreated (Bennett, Steinbach, Hardt, & Haigh, 2001). Breast cancer most commonly begins in the ducts (86%), followed by the lobes (12%), and the remainder in the surrounding tissue (ibid).

The term cancer signifies the spread of the primary tumour into surrounding tissue. Tumours that have not spread to surrounding tissue are termed non-invasive or in-situ. There is no definitive way to know how many of these in-situ tumours would progress to cancer (Humphrey, Helfand, Chan, & Woolf, 2002). For this reason, in-situ tumours in the duct (DCIS)

are often treated as if they were true cancers, and in-situ tumours of the lobe (LCIS) are generally considered to be a marker for an overall increased risk of breast cancer (Bennett et al., 2001). It is very likely that many instances of DCIS, which ultimately posed little threat to the woman's health, have been over-treated with the usual cancer therapeutics. In these cases, the treatment was more dangerous than the 'disease' (Humphrey et al., 2002).

Cancer staging is determined by the size of the tumour, lymph node involvement and presence of metastasis (Bennett et al., 2001). The stages of breast cancer range from 0 (in-situ; 100% 5-year survival) to IV (distal metastases; 10% 5-year survival). Metastasis refers to the growth of abnormal cells distant from the primary site and most often occurs within two years of initial surgical treatment (Bennett et al., 2001). This is not necessarily the case with breast cancer as some tumours can take up to 25 years to be detectable as a recurrence. For this reason, breast cancer should be thought of as a chronic disease (Love, 2000).

### Risk factors

The majority of breast cancer cases (67%) are termed sporadic, meaning the woman has no known risk factors. Almost one-quarter of women have a family history, and 10% have a known genetic link such as BRCA1 and BRCA2 (Bennett et al., 2001). In addition to a familial or heritable risk, increasing age and being a woman are the greatest risk factors. These factors are not modifiable.

Suspected risk factors include early menarche and late menopause, nulliparity, late childbearing, obesity, high fat diet, smoking, alcohol, the environment, and atypical breast cells (Bennett et al., 2001). But epidemiological studies have sometimes provided contradictory and confusing results about these and other risk factors. The following is a brief summary of recent reports regarding the risks associated with breast cancer.

### Genetic mutations

While early studies indicated that individuals possessing BRCA1 and BRCA2 mutations had a lifetime risk of breast cancer of 71-85%, a recent study by Begg (2002) suggests this risk may have been overestimated as there were other shared genetic and environmental risk factors left unexplored.

### Pregnancy and breastfeeding

The long-held belief that pregnancy has a protective effect against breast cancer was upheld by a recent meta-analysis of 47 studies (Collaborative Group, 2002). However, a report the same year from the Society of Obstetrics and Gynaecology ([SOGC]; Helawa, Levesque, & Prevencher, 2002) raised concern there may actually be a transient increased risk of breast cancer for the first 3-4 years after delivery of a singleton baby, followed by a subsequent reduced lifetime risk. In the same reports, the protective effect of breastfeeding was upheld, regardless of the number of children born to the breastfeeding mother.

### Diet and body weight

The association between diet, body fat, and breast cancer is sometimes unclear as age appears to be a mitigating factor. In 2002, Shin et al. reported that low-fat dairy consumption was associated with a moderate risk reduction in pre-menopausal women but not post-menopausal women. The following year, the Nurses' Health Study reported that consumption of eggs may increase the risk of breast cancer in pre-menopausal but not post-menopausal women (Holmes et al., 2003). In addition, the Nurses' Health Study did not support many previous epidemiological reports of a link between the consumption of animal protein and breast cancer,

although a later study that year did (Cho et al., 2003). With regard to weight gain, Russo (2002) reported that a gain of 10 kg or more increased breast cancer risk for women 55 years and older, but this risk was not evidenced with younger women. A report the following year (Yanovski et al., 2003) contradicted these findings for pre-menopausal women, reporting an association between increased body fat and breast cancer.

### Physical activity

Previous studies have demonstrated a dose-response relationship between exercise and reduced breast cancer risk (Lee, 2003). However, a recent large cohort study among postmenopausal women suggested there is little additional risk reduction with physical activity levels higher than moderate (McTeirman et al., 2003).

### Oral contraceptives

A case control study released two years ago found that oral contraceptives did not increase the risk of breast cancer in women aged 35-64. This contradicted a meta-analysis of 54 studies published in 1996 that found a modest increased risk of breast cancer among oral contraceptive users (Marchbanks et al., 2002).

### Hormonal therapy

For decades women have been prescribed hormone replacement therapy (HRT) to protect against various conditions associated with menopause. However, the Women's Health Initiative trial was halted in 2002 when combination (estrogen and progesterone) therapy was found to be associated with an increased risk of breast cancer in post-menopausal women (Working Group, 2002). Evidence provided by the United Kingdom (U.K.) 'Million Dollar' study (Beral, 2003) the following year supported this association, citing an additional 20,000

cases of breast cancer in U.K. women aged 50-64 over the past decade because of HRT.

However, there have been conflicting reports of the risk posed by breast cancer associated with HRT. Cheek et al. (2002) reviewed the case histories of 292 post-menopausal women with breast cancer and reported that while long-term use of any type of HRT increased the risk of getting breast cancer, the tumours produced were less aggressive and resulted in longer than average survival. Contradictory to this, the Women's Health Initiative trial reported that post-menopausal women on combination therapy for five years were diagnosed at a more advanced stage than women in the placebo group (Chlebowski et al., 2003). The same year, a case control study among elderly women in the U.S. found that estrogen-only therapy did not increase the risk of invasive breast cancer, while combination therapy did (Li et al., 2003).

Evidence pertaining to Tamoxifen as a chemo preventive agent for breast cancer continues to be controversial. Previous European and American studies found contradictory results in this regard and Tamoxifen therapy has been associated with an increased risk of death by other causes (Gottlieb, 2002; IBIS Investigators & Cuzick, 2002).

### Tobacco

The link between cigarette smoking and breast cancer is tenuous and recent findings suggest any associated risk may be partially dependent on the age of initiation and pregnancy history. Smoking may increase the risk of breast cancer in pre-menopausal women who started smoking within five years of menarche and had been pregnant, as well as in women who were heavy or long-term smokers and were never pregnant (Band, Le, Fang, & Deschamps, 2002). In contrast, the same study suggested that postmenopausal women who gained weight after the age of 18, and who started to smoke after a first full-term pregnancy, had a significantly lower risk of breast cancer.

### Other associations with breast cancer

Breast cancer has been linked to pesticide exposure (Charlier et al., 2003), stressful life events such as divorce (Lillberg et al., 2003), alcohol (Aronson, 2003), size at birth (McCormack et al., 2003), and antibiotic use (Velicer et al., 2004). On the other hand, recent reports of mitigating factors include the use of non-steroidal anti-inflammatory drugs (Rauscher, 2003b) and primary hypothyroidism (Rauscher, 2003a).

Fibrocystic 'disease' has been associated with an increased risk of breast cancer. It is important to note that half of all women 20-50 years of age have fibrocystic breasts (Bennett et al., 2001), a catch-all phrase for cyclic tender, lumpy breasts. This is not the same as atypia, which is a risk marker, although most women (and some physicians) associate this common condition with increased breast cancer risk. Good evidence for this association is lacking.

The WHO reports that cancer is associated with affluence and a Western lifestyle characterized by poor diet and low physical activity (WHO, 2003). The Canadian Cancer Society (CCS) proposes that at least 50% of cancer can be prevented through healthy lifestyle choices (CCS, 2003), and encourages women to eat well, exercise, and limit alcohol intake to reduce breast cancer risk.

### Research pending

More research is needed to fully understand the natural history of breast cancer and associated risk factors. A recently launched Canadian study will investigate the etiology of breast cancer, considering such factors as diet, exercise, HRT, lipstick, melatonin levels, plastics, paint, deodorant, and cleaning solvents (Morrison, 2002).

## The role of early detection

Breast cancer is a disease for which there are a lot of unanswered questions. There is no known way to prevent it from developing, there is conflicting evidence on associated risk factors, its natural history is not well understood, and treatment is not 100% effective. Therefore, early detection remains the best means of preventing the debilitation and death resulting from breast cancer (Bailar & Gornick, 1997).

Mammography, clinical breast examination (CBE) by a trained health professional, and breast self examination (BSE) are the three most recognized ways to detect cancer of the breast. In 1988, a Canadian national workshop on breast screening recommended that all women aged 50-69 years be offered an early detection program consisting of these early detection techniques. Of the three, mammography is widely considered to be the screening method of choice (Mittra, 1994). There are other types of screening methods showing promise, such as ductal lavage and magnetic resonance imaging, but these are not yet appropriate for population-based screening.

The remainder of this chapter will review evidence concerning the effectiveness of breast screening, with emphasis on breast self examination, and provide a summary of recommendations by major health care associations internationally related to breast screening.

### Breast self examination

William Halsted popularised the concept of BSE in the early 1900's. It is based on the theory that breast cancer begins as a local disease and its early detection will lead to lower mortality (Lerner, 2002). BSE includes inspection and palpation of the breasts and node-bearing areas. Fifty years ago, the American Cancer Society (ACS), National Cancer Institute (NCI), and the Canadian Cancer Society (CCS) began to produce and distribute promotional materials to the public encouraging its practice. Medical textbooks began to incorporate BSE as an early

detection technique (Haagensen, 1956). During the second wave of feminism in the 1970's, BSE received additional attention and was promoted as a way for women to take control of their health and become less reliant on the medical system (Lerner, 2002).

BSE is important for several reasons. It can find abnormal changes in breast tissue that cannot be viewed by mammography (for example, the upper chest wall and axillae). It may be especially important in women too young or old for population-based screening and for those who do not have access to, or do not avail of, screening mammography and clinical breast examination. Finally, it can detect interval cancers between regular breast screenings. BSE is inexpensive, non-invasive, and the only breast screening maneuver that can be done by virtually all women without the aid of expensive machinery or expert health care professionals.

Although BSE has been promoted for over 50 years, only about one-quarter to one-third of women surveyed examine their breasts regularly (Seidel et al., 1991; Stephens & Fowler, 1993; Strickland et al., 1997). And practice does not equal proficiency in technique or lump detection. Despite this, 75-90% of all breast cancers are found by women themselves (CCS, 1996; Engel, 1996; Greenberger & Hinthorn, 1993; Judge, Zurdema, & Fitzgerald, 1989; Semiglazov, Sagaidak, Moiseyenko, & Mikhailov, 1993; Semiglazov, Moiseyenko, Protsenko, & Kharikova, 1996) and women can detect lumps less than 2 cm in diameter when survival is greatest (Dixon, 1995; Screening Program for Breast Cancer, 1996).

#### Conflicting evidence of BSE effectiveness

As a screening technique, BSE has received support and criticism. A number of observational studies and reviews of the literature have provided evidence of its usefulness. In 1979, the Canadian Journal of Public Health (CJPH) established the case for teaching BSE, determining through a review of the literature, there was sufficient evidence of effectiveness

(Alcoe & McDermott, 1979). During the mid-eighties, a number of authors supported the role of BSE in finding tumors at an early stage (Dowle et al, 1987; Foster & Costanza, 1985; Huguley et al., 1988; Kegeles, 1985; Mant et al, 1987). In the late 80s, Hill (1988) reiterated the findings of the CJPH, through a meta-analysis of twelve BSE studies that looked at pre-morbid BSE practice or the circumstances of detection, concluding there was strong support for the value of BSE. Further evidence of support for BSE was provided by a retrospective study in 1992 when it was associated with earlier stage at detection and a significantly smaller projection of death compared to BSE found by chance (Kuroishi, 1992). Two case control studies published in the 1990's demonstrated that proficiency of BSE practice, not frequency, was associated with reduced mortality (Harvey et al., 1997; Newcomb, Weiss, & Storer, 1991). Ten years ago, Gastrin (1994) reported on the results of a large Finnish cohort study of women who were practicing BSE. The breast cancer mortality rate in the BSE group was 0.71 of the Finnish population. Other studies demonstrating a reduced risk of mortality associated with BSE practice include Huguley et al. (1988) and LeGeyte et al. (1992). Weiss (2003) states that most studies have found that cancer detected by BSE are smaller, more likely to be confined to the breast, and are associated with longer survival than those detected without BSE.

Two studies have demonstrated the importance of BSE as an adjunct to mammography. A review of 170 interval cancers within an organized Canadian breast screening program revealed that 77% were first detected by women themselves regardless of age, at an early stage, and with no evidence of lymph node involvement (Hislop, Worth, Kan & Rousseau, 1997). Also in 1997, Chart and Franssen reviewed clinical records pertaining to high risk women under surveillance for breast cancer and found that mammography was particularly effective in detecting ductal carcinoma in situ but was the initial abnormal finding in only one of the seven

invasive tumours found. In both studies, mammography alone would have missed a substantial number of breast cancer cases. The authors caution against the sole reliance on mammography for the early detection of breast cancer.

However, several authors have questioned the effectiveness of BSE. Several studies have not demonstrated an association between BSE and the early detection of breast cancer (Koibuchi et al., 1998; Kurebayashi, Shimozuma, & Sonoo, 1994; Smith & Burns, 1985; Ogawa et al., 1987) or reduced mortality (Auvinen, Elovainio, & Hakama, 1996; Kurebayashi et al., 1994; McPherson et al., 1997). A case control study reported that BSE frequency was not related to the diagnosis of advanced breast cancer (Muscat & Huncharek, 1991). Unfortunately proficiency of BSE was not reported and this may have influenced the results. A cohort study of American women (Holmberg, Ekblom Calle, Mokdad, & Byers, 1997) did not demonstrate a difference in breast cancer mortality among women performing BSE in 1959, although it must be noted that only women who performed BSE monthly were included in the BSE group. This may have limited the ability of the study to detect a mortality difference (i.e., women who performed BSE every two months were put into the non-BSE group). As well, BSE practice in 1959 may not be comparable to recent BSE practice, following decades of promotion. The authors of a recent review article did not support the practice of BSE (Hackshaw & Paul, 2003) despite a pooled relative risk for mortality of 0.64 (95% CI 0.56-0.73) and a pooled relative risk of advanced disease of 0.60 (95% CI 0.46-0.80). The authors minimize these findings by stating they are most likely due to 'bias and confounding', though these are not explained well. Other reports stated that BSE increased the anxiety of women (Frank & Mai, 1985; Senie, Rosen, & Lesser, 1981; Smith, Francis and Polissar, 1980).

### The call for randomised controlled trials

In 1983, the WHO called for randomised controlled trials to study the ability of BSE to reduce breast cancer mortality (Miller, Chamberlain, & Tsechkovski, 1985). By 1989, the relationship between BSE and reduced breast cancer mortality was seriously questioned (Alcoe, Wallace, & Beck, 1990), re-emphasizing the need for a stringent evaluation of its effectiveness. That year the call for randomised controlled trials was repeated by the International Union against Cancer Project on Evaluation of Screening for Cancer (Miller, Chamberlain, Day, Hakama, & Prorok, 1990).

It is important to review in some depth the three large-scale trials that attempted to measure the effectiveness of BSE in reducing breast cancer mortality. Because health care purports to operate within a positivistic and evidenced-based scientific paradigm, much credibility is placed on the results of these trials. Randomised, and to a lesser extent quasi-randomised trials, are widely considered to be the gold standard for evaluating a therapeutic or preventive intervention. The results of trials are therefore frequently cited in the literature. In the case of BSE, the three trials failed to show a significant mortality reduction in breast cancer and the results are often repeated, almost entirely as “proof” that BSE is not effective. It is argued here that there were significant methodological weaknesses in study design, implementation, or reporting that greatly diminish the confidence that should be placed in them as a rigorous evaluation of BSE. The following discussion of the three trials will briefly describe their methodology and results, with a critical reflection on perceived weaknesses that limit their findings.

All three studies were prospective; but only one was truly randomised. The U.K. Trial was a non-randomised, population-based study. The WHO/Russia trial was randomised, but still

population-based as the allocation of women was limited by their city of residence. Only the Shanghai Trial was randomised and not population-based. For this reason, its results were greatly anticipated and widely reported as the best evidence to date on BSE. See Table 1 for a summary of the major characteristics of the three trials.

**Table 1: Randomized controlled trials of BSE**

Trial	Participants	Follow-up/Outcome Measurement	Results
U.K.	Over 190,000 women aged 45-64 from 8 geographic areas enrolled in BSE arm; Women recruited from patient lists of general practitioners; Began in 1979	Most recent data released after 16 years of follow-up; Benefit measured by mortality reduction	No difference in groups in breast cancer mortality; No significant difference in the size of tumours detected.
WHO/Russia	193,000 women aged 40-64; Women recruited from health clinics (St. Petersburg) and factories (Moscow); Began in 1985	Most recent data released after 12 years of follow-up; Benefit measured by mortality reduction	No difference in breast cancer mortality or tumour stage; higher rate of benign biopsies in intervention group
Shanghai	266,064 women aged 31-64; Women recruited from factories; Began in 1989	Final data released after 10-11 years of follow-up; Benefit measured by mortality reduction	No difference in breast cancer mortality or the survival curve; more benign biopsies in intervention group

#### U.K. Trial

The U.K. trial (Ellman, Moss, Coleman, & Chamberlain, 1993; U.K. Trial of Early Detection of Breast Cancer Group [UKTEDBC], 1993; 1999) was a non-randomised population-based study that began in 1979 and recruited women 45-64 years of age living in eight geographic locations in England and Scotland. A total of 236,636 women were recruited into the study from the patient lists of general practitioners. Recruitment of women occurred over a three-

year period. One of the goals of this study was to assess the effect of BSE *encouragement* on mortality. A separate arm of this trial (including the Edinburgh Trial) studied the effect of biennial mammography and annual CBE on mortality. Women were compared with four control populations.

In the BSE arm of the study, two of the populations of women (Nottingham and Huddersfield) were *invited to one* class on BSE (n=34,405). After 10 and 16 years, benefit was measured by a comparison of the number of actual versus expected deaths in each population, as well as by the stage of breast cancer at diagnosis. Health data were obtained through the National Health Service Registries. The authors estimated that 99% of the women could be followed through this system.

This study did not show a reduction in mortality overall for the BSE groups or a significant difference in the size of tumours detected.

However, there were a number of methodological problems in this study that may have significantly affected the results:

1. The study was not randomised and relied on geographic comparisons. The results from this study cannot be generalized to other populations. Women enrolled in the study were not controlled for factors besides screening protocol and therefore, the effect of confounding variables like treatment standards and cancer incidence on mortality rates, cannot be ascertained.

2. Nottingham had a significantly higher pre-trial breast cancer mortality rate than Huddersfield. In fact, the breast cancer mortality rate in Nottingham was higher than all four comparison populations combined. The sixteen year follow up report did adjust for the variation in pre-trial breast cancer mortality but there was still no detectable mortality reduction in the two BSE groups combined.

3. There were known differences in available breast cancer treatment in the two communities involved in the BSE arm. In contrast to Huddersfield, women diagnosed with breast cancer in Nottingham were not routinely provided with radiotherapy, chemotherapy, or adjuvant hormonal therapy (Tamoxifen). This would undoubtedly have an impact on mortality.

4. The instruction and reinforcement of BSE was inadequate and difficult to assess. Women were invited to attend one class that offered a talk and short film, but no individual demonstration. There is no evidence of a standardized approach to BSE education, or of an assessment of BSE comprehension or skill. The two BSE populations differed with respect to reinforcement. Both populations used the media for reinforcement, but only Huddersfield sent out reminder calendars through the post.

5. Compliance to attend BSE instruction or perform BSE was poor (if measured at all). Attendance at BSE classes was low (only 31% in Huddersfield and 53% in Nottingham). In addition, only 47% of the Nottingham women who attended the classes were practising BSE one year later. There was no compliance check in the Huddersfield population.

6. All women in the BSE arm were included in the analysis of results whether or not they attended the BSE class or practiced BSE. Low compliance to BSE would greatly decrease the power of this study to detect a change in mortality as a result of BSE. When the attenders of the BSE class in Huddersfield are separated out, they had consistently lower mortality than non-attenders over the first 10 years (UKTEDBC, 1993). Attenders were not separated out in the 16-year follow-up report (UKTEDBC, 1999).

7. Differences in breast cancer mortality noted in the two populations were obscured as results from the two communities were often reported together. While there was no significant mortality reduction in the combined BSE populations (rate ratio 0.99), women in Huddersfield

were significantly less likely to die from breast cancer than the comparison population (rate ratio 0.79) after 16 years of follow up.

8. The designation of stage was based upon tumour size alone, as nodal status was not available, and the measurement of tumour size was not standardized. The size of some tumours was estimated by the naked eye, others by microscopic examination. The authors state the direction of the bias is unclear, but significant differences could have been obscured. It is worth noting that both BSE groups detected more tumours <21 mm than the comparison groups. A concurrent case-control study (Blamey, Locker, Mitchell, & Caseldine, 1988; Locker et al., 1989), that included some of the women from the BSE arm of this trial, demonstrated that women diagnosed with breast cancer who had attended a BSE class had better prognostic indicators than those who did not. This may indicate a survival benefit with BSE education.

9. The first results from this study were reported after only 7 years of follow-up. A minimum of 10 years is needed to evaluate the effectiveness of mammography screening (Blais, 2002); longer follow-up time is needed for a BSE trial as lower mortality reduction can be expected with this modality compared with mammography (Thomas et al., 1997). Early results, such as those released from this trial after only 7 years, become part of the accepted evidence against BSE that accumulates over time with gathering strength (Austoker, 2003; Baxter, 2001; Kisters & Gotzsche, 2003).

10. Results from this trial are difficult to evaluate due to the introduction of the National Breast Screening Programme in the U.K., which would screen women in all arms of the study and in itself have a potential impact on mortality.

Because of these weaknesses, it can be reasonably concluded that this trial does not provide good quality evidence to test the effectiveness of BSE. In their most recent report, even

the study authors state that the effectiveness of BSE remains unclear with this trial (UKTEDBC, 1999).

However, there may be a bias in the way the results of the U.K. trial have been used as evidence for screening effectiveness. Similar to the BSE arm, the CBE and mammography arm also failed to demonstrate reduced breast cancer mortality in those enrolled. While the BSE arm has been widely reported as evidence against BSE, the results of the mammography arm are often not reported or included in review articles at all. Two recent meta-analyses of mammography trials excluded the U.K. study (Edinburgh), as the quality of the evidence was considered too poor (Olsen & Gotzsche, 2001; United States Preventive Services Task Force [USPSTF], 2002).

#### WHO/Russia Trial

The WHO/Russia trial began in 1985 (Semiglazov et al., 1993; Semiglazov et al., 1996; Semiglazov et al., 1999). This population-based study included 193,000 women aged 40-64 from two large centres: Moscow and St. Petersburg. The women were randomised, by clusters, to intervention and control groups. The primary goal of the study was to evaluate the impact of BSE on mortality.

Both groups of women were similar in that they received standardized multidimensional BSE education (using videos and breast models) and reinforcement through the mailing of personal calendars every year. The frequency and competency of BSE practice were assessed through an interview format on 400 randomly selected women at 6 months, 1 year and 2 years.

However, there were differences in the two groups. Women in the Moscow population were randomly recruited from more than 200 factories. The BSE group received three hours of BSE instruction (including practise time) in groups of up to twenty. Women in St. Petersburg

were recruited from 28 polyclinics (health clinics). The intervention group were provided with standardized information about BSE from doctors and nurses at their routine annual check-up, which included CBE. Therefore, this population assessed any additional effect of BSE over and above CBE.

The reporting of results from this trial is curious. At 9 and 12 years of follow-up, data were released on the St. Petersburg population only. In addition, the full results were released in Russian only. An English translation of the results was available at nine years; however, it was poorly translated and very short. English results available at 12 years were scant.

At 5, 9, and 12 years of follow-up, there was no evidence of a significant difference in mortality or tumour stage between the control and intervention group. Women in the BSE group had more excisional biopsies at five years (RR=1.5) and had sought more medical advice at 9 and 12 years than women in the control group. Follow-up continued until 2001 (14 years of follow-up).

However, as with the U.K. trial, there were many methodological weaknesses that limit the strength of this study:

1. Reinforcement was variable and poorly defined. In both groups, annual reinforcement was given to women *when feasible*. If the St. Petersburg women did not attend their annual check up, they did not receive CBE and BSE reinforcement (which were designed as broadcast messages in the clinics). Additional motivation and information was provided twice a year, or 'whenever deemed necessary' to the Moscow women to reinforce BSE practice but the nature or frequency of this reinforcement was not reported.

2. Compliance was poor. After one year, only 64% of women from the two populations were evaluated as practising BSE; by four years, compliance had fallen to 18%

(Thomas et al., 1997). Due to acknowledged poor compliance, re-education was *attempted* at five years (the number of women reached by this re-education not specified). A minimum compliance of 50-70% of the enrolled women would have to perform BSE regularly to detect a 30% reduction in mortality. The 18% compliance at four years greatly diminishes the power of the study to detect a change. Interestingly, Baxter (2001) reported a higher compliance (55.5% of women examining their breasts five times per year at 5 years) but still acknowledged that the trial lacked sufficient power to detect even a 20% difference in mortality between the two groups because of the poor compliance (combined with a low cancer incidence rate).

3. Similar to the U.K. trial, all women in the BSE group were included in the data analysis for mortality, *whether or not they had been taught BSE or were compliant with BSE practice.*

4. Most women were pre-menopausal which could have contributed to higher mortality rates. Only 37% of women in the St. Petersburg BSE group were 50 years of age or older, when survival is greater. The lower rate of mortality in post-menopausal women is related to easier ease of detection, and generally less aggressive tumours in this age group (National Institutes of Health, 1997). Stratification of results is important. When the ages of the women were taken into consideration, survival in the BSE group was better demonstrated in women aged 50-59 than in women 40-49, beginning at about 7 years of follow-up (approximately 80 vs. 60% respectively; Semiglazov et al., 1996). If the majority of women in the study had been post-menopausal, a change in mortality would have been more likely.

5. The breast cancer mortality rate is higher in Russia than other developed countries of the world. Even though breast cancer treatment is considered standardized, 40% of Russian women die within four years. As reported by the NCIC (2003), the average five-year survival

rate in Canadian women with breast cancer is 82%. The higher than average mortality rate for breast cancer in Russia may reflect poor detection, poor treatment, or a combination of both.

6. Most women in Russia do not have access to mammography screening. This is not the standard of health care experienced by women in most Western countries and the results of this trial may not be generalizable to them. Breast self examination is not considered a substitute for mammography screening. Women in this study had access to diagnostic mammography, once a suspicious breast change was detected. This may have resulted in later detection of breast cancer and higher mortality than would be seen in countries where most women have access to screening mammography. Indeed, the majority of breast cancers found in the St. Petersburg women (in both the treatment and control groups) were described as locally or regionally advanced.

7. All women in the St. Petersburg arm received CBE at their routine annual check-up. The effectiveness of BSE over CBE may not be appreciable in this population, especially with such low compliance.

8. Political changes in Russia since the beginning of this trial in 1985 most likely resulted in contamination of the control and intervention groups and losses in follow-up. By nine years, 34% of enrolled women were lost. The lower number of women that could be followed up reduces the power of the trial to detect a change.

9. Follow-up time was very short. Although the nine-year results echoed the five-year results that there was no significant difference in survival in the treatment group, it is important to note that the actual median follow-up time was only 44 months. This is too short to detect a change with mammography screening which is far more sensitive and specific. More follow-up time may provide evidence of a benefit, particularly in light of the poor compliance to

practice. Indeed, there was an indication of a trend in that direction. There was more evidence of survival in the BSE group at nine years than at five, and the absolute difference at nine years was 10% (65% vs. 55%).

10. Stratification by nodal status indicates positive results. In women with positive lymph nodes, survival at nine years was markedly improved in the BSE group (60%) compared with the control group (28%). This correlation requires more investigation.

This study was superior to the U.K. Trial in that it was randomised, provided standardized BSE information, an assessment of compliance, and occurred within the context of standardized breast cancer treatment. However, the methodological limitations weaken the study. In addition to others, both Thomas et al. (the investigators of the Shanghai Trial, 1997) and Baxter (2001), on behalf of the Canadian Task Force on Preventive Health Care, declared that the WHO/Russia trial does not provide an adequate evaluation of BSE efficacy.

### Shanghai Trial

The most recent trial began in Shanghai in 1989 (Thomas et al., 1997; Thomas, Gao et al., 2002). This randomised controlled trial involved 266,064 female employees (aged 31-64) working in 519 textile factories within the Chinese socialist system. The factory was the unit of randomisation. The goal was to assess the efficacy of BSE instruction in reducing breast cancer mortality, although stage of cancer at diagnosis was also assessed. This population of women provided an excellent opportunity to assess BSE effectiveness for a number of reasons: The women could easily be randomised according to workplace (and thus living quarters); the BSE education and periodic reinforcement would be easy to implement; and treatment for breast cancer in this population was considered standardized and adequate.

Women in the experimental group received extensive standardized and multi-dimensional BSE instruction and follow up, both individually and in groups. Silicone breast models were employed with time for demonstration and practice. Initial instruction in BSE was followed by reinforcement sessions 1 and 3 years later, by BSE practice under medical supervision at least every 6 months for 5 years, and by ongoing reminders to practice BSE monthly (variable by factory). Standardized competency checks for BSE proficiency were completed on a random sample of the BSE group immediately before, immediately after, and one year after the reinforcement sessions. Competency was assessed by asking women to a) find lumps in silicone models, and b) demonstrate BSE on themselves. These women were compared with a control group that received information sessions on back pain.

Almost 80% of the women in the BSE group attended the baseline instruction and two reinforcement sessions. By the fifth year of follow-up, the proficiency check only captured 49% of enrolled women, but this is unlikely to have significantly affected the findings. Generally, the women's proficiency at BSE was considered acceptable, particularly after the educational video reinforcement. Only 7.5% of women were lost in follow-up.

Final results were released in 2002 after 10-11 years of follow up. The same number of cancers were found in the BSE and control groups, although there were more benign lesions found in the BSE group than the control group (the ratio of benign to malignant biopsies was 4.2 and 2.7 respectively). The cancers found in the BSE group tended to be smaller than those in the instruction group, though not significantly, and the extent of lymph node involvement was the same in the two groups, essentially providing the same TNM profile. Almost 82% of women in the instruction group found their cancer themselves while doing BSE. There was no significant difference in the mortality rate or survival curve for women in the two groups.

This trial is superior to the WHO/Russia trial in that it was randomised and not population based. In addition, women in the BSE group received extensive reinforcement and re-education, and competency checks that did not rely on reporting. However, there are also a number of limitations in this study.

1. Despite routine competency checks, there is no way of knowing how many women regularly and competently practiced BSE. Like other health protective activities that are of a personal nature, one must rely on reports of behaviour. It is possible the competency checks overestimated the women's practice of BSE as they may have been more likely to perform BSE more thoroughly and competently while being observed than they would in private. In fact, the performance of BSE by these women has been reported as being of only moderate proficiency (Harris & Kinsinger, 2002).

2. The women recruited were very young, with 60% less than 50 years of age. BSE may be less successful in reducing mortality in pre-menopausal women owing to the more aggressive nature of the disease in this age group.

3. There are comparatively low incidence rates of breast cancer in Asia (Blais, 2002). With a population so young and at relatively low risk, the power of the study would have to be quite large to detect even a small change in mortality. The combination of a young study group and low incidence increases the rate of false positives. This trial may not be comparable to a trial on older women in North America.

4. None of the women had access to mammography and 92% did not have access to CBE. In fact, this trial evaluates whether BSE alone can reduce deaths from breast cancer, not whether the addition of BSE to screening mammography and CBE can reduce mortality. BSE is not recommended as a sole screening mechanism. For this reason, a mortality reduction may be

less evident in this population than others with access to supplementary means of breast cancer detection. The authors state that BSE is not a substitute for regular mammography screening and may not reduce mortality in its absence.

5. Asia is known for its high rates of late-presentation breast cancer associated with economic and cultural factors (Epstein, 2003). Whether related to relatively lower standards of screening, diagnosis or treatment, or other factors, it may not be predictive of how effective it would be in the Western world where higher standards of health care are more common.

6. A socialist system may not provide the best socio-political environment in which to carry out a randomised controlled trial that measures a health promotion behaviour requiring empowerment. Part of the competency check involved the medical workers observing women performing BSE on themselves. It is presumed the women were expected to participate in this competency check. The effect of this direct observation of the women on them cannot be known but may have paradoxically disempowered them.

7. Excellent BSE education and study methodology cannot overcome geographic disparities in screening availability. In this study, women in the BSE group were exposed to high quality education and follow-up and consistently found more lumps, at smaller diameter, and with greater specificity than women in the control group. In a population with concurrent screening by mammography and CBE, there may have been a detectable mortality reduction.

The trial investigators clearly point out that they studied the effects of BSE *instruction*, not practice, on breast cancer mortality. While instruction did not contribute to reduced breast cancer mortality in their study, it should not be inferred that there would be no survival benefit to motivated women who performed BSE regularly and competently. For this reason, they do not recommend that motivated women be discouraged from performing BSE. They do recommend

however, that women who choose to practice BSE be told that its efficacy is unproven and it may lead to a biopsy for a benign breast change.

#### A summary of the findings

There are factors that are present in one, two, or all three BSE trials that compromise the strength of the findings. Firstly, poor research design and implementation. For example, BSE teaching and reinforcement not standardized, high non-compliance and dropout rates, short follow-up times, analysis of all women enrolled regardless of participation, and reliance on self-report to assess the frequency and/or competency of BSE practice. Secondly, these trials were carried out in the absence of optimal diagnosis or treatment protocols. BSE is not recommended as a sole screening mechanism or a replacement for sub-standard treatment. Thirdly, all three trials were using mortality reduction as the primary endpoint for evaluation. Mortality reduction may be more suitable for a treatment trial. BSE is a screening technique and should be evaluated as such, with measures of sensitivity and specificity. As well, there may be other benefits of BSE overlooked in this framework such as an increased feeling of control and empowerment among women active in the intervention arm. Fourthly, at the time of these trials, there was no known proven way to assess BSE competency (Chart & Franssen, 1997). As all trials were attempting to measure mortality reduction, a reliable measure of competency that was tested and validated in the literature should have been fundamental in study design. Unfortunately, this was not the case.

At the present time, there are no other known randomised trials likely to yield additional valid information on the efficacy of BSE to reduce breast cancer mortality. And perhaps a randomised controlled trial is not the best mechanism to evaluate BSE. As stated by Bennett et al. (2001) "a truly prospective, randomised study comparing breast self-examination to no breast self-examination probably would be impossible to carry out" (p. 13). Similarly, Warner (2002)

states that BSE could “never be evaluated using standard clinical trial methodology” (p. 163). In reference to the Shanghai trial, Baines wrote “we have a detailed description of the problems...encountered and the complexity of issues that arise when a trial is conducted with human beings, with wills of their own, and not laboratory animals, taking place in cities and not clinics, and involving large, not small populations” (p. 339).

Because large population-based studies of this nature (randomised trials in particular) are considered to provide the best available evidence on a preventive or treatment modality, these studies carry a lot of weight. The results of these trials have influenced large organizations and advisory bodies to change their recommendations related to BSE.

#### Fallout from the results of the randomised controlled trials on BSE

##### Canadian Task Force on Preventive Health Care

The Canadian Task Force on Preventive Health Care uses a standardized approach to evaluate the effectiveness of preventive health care practices offered in a routine periodic health examination. It periodically reviews published research findings and issues evidence-based recommendations regarding inclusion or exclusion of the intervention under review. They have various grades of recommendations ranging from A (good evidence to include) to E (good evidence to exclude; see Table 2). Their 1994 report indicated there was insufficient evidence to recommend for or against the teaching of BSE (a C recommendation; Morrison, 1995). At the time, this was consistent with their counterpart organization, the U.S. Preventive Services Task Force (Eastman, 1996).

**Table 2: Grades of recommendations of the Canadian Task Force on Preventive Health Care (Baxter, 2001)**

A	Good evidence to support the recommendation that the condition or maneuver be specifically considered in a periodic health examination (PHE)
B	Fair evidence to support the recommendation that the condition or maneuver be specifically considered in a PHE
C	Insufficient evidence regarding the inclusion of the condition or maneuver in, or its exclusion from, a PHE, but recommendations may be made on other grounds
D	Fair evidence to support the recommendation that the condition or maneuver be specifically excluded from a PHE
E	Good evidence to support the recommendation that the condition or maneuver be specifically excluded from a PHE

In 2001 the Canadian Task Force on Preventive Health Care downgraded their recommendation to D (Baxter, 2001), indicating there is fair evidence to recommend that routine teaching of BSE be excluded by physicians from the periodic health examination of women aged 40-69 (insufficient evidence precluded recommendations regarding women less than 40 or 70 and older). Their conclusions were based on a review of the three large trials of BSE effectiveness in reducing breast cancer mortality, as well as one cohort and four case control studies evaluating BSE as a screening technique. It is important to note the Shanghai Trial had released only their early findings at the time of this review. They reported finding insufficient evidence of benefit of regular BSE, *or instruction in BSE*, compared with no BSE. In addition to finding fair evidence of no benefit, there was reportedly good evidence of harm in relation to an increased number of physician visits, 'unnecessary' biopsies for benign changes, and emotional distress. The report recommends that any woman wanting to examine her breasts should be counselled about the potential risks associated with BSE before she receives thorough instruction.

Baxter, a surgical resident who completed the review, reports that the sensitivity of BSE alone is 26% (referring to the ability of BSE to detect breast cancer). She also reports that when women are educated in BSE technique, they can find 40-89% of lumps embedded in silicone

models, with a specificity of 66-81% (indicating how well they could distinguish 'malignant' lumps from normal changes).

There were several analytical weaknesses in Baxter's report. Firstly, while she acknowledged that most breast tumours were found by women themselves, she included in her review only those tumours found by women engaged in a "systematic method of self-inspection and palpation of the breast and axilla" (p. 1839), and not breast lumps found 'incidentally'. As reported elsewhere as well, most breast tumours are found 'incidentally'. Auvinen (1996) reported that only 7.6% of women who were practicing BSE found their tumours during the performance of BSE; they were far more likely to find a breast change while engaged in other activities like bathing. Excluding 'incidental' breast cancers found by women greatly diminishes the ability of self-detected tumours to show a mortality reduction. Secondly, Baxter excluded good studies that showed a benefit of BSE while over-emphasizing studies that are not methodologically sound. She acknowledged that the WHO/Russia trial lacked power to detect a change in mortality, and was therefore unable to evaluate mass education of BSE, but she included this trial in the weight of her evidence. At the same time, she excluded the results of a nested case-control study within the U.K. trial that did demonstrate a significant mortality reduction in women who attended the classes (Locker et al., 1989), as she considered the poorly executed U.K. quasi-randomized trial to be better evidence. Thirdly, Baxter admits there is no conclusive evidence of the most effective way to do, teach, or reinforce BSE. Despite these unknowns, it is evaluated by stringent standards inherent in randomized controlled trials and other epidemiological studies. Issuing recommendations to physicians about a screening technique that is not well understood may be premature. Fourthly, while concluding that women should not be taught to examine their breasts, she recommended they be instructed to promptly

report any breast changes or concerns to their physician. She did not indicate how women would know what constituted a breast change if they did not examine their breasts. Fifthly, the evaluation methodology may be biased. This report is based on the review of one individual, and the techniques she used were better suited for an evaluation of treatment, not screening.

This report created some excitement in the media and raised serious questions about the usefulness of BSE as a preventive health practice for women. What is concerning about this academic debate is that health professionals have begun to discourage women from examining their breasts (or at least have stopped encouraging women). For some health care professionals, it is “proof” that women should not be taught to examine their breasts, or should be cautioned when they are taught that its effectiveness has not been proven and they may be ‘harmed’ by examining their breasts (Picard, 2001; Priest 2001).

#### Cochrane Collaboration

In 2003, a Cochrane Collaboration systematic review reinforced these findings. Following a review of the WHO/Russia and Shanghai trials, they concluded that BSE could not be recommended as a screening tool for breast cancer (Kosters & Gotzsche, 2003).

#### Evidence regarding the effectiveness of other screening methods

##### Clinical breast examination

CBE comprises systematic inspection and palpation of the breasts and its lymph draining regions by a trained health professional. It is the least studied of the breast screening modalities. No screening trial has examined the benefits of CBE alone (without accompanying mammography) compared to no screening, limiting the quality of evidence pertaining to it. Most

data about CBE is derived from observational studies and the large trials of screening mammography that have included CBE as a screening maneuver.

CBE has a reported sensitivity of 40-69% (Humphrey et al., 2003; Jatoi, 2003) and can find tumors that are node-negative and less than 2 cm diameter, when survival is greatest (Chart & Frannsen, 1997). Other reported evidence of screening effectiveness include a specificity of 88-99% (Humphrey et al., 2003; Jatoi, 2003), a positive predictive value of 4-50% (PPV, the percentage of abnormalities detected that are cancer), and a 13% risk of false positives after 10 years (Humphrey et al., 2003). Weiss (2003) reports that CBE can detect about 60% of the cancers found by mammography.

Like BSE, CBE can find cancers not detected by mammography, for example invasive lobular carcinoma, Paget's disease, some invasive ductal carcinomas, and cancers in areas of breast tissue not captured on the mammogram.

When combined with mammography, CBE increases the cancer detection rate. Several studies have demonstrated that 35-40% more cancers are detected when CBE is combined with mammography, compared to mammography alone (Baker 1982; Chiarelli & Whittingham, 1998; Miller, Baines, To, & Wall, 1992). Without CBE, these additional cancers would have been missed. In addition, an abnormal finding on both CBE and mammography identifies women who should be fast-tracked for follow-up, as a cancer diagnosis is over three times more likely than with an abnormal mammography screen alone (Lybstug, 1997).

It is recommended that CBE be part of any breast screening program (Albert & Schultz, 2003). It is easily taught to health professionals and requires no special equipment. It also has great potential for countries with limited resources, but more research is required to evaluate its efficacy and effectiveness.

## Mammography

Mammography was first introduced as a screening tool for breast cancer in 1960 (Batt, 1994). The mammogram is a radiographic (x-ray) image of breast tissue and usually consists of a cranio-caudal and mediolateral oblique view of both breasts. It is important to distinguish between diagnostic mammography, which is performed on specific women who have symptoms of breast disease, and screening mammography, which is provided to a population of well women with the goal of reducing mortality through early detection. Nearly all North American health organizations support screening mammography, although groups vary in the recommended age to begin, the screening interval, and the role of CBE.

Humphrey et al. (2002) reports on the screening effectiveness of mammography, from data obtained from randomized controlled trials. Sensitivity has been reported from as low as 39% to as high as 89% and specificity from 94-97%. The PPV has been shown to increase with age, but has been reported as low as 2% to a high of 78%. Like other cancer screening techniques, mammography leads to additional tests to rule out malignancy. After 10 years of biennial screening, 23% of women have diagnostic work-up; this is just less than twice the rate reported for CBE. In fact, Humphrey et al. state that for every \$100 spent on screening mammography, \$33 is spent on diagnostic work-up such as additional views, ultrasound, clinical examination, and biopsy. Olsen and Gotzsche (2001) reported in their meta-analysis of the trials that the incidence of mastectomies and lumpectomies were 30-40% higher in the screening groups than in the comparison groups in every study since 1970, corresponding to about 40 extra surgeries per 10,000 women screened.

Mammography has largely been credited with the reduction in breast cancer deaths over the past decade. However, the long-term effect of mammography screening has not been well established (Tabar et al., 2003). There have been seven randomised controlled trials on mammography published to date (see Table 3 for a summary of information related to these). These trials have occurred in Canada, the U.S., Sweden and Scotland. It was because of the results of the early trials (e.g., HIP, Edinburgh) that reported a significant mortality reduction in breast cancer that mass screening programs were implemented in many parts of the world. While there have always been critics of population-based mammography screening, recently its benefits have been seriously questioned.

**Table 3: Randomized controlled trials of mammography**

	HIP, New York	CNBSS- 1, Canada	CNBSS- 2, Canada	Edinburgh, Scotland	Gothenbur g, Sweden	Stockhol m, Sweden	Malmo, Sweden	Swedish 2-county
Age and year of enrollment	Women 40-64 enrolled in 1963	Women 40-49 enrolled in 1980	Women 50-59 enrolled in 1980	Women 45- 64 enrolled in 1978	Women 39-59 enrolled in 1982	Women 40-64 enrolled in 1981	Women 45-70 enrolled in 1976	Women 40-74 enrolled in 1977
Study groups	Mammo + CBE vs. usual care	Mammo + CBE vs. usual care	Mammo + CBE vs. CBE	Mammo + CBE vs. Usual care	Mammo vs. usual care	Mammo vs. usual care	Mammo vs. usual care	Mammo vs. usual care
Years of follow-up	18	13	13	14	12	11.4	11-13 (50- 70); 15.5 (40-49)	20 (50- 74); 15.5 (40-49)
RR for all cause mortality	0.98	1.02	1.06	0.8 (statistically significant)	0.98	Not reported	0.99	1

#### Cochrane Collaboration

In 2001, the Cochrane Collaboration conducted a meta-analysis of reports on the seven trials since they began in 1963 (Olsen & Gotzsche, 2001). They determined that none of the trials produced high quality data. Two had medium quality data (CNBSS, Malmo) and three had poor

quality data (Gothenburg, Stockholm, and Swedish Two-County). The Edinburgh and HIP trials were considered too flawed to be analyzed with the others.

Overall, Olsen and Grotzsche (2001) found that breast cancer mortality data was unreliable and biased towards screening. They did not find evidence of a significant reduction in breast cancer mortality in the two trials with medium quality data. Only the trials with poor quality data demonstrated a mortality reduction. In addition, they concluded that mammography was more likely to find slow-growing tumors, the treatment of which could neutralize any survival benefit gained from screening. In addition to finding no reliable evidence of mortality reduction, they reported that screened women had more medical and surgical treatments and posed the question of whether mammography does more harm than good.

Olsen and Grotzsche (2001) identified issues compromising the quality of the trials including inadequate or poorly described randomization and inaccurate records of causes of deaths. The authors recommended that all causes of mortality be reported in all trials so that mortality related to breast cancer treatment is included. Otherwise, deaths associated with breast cancer would continue to be attributed to other causes. As well, they found evidence that death among women in the control groups were more likely to be attributed to breast cancer than those in the screened group. They also reviewed 17 meta-analyses of screening mammography trials and found them to be deficient in their reporting of methods (Walter & Jadad, 1999) and that few considered the quality of the trial in their analysis.

#### Canadian National Breast Screening Study

One of the most notable among the trials reported on by the Cochrane Collaboration was the Canadian trial on almost 40,000 women 50-59 years of age (CNBSS-2; Miller, To, Baines, & Wall, 2000). Investigators in this trial compared annual mammography and CBE, with CBE

alone (all women received BSE instruction). Thirteen year follow-up data demonstrated that the addition of mammography to CBE and BSE had no impact on breast cancer mortality, as there were an equivalent number of deaths in both groups. While the CBE group were more likely to find tumors greater than 2 cm, the mammography group was more likely to find DCIS (for which the natural history is unknown).

One year following the Cochrane Collaboration report, the CNBSS released their 13-year follow-up data on almost 50,000 women 40-49 (CNBSS-1; Miller, To, Baines, & Wall, 2002). The primary question in this trial was whether organized screening for women in this age group was superlative to usual care in the Canadian health care system. This was the only trial designed to assess the benefit of screening mammography among women 40-49. All women had initial CBE and BSE, and women in the mammography group were given annual CBE and BSE instruction. After 13 years, a similar number of cancers were found in the two groups (although the mammography group found more DCIS) and there was no significant difference in mortality in the two groups (RR=. 97). This was consistent with 7 and 10-year data previously published from this trial.

The two arms of the CNBSS are important to highlight as this trial is considered by most to be the most methodologically sound of all trials conducted on screening mammography to date. Neither arm of the trial provided evidence to support a population-based screening mammography program.

#### United States Preventive Services Task Force

In the same issue as the CNBSS-1 report, the U.S. Preventive Services Task Force released a summary report of the cumulative evidence on breast cancer screening (Humphrey et al., 2002). They reviewed the same evidence as the Cochrane Collaboration and came to

different conclusions on the quality of the studies and validity of the findings. While acknowledging the methodological flaws in the trials, they found insufficient evidence to conclude they were serious enough to refute previous published findings on the benefit of screening mammography (with the exception of the Edinburgh trial which was the only trial they excluded). They concluded there was a benefit to screening mammography in women 40-49 (RR= .85) and in women 50-59 (RR= .78), although annual mammography was not shown to be superlative to biennial screening.

While Humphrey et al. (2002) criticized the Cochrane Collaboration for basing their findings on only two trials, their own review methodology should be noted. They excluded the Canadian trial in some analyses on the grounds that the method of recruitment (by media and not letter of invitation) would result in a self-selection bias. The exclusion is especially concerning as the authors admit it was the only trial, of the seven that included women aged 40-49, that had sufficient power to detect a change in mortality. In addition, their meta-analysis combined studies that used different methods of analysis, which is not recommended. The findings of the U.S. Preventive Services Task Force are hinged on their assessment that all screening mammography trials (except Edinburgh) were of medium-quality and should be included in the review.

#### Ongoing studies

There are two ongoing screening mammography trials that have yet to release findings. The Singapore Breast Screening Project began in 1994 and enrolled over 166,000 women 50-64 years of age. The U.K. Age Trial began in 1991 and plans to enroll almost 200,000 women aged 40-41. Perhaps these trials will provide good-quality evidence pertaining to the effectiveness of mammography screening for women 40 to 64 years of age.

However, one thing is certain: Mammography is not an ideal tool for breast cancer detection and should not be relied on as a sole screening maneuver. Even the most optimistic reports of mortality reduction demonstrate it cannot prevent the vast majority of deaths associated with breast cancer.

#### Inconsistent application of evidence from screening mammography and BSE trials

It is apparent that it is very difficult to conduct high-quality randomized controlled trials on breast screening. The evidence from both the BSE and screening mammography trials is compromised by methodological weaknesses. However, the fallout from the two types of trials has been quite different and there are inconsistencies and assumptions in the trials that need to be considered.

There has been very little discussion in the academic literature about the quality of the BSE trials, and the subsequent validity of the findings. The evidence appears to have been accepted *carte blanche* with the result that major health care organizations subsequently changed their screening recommendations and/or health care practices. In addition to the downgrading of BSE from a C to a D recommendation by the Canadian Task Force on Preventive Health Care, the American Cancer Society has begun to de-emphasize the role of BSE, describing it only as an 'option' for women. In contrast, while the quality of the early screening mammography trials have been seriously questioned of late, and the latest trial data does not provide evidence of any added benefit in mortality reduction, the Canadian Task Force on Preventive Health Care did not downgrade their recommendations about mammography. In fact, their recommendation for screening mammography for women 50-69 has remained at an A since 1994 and the rating for women 40-49 was upgraded to C in 2001.

The utilization of evidence related to screening appears to be inconsistent. The U.S. Preventive Services Task Force acknowledged that the only trial that had sufficient power to detect a mortality reduction among women 40-49 years of age did not, even after 13 years. However, their 2002 update indicates there is fair evidence that screening in this age group significantly reduces mortality from breast cancer. On the other hand, they do not recommend for or against BSE stating that the evidence from the trials is so limited.

One of the major criticisms of BSE is the rate of follow-up necessary to rule out breast cancer and the associated anxiety it causes in women. This is stated in the analysis of data related to both the Canadian and American preventive recommendations. However, while there is ample evidence of increased work-up after mammography, including surgery, this is not considered a deterrent to recommending it. Even higher than the previous projection of a 23% false positive rate after 10 years of mammography screening, Elmore et al. (1998) estimated the 10-year cumulative rate to be 49.1%, with all women requiring additional workup such as a biopsy. In addition, mammography has been shown to 'over-diagnose' breast cancer, in the form of DCIS, which may not have ever become clinically detectable in the woman's lifetime (Miller et al., 2002). DCIS is often treated by mastectomy, lumpectomy, and radiation, carrying health risks and increased anxiety for women (Humphrey et al., 2002). For some women, anxiety associated with mammography is persistent even after cancer is ruled out (Humphrey et al., 2002; Lampic, Thurfjell, & Sjoden, 2003). In their recommendations, the U.S. Preventive Services Task Force do not even mention the increased rate of surgery associated with mammography screening; however, they state there is 'fair evidence' of follow-up for benign breast changes for BSE. In addition to harms associated with diagnostic work-up, there are risks inherent in mammography screening itself, while BSE has no associated health risks. It has been estimated that

mammography will cause 8 deaths in every 100,000 women 40 years of age and older screened over 10 years (Humphrey et al., 2002).

In providing evidence related to BSE, Baxter (2001) includes a section on costs associated with teaching and reinforcing it, which “potentially divert resources from other preventive strategies” (p. 1842), and costs associated with increased health care utilization by women who perform BSE regularly. This is an interesting statement. While the performance of BSE does not cost the health care system any money, mammography screening is highly technological and requires expert implementation and evaluation, carrying a significant cost to the health care system, and in many countries, to women themselves. In addition, women do not order investigative work-up after a change is suspected with BSE (or any other breast screening). If there is an over-utilization of health care services, it is by physicians and other primary care providers.

Results of the Canadian trial on women 40-49 were criticized because the follow-up time of 13 years was considered to be too short. However, neither the WHO/Russia trial or the Shanghai trial had yet reached maturity when their results were released (Baxter, 2001). The Shanghai trial (largely considered to be the best BSE trial to date) released final results after only 10-11 years follow-up. There are no known plans to extend the follow-up of this trial to determine mortality reduction over a longer period of time, which may be important in a screening test that is considered less effective in reducing mortality than mammography. Follow-up of mammography trials have continued as long as 20 years (Swedish Two-county Trial).

Baxter's (2001) review of BSE recommended that all women be informed of inherent risk associated with its practice. While the risks of mammography appear much greater, this is not a common recommendation in relation to its promotion. In fact, Goodman (2002) reports that

most women are not aware that mammography increases the risk of lumpectomy and mastectomy.

There are assumptions in screening trials that need to be stated explicitly. In the BSE trials, it is assumed that BSE instruction is equivalent to good performance or even performance at all. This is not necessarily the case. For example, while the Shanghai trial measured competency of BSE performance, there is no way to determine the frequency and quality of BSE practice by women over time. Equating instruction with performance will overestimate the ability of BSE trials to detect a mortality reduction. With regard to the mammography trials, there is an assumption that breast cancer leads to death in every woman and that all women aged 55 without breast cancer will live 8 to 11 years. This will overestimate mortality reduction associated with mammography.

See Table 4 for a summary of recommendations of leading health organizations related to breast screening.

**Table 4: Recommendations of leading health organizations related to population-based breast screening (including grade of recommendation, where indicated)**

Organization	Mammography	CBE	BSE
Canadian Task Force on Preventive Health Care	40-49: Current evidence does not support the inclusion or exclusion of mammography [C] 50-69: Good evidence to screen every 1-2 years	50-69: Good evidence to screen every 1-2 years  40-49: Fair evidence to exclude CBE [D]	Women 40-69: Fair evidence that teaching BSE be excluded [D]  Women <40 and >70: Insufficient evidence to make a recommendation
United States Preventive Services Task Force	40+: Fair evidence for every 1-2 years, with or without CBE	Insufficient evidence to recommend for or against screening by CBE alone	Insufficient evidence to recommend for or against screening by BSE
Canadian Cancer Society	50-69: Every two years in	All women: Every two years, in	All adult women, especially those 40+:

Organization	Mammography	CBE	BSE
	combination with CBE and BSE	combination with BSE and mammography	Regular BSE recommended
American Cancer Society	40+: Every year	20-39: About every 3 years 40+: Every year	Women 20+: An option for women
WHO	40+: Limited effectiveness 50-69: Every 2-3 years, with or without CBE	Insufficient evidence for population-based screening by CBE but should be offered to women in primary care	Insufficient evidence for population-based screening by BSE but should be promoted in the community
National Cancer Institute (U.S.)	40-49: Every 1-2 years 50+ : Every 1-2 years	No information	No information
International Agency for Research on Cancer (IARC)	40-49: Limited evidence 50-69: Sufficient evidence of effectiveness Women <40 and >69: inadequate evidence of effectiveness	Inadequate evidence CBE reduces mortality	Inadequate evidence BSE reduces mortality
American Medical Association	40+: Every year	40+: Every year	Recommended
Canadian Public Health Association	50-69 every 2 years	50-69: Every 2 years within an organized breast screening program	50-69: Should be taught every 2 years within an organized breast screening program
American College of Radiology	40+: Every year	No information	No information
American College of Obstetricians and Gynecologists	40-49: Every 1-2 years 50+: Every year	19+: Recommended	Recommended
American Academy of Family Physicians	50+: Every 1-2 years	No information	Recommended
American College of Preventive Medicine	50+: Every 1-2 years	No information	No information
Canadian Breast	40+: Recommended	Recommended	Recommended

Organization	Mammography	CBE	BSE
Cancer Network			
American National Breast Cancer Coalition	Insufficient evidence to recommend for or against mammography	No information	Insufficient evidence to recommend for or against BSE; not recommended for population-based education

The Canadian Medical Association and the American Public Health Association did not provide requested information about their breast screening recommendations.

There is apparent difficulty in measuring the effectiveness of BSE by large epidemiological studies. The evidence produced to date is questionable, either because the methodology was flawed or inappropriate. What is known is that the effectiveness of BSE is not proven, but nor is it disproven. There are too many questions raised in the review of BSE trials to conclude that the question of its effectiveness has been definitively addressed. And since there are no BSE trials ongoing at the present time, there is no clear direction forthcoming. If the randomized controlled trial is not able to effectively address the question of BSE effectiveness, it is unlikely that observational studies will be able to shed more light on the situation. In addition to casting serious doubt on a hitherto widely promoted self-care practice, the epidemiological studies on BSE effectiveness, and their resulting media fallout, may have confused women further.

### Summary

This chapter has provided background information about breast cancer highlighting the myriad of messages related to risk factors and screening recommendations to which women are exposed. These messages are coming from the media, health professionals and organizations, lay and academic publications, family and friends. They are often contradictory to one another and

are debated by all. It has been argued that evidence related to the BSE and mammography trials has been inconsistently utilized by influential health organizations in a way that has favored mammography and been unfairly critical of BSE. The conflicting and changing information related to breast screening may have an impact on women's attitudes toward BSE. It is therefore important to look at how women feel about BSE and how this relates to their behavior. The following chapter will explore the academic literature related to women's knowledge, attitudes, beliefs and practices related to BSE. It is hoped this review will provide some insight into the factors influencing women's decisions regarding BSE, which should, in turn, increase understanding about BSE as a screening technique for breast cancer.

## Chapter III

### Women's Knowledge, Attitudes, Beliefs and Practices related to BSE

#### Introduction

This chapter concerns women's knowledge, attitudes, beliefs and practices related to BSE, and to a lesser degree, breast cancer following a review of the English academic literature for the past five years. The following databases were electronically searched: Medline and CINAHL from 1999 to 2003 and Psych INFO (all years) using the keyword string breast self examination and woman and perception; Medline and CINAHL from 1999 to 2003 using additional three keyword strings (a) breast self examination and attitude or belief or knowledge, (b) qualitative and breast self examination, and (c) qualitative and breast self examination and attitude or belief or knowledge. All written publications types in English were accepted (e.g., journal articles, dissertations, book chapters). Articles were also reviewed through an electronic alert of the table of contents of the following journals: Lancet, American Journal of Public Health, Canadian Journal of Public Health, Journal of the American Medical Association, Canadian Medical Association Journal, Social Science and Medicine, British Medical Journal, Public Health Nursing, Health Care for Women International, Women and Health, and Sociology of Health and Illness. Additionally, an SDI account automatically generated all current articles in Medline and CINAHL with the key word string breast self examination.

The first part of this chapter will provide a summary of the BSE studies by epidemiological type. The studies are introduced in this manner to highlight the fact that the majority found were observational. The second part will provide a brief description of the demographic profile of the women studied. The third section will present a summary of findings of women's knowledge, attitudes, beliefs, and practices related to BSE. The chapter will

conclude with a critique of the literature reviewed and a commentary about what research is needed to more fully understand women's practice of BSE. Please refer to Table 5 at the end of this chapter for a summary of all studies, organized by study type, highlighting their purpose, participant characteristics, and findings.

### Types of studies

The studies regarding women's knowledge, attitudes, beliefs and practices related to BSE were comprised of quantitative (experimental, quasi-experimental, observational), qualitative, and a combination of quantitative and qualitative approaches.

#### Quantitative

##### Experimental studies

All of the experimental studies of women's knowledge, attitudes, beliefs and practices related to BSE involved a manipulation of educational messaging to better understand cognitive factors related to increased compliance, and to a lesser degree, proficiency. Variables investigated include the impact of imagery and message framing on BSE compliance (Trotto, 2002; Williams, Clarke, & Borland, 2001), thoroughness (Leight, Deiriggi, Hursch, Miller, & Leight, 2000), and frequency and confidence (Janda, Stanek, Newman, Obermair, & Trimmel, 2002).

##### Quasi-experimental studies

Similarly, the quasi-experimental studies assessed the impact of various types of educational initiatives on BSE knowledge, attitudes, beliefs and practices and included studies on adolescent girls (Ludwick & Gaczkowshi, 2001), young adult women (Sadler, 2001; Thomas,

Stamler, Lafreniere, & Delahunt, 2002) and low-income women (Hiatt et al., 2001). Another study tested the efficacy of age- and race-sensitive education on increasing knowledge and proficiency (Wood, Duffy, Morris, & Carnes, 2002). Some of these quasi-experimental studies used cognitive models such as the Health Belief Model (Rosenstock, Strecher, & Becker, 1988) and Social Learning Theory (Bandura, 1977) to guide data collection and analysis, as indicated in Table 5.

### Observational studies

The majority of studies found were observational; of these, most were cross-sectional surveys utilizing a written questionnaire, interview, or combination of the two. Cognitive models such as Champion's revised Health Belief Model (1993) were explicitly referenced in some studies to explore women's knowledge, attitudes, beliefs, and practices related to BSE (Graham, 2002; Petro-Nustus & Mikhail, 2002). Most surveys reviewed were designed to increase compliance by exploring variables such as self-efficacy (Egbert & Parrott, 2001), access to health services (Facione, 1999), socio-demographic status (Siahpush & Singh, 2002), and social support (Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002). Other observational studies included a case-control study to assess the relationship between cognitive appraisal, coping, emotional distress, and BSE practice among women with a first degree relative of breast cancer (Cohen, 2002), and a correlational study to assess factors influencing women's decision-making related to BSE performance (Gasalberti, 2002).

### Qualitative studies

The qualitative studies employed interviews, case studies, and focus groups to explore the relationship between social, structural, and personal variables (such as knowledge, attitudes,

beliefs, motivation, and socio-demographic profile) and behaviour related to breast cancer detection and treatment (Bener et al., 2002; Canales & Wilkinson, 2002; McMichael, Kirk, Manderson, Hoban, & Potts, 2000; Phillips, Cohen, & Moses, 1999).

#### Quantitative and qualitative studies

Qualitative research methods were used in combination with quantitative approaches to capture and explore, in greater detail, factors related to the practice of BSE and other breast screening behaviours. Two studies employed preliminary focus groups to explore variables to be considered for inclusion in a later quasi-experimental study aimed at increasing BSE compliance (Lu, 2001; Taylor & Jones, 2002). Similarly, Jirojwong and Manderson (2001) conducted exploratory interviews in the development of a cross-sectional survey to increase understanding about the practice of BSE. On the other hand, two studies used qualitative approaches to further explore findings from a quantitative study related to the secondary prevention of breast cancer (Remennick, 1999) and the non-practice of BSE by women (Fish and Wilkinson, 2003)

#### Demographic profile of women studied

Almost one-third of the studies include samples of American women of various ethnic backgrounds including African American, Caucasian, Latino, Asian Indian, and Chinese. There were several studies of women from Australia, the Middle East, Western Europe, and the United Kingdom and two studies from South-East Asia and Africa. Only one study was found on Canadian women and this was a quasi-experimental study conducted in Ontario with female employees from twelve automotive plants to examine the responses of women to two educational interventions related to screening, including BSE (Thomas, Stamler et al., 2002).

Where age was indicated, the majority of studies were conducted on pre-menopausal women, some as young as adolescents 14-18 years of age (Ludwick & Gaczkowski, 2001). Several studies included women from various age groups, for example Janda, Obermair, Haidinger, Waldhoer, and Vutuc (2000) included women aged 20 to 80 years; similarly, Siahpush and Singh (2002) studied women 18 to 70 plus. Interestingly, Wood et al. (2002) investigated the efficacy of a breast health video educational kit on older women, 60 to 105 years of age, making this sample the oldest one found in this review.

Where this was reported, the majority of women studied were married, with a high school education or better, and without a history or any symptomatology of breast cancer. However, there were four studies whose target group were low income women. Three of these were American studies carried out with African American or multicultural women (Hiatt et al., 2000; Katapodi et al., 2002; Wood et al., 2002).

While most of the studies did not indicate whether the women were employed or not, some were focused on a particular employment group of women including teachers in Iran (Jarvandi, Montazeri, Harirchi, & Kazemnejad, 2002) and Nigeria (Odusanya, 2001), health workers in Iran (Haji-Mahmoodi, Montazeri, Jarvandi, & Ebrahim, 2002), public health nurses in Singapore (Chong, Krishnan, Hong, & Swah, 2002), physicians in Norway (Rosvold, Hjartaker, Bjertness, & Lund, 2001) and the United States (Frank, Rimer, Brogan, & Elon, 2000), beauticians in Taiwan (Lu, 2001), American farm workers (Egbert & Parrott, 2001) and automotive workers in Canada (Thomas, Stamler et al., 2002).

## Findings: Women's knowledge, attitudes, beliefs and practice related to BSE

### Women's practice of BSE

In general, the majority of studies found that women do not perform BSE every month, or even at all. Sixteen studies reported on women's practice of BSE. Of these, only eight studies reported information related to the monthly performance of BSE and these ranged from a low of 6% (Haji-Mahmoodi et al., 2002; Jarvandi et al., 2002) to a high of 33% (Williams et al., 2001). Several studies did not specify the frequency of reported BSE practice reporting only that women "did BSE" (e.g., Jirojwong & Manderson, 2001; Sadler et al., 2001).

### Demographic variables related to BSE practice

Demographic factors such as marital status, age, socio-economic status, ethnicity and geographic area of residence were explored in many studies related to women's practice of BSE. Generally, married women reported more BSE practice than single women (Janda et al., 2000; Jarvandi et al., 2002; Siahpush & Singh, 2002), although a small descriptive study by Lauver, Kane, Bodden, McNeel, and Smith (1999) contradicted these findings. There is also conflicting evidence of the relationship between age and BSE, with younger women reported to be more likely to perform BSE in some studies (Janda et al., 2000; Siahpush & Singh), while more studies found older women to be more likely (Cohen, 2002; Facione, 1999; Haji-Mahmoodi et al., 2002; Jarvandi et al., 2002; Rosvold et al., 2001). With respect to socio-economic status, women with higher education were more likely to perform BSE (Cohen; Haji-Mahmoodi et al.; Janda et al., 2000; Katapodi et al., 2002; Siahpush & Singh) or to perform BSE more thoroughly (Gasalberti, 2002). Women less likely to perform BSE were those of lower income (Facione; Katapodi et al.) or those having no health insurance or only public health insurance (Hiatt et al., 2001). One study

that looked at ethnic status reported that black South African women were more likely to examine their breasts than white South African women (Peltzer, 2001). BSE practice was associated with women living in a rural area in two studies (Janda et al. 2000; Siapush & Singh).

#### Cognitive factors related to BSE practice

As previously discussed, some studies employed a model to help explain the cognitive processes underlying an individual's decision to maintain or change a health-related behaviour. By far the most popular model encountered in studies related to breast self examination was the Health Belief Model (Rosenstock et al., 1988) and its derivative, Champion's revised Health Belief Model (Champion, 1993). In fact, this was the only model found in this review of the literature that was operationalized to predict or explain BSE practice. The main components of this model in relation to a health behaviour are the individual's perception of the following: their susceptibility to the health condition, its seriousness, the benefits of taking action, barriers to action, as well as the individual's motivation (degree of interest) and confidence to perform the activity. Table 5 indicates when a cognitive model was employed in a study.

Several studies provided evidence to support the role of perceived susceptibility to breast cancer as a key determinant of BSE practice including those using components of the Health Belief Model (Ashton, Karnilowicz, & Fooks, 2001; Janda et al., 2000; Petro-Nustus & Mikhail, 2002) or not (Bener et al., 2002; Cohen, 2002; Fish & Wilkinson, 2003; Lauver et al., 1999; Rosvold et al., 2001). Similarly, perceived seriousness of breast cancer was found to be significantly associated with BSE in some studies (Graham, 2002; Petro-Nustus & Mikhail; Umeh & Rogan-Gibson, 2001). Perceived benefits of BSE correlated with its performance (Petro-Nustus & Mikhail) including a perception by women of having some control over prevention (Cohen), or their health status (Remennick, 1999), and a belief in the associated

benefit of mammography (Lauver). A woman's motivation (Petro-Nustus & Mikhail) and perception of confidence to perform BSE (Ashton et al.; Egbert & Parrott; Petro-Nustus & Mikhail; Remennick) were also associated with its performance.

Barriers, such as fear and worry, were identified as a key variable in decreasing the frequency or thoroughness of BSE in studies using components of the Health Belief Model (Gasalberti, 2002; Graham; Petro-Nustus & Mikhail; Phillips et al., 2002; Umeh & Rogan-Gibson) and those not (Bener et al., 2002; Fish & Wilkinson). Other barriers such as time, embarrassment, forgetfulness, mistrust of the health care system, a belief in pre-destination, and the perception of no available health care dollars were also identified as important (Bener et al.; Fish & Wilkinson; Egbert & Parrott, 2001; Facione, 1999; Rosvold et al.).

#### The gap between cognition and practice

Despite the preceding evidence of support for components of the Health Belief Model, cognition did not generally correlate well with practice. Knowledge about BSE or believing that breast cancer was a serious disease did not necessarily result in women examining their breasts on a regular basis. In studies reporting the lowest frequency of BSE monthly practice, most women believed they were at risk for breast cancer (Jarvandi et al., 2002) or reported that they knew how to do BSE and did not believe it was time-consuming, difficult or troublesome (Haji-Mahmoodi et al., 2002). A belief in the benefit of early detection (Jirojwong et al., 2001) or the usefulness of BSE in particular (Rosvold et al., 2001) also did not translate into high rates of BSE practice, as less than one third of the women in these studies reported regular BSE practice.

### Knowledge as a potential mediating factor in BSE performance

Knowledge regarding breast self examination or breast cancer may be related to this observed gap between cognition and practice. Although knowledge alone was not found to be a sufficient cue to action in one study (Petro-Nustus & Mikhail, 2002), an association between knowledge of BSE and breast cancer, and BSE practice, was supported in several studies (Bener et al., 2002; Egbert & Parrott, 2001; Fish & Wilkinson, 2003; Haji-Mahmoodi, 2002; Jarvandi et al., 2002; Jirojwong & Manderson, 2001; Lauver et al., 1999). Odusanya (2001) found that even though the vast majority (85%) of Nigerian teachers sampled knew breast cancer was a serious disease, only 25% were deemed to have an adequate knowledge base of BSE and only 11% did BSE monthly. Similarly, in a study by Sadler et al. (2001), only 45% of the women reported an adequate knowledge base of breast cancer, including BSE, and only 41% ever did BSE (frequency not indicated). Other studies reported a low knowledge base of women regarding breast cancer, especially increasing age as a risk factor (Grunfeld, Ramirez, Hunter, & Richards, 2002; Remennick, 1999; Wood et al., 2002) or symptoms associated with breast cancer (Grunfeld et al.). Of these, only Remennick (1999) reported on the practice of BSE by the women sampled (37%).

Women's beliefs regarding the causality of breast cancer, particularly their misperceptions, have been reported in the literature. Etiology of breast cancer has been reported by women to be associated with breast palpation and benign tumours and cysts (Jirojwong & Manderson, 2001), injury to the breast or another part of the body (Bener et al, 2002; Jirojwong & Manderson; Phillips et al, 1999), infection and pollution (Bener et al.), karma (Jirojwong & Manderson) and disharmony with God (Phillips et al.). The impact of these misperceptions on the practice of BSE has not been well studied.

Various studies investigated women's beliefs toward health and breast cancer and these may provide important clues to the decisions they make regarding BSE. Gasalberti (2002) reported that BSE might be viewed as looking for trouble if women hold the view that health is 'the absence of disease'. Phillips et al. (1999) reported that low and middle-income African American women had the perception that breast cancer was an imminent death sentence.

#### Social support and BSE performance

Family and friends may also play a role in determining whether or not a woman examines her breasts. In a study of beauticians in Taiwan, Lu (2001) found that the woman's perception of the social norm was an important predictor for BSE intention, frequency and accuracy. Bener et al. (2002) reported that a supportive social milieu (defined as family and friends) strongly influenced preventive practices including BSE, and Egbert and Parrott (2001) also found that family norms were associated with BSE. In addition, social norms influence what may be considered taboo subjects for conversation, leading to false or misleading perceptions. For example, Phillips et al. (1999) found that breast cancer was seldom discussed in African American culture leading to the perception that it is a white woman's disease.

#### Socio-economic status and BSE performance

As previously reported, women with lower income or who perceive they have inadequate health insurance are less likely to perform BSE (Facione, 1999; Hiatt et al., 2001; Katapodi et al., 2002). Characteristics of women at lower income levels, such as their knowledge and beliefs toward breast cancer, may provide some understanding of their low performance of BSE. Poor knowledge was associated with lower socio-economic status in at least one study (Grinfeld et al., 2002). Facione proposed that the perceived cost of diagnosis and treatment of breast cancer

may deter BSE in women earning a low income. Phillips et al. (1999) found in their qualitative study with low and middle income women that their beliefs related to breast cancer and screening varied according to socio-economic status. For example, women in the middle-income group were the only ones who felt that early detection was important. In addition, perceived vulnerability decreased as income increased.

### Educational messages and BSE performance

Specific forms of educational approaches have been reported to be effective in increasing the rate and proficiency of BSE, such as using a video (Janda et al., 2002), and providing a class followed by an informational pamphlet mailout (Thomas, Stamler et al, 2002). Other studies have reported increased frequency (Hiatt et al., 2001; Ludwick & Gaczkowski, 2001) and thoroughness (Leight et al, 2000; Wood et al, 2002) following a BSE intervention.

The framing of messages in educational interventions may impact on BSE performance. Trotto (2002) found that loss-framed messages (which stress the risks associated with not doing BSE) were more effective than gain-framed messages (that stress the benefits of performing the behaviour) to increase compliance, especially if the woman was already worried about breast cancer. Similarly, Williams, Clarke, and Borland (2001) found that loss-framed messages were superior to gain-framed messages in increasing the practice of early detection techniques like BSE while not increasing the women's anxiety about the disease. However, they found gain-framed messages were better for changing attitudes like screening intention.

### A critique of this literature

While these studies provide valuable information about the knowledge, attitudes, beliefs and practices related to BSE, most studies were quantitative, atheoretical, observational and

produced a solely descriptive account of women who did or did not perform BSE. These studies were also primarily individual in focus with little or no consideration of the role of the larger social environment in the decision-making process. When the socio-economic status and ethnicity of the women were reported, it was usually without a consideration of the relationships between variables, thus limiting the ability of the study to extend understanding of the phenomena.

Some studies that sought to increase understanding of the factors influencing women's practice of BSE used components of cognitive models and explored only the variables that are inherent in those (Ashton et al, 2001; Petro-Nustus & Mikhail, 2002). Even studies that did not explicitly state they were using a cognitive model often explored and reported on variables very similar to those found in standard models, like the Health Belief Model (Egbert & Parrott, 2001; Rosvold et al., 2001). Cognitive models have been criticized for presenting health beliefs as stable entities within individuals that are inherently logical and for ignoring the social and cultural context within which they are created (Marks, Murray, Evans, & Willig, 2000). This critique connects with the literature review which highlighted the inadequacy of the cognitive models for explaining women's BSE practices and for ignoring the social and cultural context.

The intervention studies were designed primarily to increase women's compliance with BSE, through manipulation of educational intervention or message framing. Compliance was most often measured by frequency of practice, and sometimes these were poorly described. For example, Sadler et al. (2001) reported that 40.7% of women did BSE without any qualification of frequency. Proficiency of BSE practice, essential to the early detection of abnormal breast changes, was often not studied or reported as well.

The observational studies reported mainly on women's knowledge and practice of BSE. Surveys employed in the majority of studies used standardized questions exploring pre-determined variables. This would naturally limit the scope of the study, confined by the survey instrument or the researcher's perception of the most salient factors. Some of the investigations related to women's practice of BSE were part of large national surveys that explored many health behaviours (Janda et al., 2000; Rosvold et al., 2001), or surveys which investigated factors related to other screening behaviours in addition to BSE, such as the Pap test or mammography (Jirojwong & Manderson, 2001; Siahpush & Singh, 2002), thereby limiting the amount of information that could be collected, analyzed and reported about BSE. Other studies seemed to collect minimal information. One study reported on women's 'attitudes' about BSE based on their response to one question about its importance (Peltzer, 2001). Most observational studies were not carried out on random samples and the sample sizes were generally quite small, sometimes with a broad age range of women represented (Ashton et al., 2001; Gasalberti, 2002). Additionally, findings were weakened by short follow-up times. A notable example is the study of adolescent girls that reported that compliance to BSE could be improved after a one-time intervention, based on their performance of BSE one month later (Ludwick & Gaczowski, 2001). The long-term changes for the women in this and other studies are unknown, thus weakening their validity and generalizability.

Generally, the qualitative studies sought to increase women's compliance to BSE, and other health care behaviours, through a more in-depth exploration of their knowledge, beliefs, and attitudes. However, the narrow focus of the studies and the descriptive nature of the reports limit their ability to illuminate the complex web of factors that may influence a woman's decision to examine her breasts. An example of this is the study conducted by Bener et al. (2002)

with focus groups of United Arab Emirati women. While it did seek to explore the social milieu, it remained focused on measuring cognition and behaviour in order to increase compliance. An interesting study by Philips et al. (1999) examined the relationship between African American women's beliefs of breast cancer and screening and their socioeconomic status. While it may appear broader in scope than other studies, it focused only on the relationship between socio-demographic variables and screening beliefs and behaviours. The qualitative studies included in this review were mainly focused on how to remove barriers to, and strengthen facilitators of, BSE and other health-seeking behavior, rather than examining the perceived social environment in any depth.

Most of the combination quantitative and qualitative studies were also designed to increase understanding of the factors associated with women's practice of BSE, and other screening behaviours, in order to increase compliance. One example is the study by Jirojwong and Manderson (2001) that explored the cultural and social factors related to women's use of the Pap test and BSE, including their perceptions of the body, cancer, and causes of disease. While it appeared to be broad in scope, the findings were restricted to a descriptive account of BSE performance, and potential associated barriers, with information collected through a written questionnaire. The qualitative component of this study assisted only in the identification of variables to be considered for the survey instrument later employed. Qualitative methods were not employed to provide insight into how or why these variables were important.

Fish and Wilkinson's follow-up of the U.K. Lesbians and Health Care Study (2003) explored reasons behind the non-performance of BSE through open-ended questions on a survey instrument. While the open-ended questions allowed respondents to identify any factor they felt important in influencing their decision not to do BSE, this type of survey format would not allow

for an in-depth exploration of the personal and social context. In contrast to this, Remennick's study of Russian immigrants in Israel (1999) did employ interviews with women after they had completed a national survey related to breast cancer screening. This allowed for an exploration of issues related to their non-practice of BSE, and the authors proposed three explanations for the gap between these women's cognitions and their behavior. However, the intent of the study was to improve the compliance of women to the breast screening recommendations of health professionals.

#### What research is needed

Most research on BSE has been designed to explore the demographic variables associated with practice, to increase compliance, measure proficiency, or test its effectiveness as a secondary prevention technique. As a result, in a general sense, we know the profile of women who are most likely to examine their breasts, how to design BSE educational campaigns to increase the impact of targeted messages, and how to teach women to perform BSE to increase the likelihood of detecting an abnormality. Of late, we have learned that large trials have been unable to demonstrate a mortality reduction associated with BSE, casting serious doubt over the usefulness of teaching women how to do it, and even in conducting further research in this area. Yet very little is understood about how women really feel about BSE.

Most women are aware that breast cancer is a life-threatening disease, are afraid of developing it, and believe that BSE is one way of finding it as early as possible to minimize morbidity and mortality. Yet most women do not examine their breasts regularly, if at all. Previous research has failed to provide a satisfactory explanation for the gap between women's cognition and practice related to BSE, perhaps related to an over-simplification of phenomena under study. This gap is particularly important as the private and public health care system spend

so much time (and money) on health promotion campaigns aimed at changing individual behaviour, including BSE.

Women have been bombarded over the past twenty years, and particularly over the past decade with the advent of organized screening programs and prevention campaigns, with messages related to breast cancer and actions they can take to limit their risk. These messages have often been contradictory. Even health professionals do not easily understand whether this is the result of ongoing research findings, or is more reflective of the varying mandates of health-related organizations and associations.

There is no doubt about the fallout from the three largest BSE trials that failed to demonstrate a mortality reduction. One example is that Canadian physicians have been advised to discontinue teaching women how to examine their breasts. This has an inevitable impact on the educational programs of health-related organizations and health messaging in the popular media. While women were encouraged to examine their breasts for the past 50 years, they are now hearing from health professionals and other sources not only that BSE may not improve their health, it may actually be harmful to them. The impact of these changing and contradictory messages is unknown.

What is needed is a greater understanding of BSE than can be learned through testing its efficacy in large trials or examining predetermined variables in quantitative, largely observational, studies. It is essential to understand how women really feel about BSE. The research problem is that there is a poor understanding of the meaning of BSE to women within a society that does not value it.

To address this problem, a different approach to research must be taken. Most research related to women's health issues have been conducted on women, rather than with women. As

'subjects' of research, women have not had significant influence over the framing of the research problem, or the issues to be explored within that problem. In order to achieve a greater understanding of BSE, women must be given the opportunity to explore and express freely the personal and social factors they feel are important in its practice. This is larger than examining the decision-making process alone. An understanding of context is important, both internal and external to the woman, such as their perceptions of health, cancer, their body, what it means to be a woman, and their relationships with the world including the health care system. This exploration will not adequately occur in one interview or focus group; time for discussion and reflection is needed to allow issues to emerge that may have been previously unknown, ignored or only partially addressed. In a group context, women can talk to each other and explore issues related to BSE that are relevant to them. It is important that this type of research is informed by feminist theory that would provide women with an active and meaningful role in the exploration of the research problem and incorporate gender as a key focal point in the analysis.

### Summary

This chapter has demonstrated that despite a large amount of research carried out on BSE, very little is known about how women really feel about it. Coupled with the changing and contradictory messages women hear about breast cancer, and breast screening in particular, it is important to explore in more depth personal and social factors that may influence a woman's practice of BSE. The following chapter describes the contribution of a feminist theoretical framework to the study of women's health including a discussion of the feminist action research design chosen for this study.

**Table 5: Research regarding women's knowledge, beliefs, attitudes and practices related to BSE and breast cancer**

Author	Sample	Purpose	Findings
<b>I. Experimental Studies</b>			
Janda, Stanek, Newman, Obermair, & Trimmel (2002)	251 premenopausal Austrian women; mean age 33.4 yrs	To evaluate the impact of a BSE videotape on BSE behaviour, beliefs and attitudes	Women in the video group performed BSE more frequently than those in the non-video group but confidence did not increase in either group; having a role model explained the greatest variance in BSE frequency (13%).
Leight, Deiriggi, Hursh, Miller, & Leight (2000)	41 nursing students 20-40 years of age	To measure the effect of a structured training protocol (order in which BSE information is presented) on improving BSE thoroughness in 2 search patterns	There was a significant difference pre-and post training in both measures of thoroughness but neither search pattern was clearly superior.
Trotto (2002)	120 college women	To better understand how to present educational material (including imagery and framing) to women to increase likelihood of BSE compliance	Loss-framed messages in combination with worry about the disease may increase compliance.
Williams, Clarke, & Borland (2001)	539 Australian women; mean age 45.7	To study the effects of gain-loss message framing on breast cancer-related cognitions and behavior, including BSE	Loss-framed messages superior to gain-framed messages for promoting early detection behaviours and does not increase women's worry about BSE/breast cancer; gain-framed messages better for promoting attitudinal change like anxiety or screening intention; framing effects mediated by self-efficacy.
<b>II. Quasi-Experimental Studies</b>			
Hiatt et al. (2001)	1599 low-income African American, Chinese, Latina and White women aged 40-75 living in U.S.  Part of the large Breast and Cervical Cancer Intervention Study (BACCIS);	To examine the effect of 3 interventions (outreach worker, educational material, or patient navigator) on screening knowledge, attitudes and behaviour (including BSE)	All 3 interventions led to higher BSE rates; lower rates observed in women with no health insurance or only public insurance.
Ludwick & Gaczowski (2001)	Adolescent American girls 14-18 years old (mean	To determine if a one-time intervention program can change the beliefs,	A one-time intervention can increase BSE practice and knowledge among adolescents one month later.

Author	Sample	Purpose	Findings
	age 15)	knowledge and practices of BSE among adolescent girls  Health Belief Model	
Sadler et al. (2001)	194 American Asian Indian women; mean age 38	To examine breast cancer knowledge, attitudes and screening behaviour before and after a breast cancer education campaign  Health Belief Model	Most women reported they did not do BSE, their knowledge base about BSE was inadequate and they had never received a demonstration on BSE.
Thomas, Stamler, Lafreniere, & Delahunt (2002)	437 Canadian women; majority 30-49 years of age	To examine the responses of women to two educational interventions related to screening, including BSE	Confidence in BSE to detect a lump increased across all age groups; Mailed pamphlets and class produced the greatest change in increasing likelihood of BSE monthly performance.
Wood, Duffy, Morris, & Carnes (2002)	328 American women; Aged 60 to 105	To test the efficacy of an age and race-sensitive breast health video on increasing older women's BSE proficiency, and knowledge of breast cancer risk and screening  Social Learning Theory	Intervention increased knowledge about breast cancer risk and screening, and BSE proficiency.
<b>III. Observational Studies</b>			
Ashton, Karnilowicz, & Fooks (2001)	87 Australian women aged 18-64  Survey	To investigate the frequency and components of Champion's Health Belief Model underlying compliance or non-compliance with BSE  Health Belief Model	Health belief model variables are important; Frequency of BSE is most significantly associated with confidence to perform BSE and perception of susceptibility.
Chong, Krishnan, Hong, & Swah (2002)	431 Public Health Nurses (PHN) in Singapore  Survey	To examine the knowledge and practices of breast cancer screening (including BSE) among PHNs who are patient educators	PHNs generally did not have good knowledge of breast cancer screening although level of knowledge varied with job responsibility and qualifications.
Cohen (2002)	80 women 20-40 years of age with first degree relatives with breast cancer matched	To examine the patterns of BSE related to cognitive appraisal, coping and emotional distress.	Women with family history did BSE more than those without and women with relatives with recurrence or metastasis performed more BSE again. In general, BSE compliance

Author	Sample	Purpose	Findings
	with 47 controls  Case-control study		associated with lower levels of depression and more problem-focused coping. In women with family history, BSE also associated with higher perception of control over prevention, higher perception of risk for breast cancer, and higher levels of state anxiety.
Egbert & Parrott (2001)	206 U.S. farm workers; mean age 48  Part of a larger study	To explore variables leading to women's perceived self-efficacy in performing regular breast cancer detection practices (including BSE).	Perceived knowledge, family norms, and women's confidence in BSE skills associated with BSE performance; time and embarrassment were barriers.
Facione (1999)	838 U.S. women with wide-ranging demographic variables  Survey	To determine if access to health services was a barrier to BSE	Less frequent BSE associated with women reporting lower income and no available health care dollars. Perceived cost of diagnosis and treatment may deter BSE in lower income women.
Frank, Rimer, Brogan, & Elon (2000)	4501 US Physicians aged 30-70  Part of the Women's Health Physician Survey	To explore predictors of physicians' personal compliance with breast cancer screening, including BSE	Most women did not do BSE monthly; factors influencing practice not discussed.
Gasalberti (2002)	93 racially-diverse American women; 21 years of age and older  Correlational study	To study the factors influencing the decision to perform BSE  Champion's Health Belief Model	Barriers (especially worry about breast cancer) and thoroughness inversely related; no relationship between barriers and frequency.
Graham (2002)	179 black US women aged 20-49  Survey	To explore the relationship between health beliefs and practice of BSE  Champion's Health Belief Model	Health beliefs were much stronger in determining BSE performance than demographic characteristics; frequency related to a perception of seriousness, benefits, and motivation and inversely related to barriers.
Grunfeld, Ramirez, Hunter, & Richards (2002)	996 U.K. women; mean age  Part of a national survey	To elicit knowledge and beliefs about breast cancer among the general female population and understand factors influencing patient delay in seeking care for a breast symptom	Women had limited knowledge of breast cancer and negative feelings about the side effects of treatment (although they generally felt the outcome of treatment was positive).

Author	Sample	Purpose	Findings
Haji-Mahmoodi, Montazeri, Jarvandi, Ebrahim, & Haghghat (2002)	410 health workers in Iran  Survey	To examine knowledge of breast cancer, attitudes toward and practice of BSE	Most of the women felt BSE was not difficult, time-consuming or troublesome although most did not do it monthly.
Janda, Obermair, Haidinger, Waldhoer, & Vutuc (2000)	195 Austrian women; 20-80 years of age  Part of a national survey	To assess knowledge of BSE and BSE practice	Women more likely to do BSE were those who felt more susceptible and older women with a family history.
Jarvandi, Montazeri, Harirchi, & Kazemnejad (2002)	587 Iranian teachers  Survey	To explore the beliefs and behaviours of Iranian teachers toward BSE	BSE non-performance associated with lack of knowledge.
Katapodi, Facione, Miaskowski, Dodd, & Waters (2002)	833 low income Latina, Caucasian, African American women living in U.S.; mean age 46  Survey	To examine the relationship between women's social support and their adherence to recommended breast cancer screening guidelines	Women who did not adhere to screening guidelines including BSE reported less social support; higher social support correlated with higher income and education.
Lauver, Kane, Bodden, McNeel, & Smith (1999)	119 women; mean age 63  Survey	To distinguish women who engaged in recommended breast cancer screening activities (including BSE) from those who did not	Significant variables associated with BSE practice included history of breast biopsy, family history of breast cancer, being single, higher perceived worth of mammography, lower perceived risk of breast cancer, and prior instruction in BSE practice. These were different than the variables affecting use of professional screening.
Oduşanya (2001)	188 female schoolteachers in Nigeria  Survey	To examine the knowledge, attitudes and practices of schoolteachers concerning breast cancer	Low BSE practice associated with low knowledge base.
Peltzer (2001)	300 South African women (half Black) 19-81 years of age	To investigate attitudes and practices of BSE	Attitude was an independent predictor of BSE practice.

Author	Sample	Purpose	Findings
	Survey		
Petro-Nustus & Mikhail (2002)	519 Jordanian women; mean age 25  Correlational study	To study factors and beliefs related to BSE  Champion's Health Belief Model	Confidence, motivation, reduced barriers and perceived susceptibility were key variables related to BSE practice (explaining 21% of variance); knowledge alone is not a sufficient cue to practice.
Rosvold, Hjartaker, Bjertness, & Lund (2001)	284 Norwegian Physician; mean age 39  Part of a national survey	Examined BSE (and Pap) practice in physicians in accordance with recommendations and compared with a national survey of university educated women	Majority of Norwegian physicians do not perform BSE despite the fact that most felt it was a useful technique. Physicians in Norway perform BSE more than other Norwegian university educated women
Siahpush & Singh (2002)	10,179 Australian women aged 18-70+  Part of a national survey	To examine the association between socio-demographic variables and BSE and other breast screening	BSE associated with women who are younger, married, rural and with higher education.
Umeh & Rogan-Gibson (2001)	178 asymptomatic women aged 18-35 living in England  Survey	To study the role of health perceptions in young women's practice of BSE  Health Belief Model	Lower perceived seriousness of breast cancer and fewer perceived obstacles to practicing BSE predicted BSE performance; barriers most important predictor.
<b>IV. Qualitative Studies</b>			
Bener et al. (2002)	41 United Arab Emirati (UAE) women aged 25-45 living in Al Ain in one of four focus group discussions	To explore perceptions, knowledge, attitudes, beliefs and practices about breast cancer and screening among UAE women	Factors encouraging BSE performance included high levels of knowledge, feeling susceptible, an attitude of personal responsibility for health, and a supportive social milieu (friends and family). Deterring factors included anxiety and fear (including fear of the doctor for some), embarrassment, mistrust of the health care system, and a belief in pre-destination.
Canales & Wilkinson (2002)	12 U.S. women aged 50-64 interviewed	To explore the breast health practices of healthy women and their motivation if they do follow recommendations	Taking Charge of Self was the generated theory (how they engage in a process of learning how to take charge of their lives).
McMichael, Kirk, Manderson, Hoban, & Potts	Australian Indigenous women involved in interviews, case	To identify the social, structural and personal factors among indigenous women in Queensland	Barriers to diagnosis, treatment and care can be addressed by increasing women's awareness of breast cancer and the benefits of preventive health

Author	Sample	Purpose	Findings
(2000)	studies and focus group discussions	associated with the detection of breast cancer and the treatment and post-treatment support they receive	behaviour, by improving the quality of health care and counseling services for this population
Phillips, Cohen, & Moses (1999)	26 low and middle income African American women in Maryland aged 40-65 in one of three focus group discussions	To explore the behaviours, attitudes and practices related to breast cancer and breast cancer screening among low and middle income African American women and to assess the effect of socio-demographic variables  Health Belief Model	Beliefs related to breast cancer and screening varied with socio-economic status. Middle-income group only group thought early detection was useful; perceived vulnerability decreased as income increased. Causes of breast cancer varied among employment groups. Fear was the main barrier; breast cancer viewed as an imminent death sentence. Breast cancer seldom discussed in African American culture.
<b>V. Combination Quantitative and Qualitative</b>			
Fish & Wilkinson (2003)	N=1066 lesbians  Part of a national survey containing open-ended questions	To explore the reasons behind the non-practice of BSE by lesbians who reported they had never done BSE	Six major reasons given by lesbians reporting never doing BSE proposed. Authors advocate for breast awareness rather than BSE education.
Jirojwong & Manderson (2001)	145 Thai immigrant women living in Australia; 18- 77 years of age  Survey conducted after variables explored through interviews with women	To explore the cultural and social factors related to their use of Pap and BSE and to describe their beliefs and perceptions about the body, breast and cervical cancer and their causes  Health Belief Model and the Stages of Change Theory	These women felt susceptible to breast cancer and believed in the benefit of BSE, but most did not do BSE monthly. Reasons proposed. Causes of breast cancer also explored.
Lu (2001)	198 Beauticians in Taiwan; mean age 28  Survey conducted after important items to be included explored through focus group discussion	To explore the effects of a BSE educational intervention on BSE intention, frequency and accuracy among women identified as having barriers to BSE  Champion's Health Belief Model	Education with follow-up reminders significantly increased frequency, accuracy and reduced barriers. Social norm influence was a predictor for BSE intention, frequency, and accuracy and is proposed as a direct measure of BSE performance.
Remennick	620 Russian	To discuss cognitions,	Russian immigrants refrain from

Author	Sample	Purpose	Findings
(1999)	<p>immigrants living in Israel; mean age 49</p> <p>Survey followed by in-depth interviews; part of a national survey</p>	<p>attitudes and practices aimed at secondary prevention of breast cancer</p> <p>Health Belief Model</p>	<p>screening activities including BSE (not consistent with pre-immigrant practices), despite having knowledge about breast cancer and the role of screening, universal access to health care, and feeling susceptible to breast cancer. Three explanations proposed for the gap between cognition and practice.</p>
Taylor & Jones (2002)	<p>African American women 20-40 years of age</p> <p>Components to include in BSE intervention explored through focus groups; 89 women assigned to treatment or comparison group</p>	<p>To examine the effects of a culturally sensitive BSE program on frequency and proficiency</p>	<p>The culturally sensitive program did not increase BSE frequency more than the comparative group; both groups made significant improvement.</p>

## Chapter IV

### Investigating Women - Theoretical and Methodological Considerations

#### Introduction

A feminist action research approach was utilized in this study to explore the meaning of BSE to women. Much previous research pertaining to women has considered them as 'subjects'; passive recipients of the process whose sole purpose was to provide useful data that could be evaluated and controlled by the researcher(s) alone. In contrast, this inquiry valued women as full participants in the process, so that they were actively engaged in the research process and had influence over how the research problem was explored. Consistent with a feminist approach, the everyday experiences of women were shared and reflected upon to illuminate the ways in which accepted social practices oppress and marginalize women. As well, the methods utilized in conducting the research, and the outcomes produced, had the potential to empower the women involved, through consciousness-raising, and thereby improve their quality of life.

#### Feminism

Feminism is a political and theoretical framework that acknowledges the oppression of women and other marginalized groups and seeks to end that oppression. Its central tenet is that women's personal experiences are reflective of their social and political environment. Feminists challenge 'taken for granted' meanings and practices they see as being oppressive and stigmatizing. They endeavour to expose the ways in which members of dominant social groups subjugate the voices and activities of marginalized groups.

However, there is no one definitive 'feminism'; varying definitions and approaches are influenced by a wide variety of academic disciplines, their theories and methods, and by a

variety of political allegiances (Wilkinson, 2003). Differences in the definition of feminism exist among people of different classes, races, generations and sexual orientations (Reinharz, 1992). A feminist approach rejects the notion of one authoritative 'right' way to define itself or do research. Women's lives are diverse, complex, contradictory, and contextual (Miller, 1997). Because of this plurality, there exists an array of feminist theories and ways of conducting feminist inquiry. A feminist approach asserts that traditional ways of producing knowledge have not always been objective, fair, or inclusive of women and seeks innovative and alternative ways to present reality. Reinharz (1992) quotes Spender in saying that:

At the core of feminist ideas is the crucial insight that there is no one truth, no one authority, no one objective method which leads to the production of pure knowledge .... feminist knowledge is based on the premise that the experience of all human beings is valid and must not be excluded from our understanding .... This is why patriarchal knowledge and the methods of producing it are a fundamental part of women's oppression, and why patriarchal knowledge must be challenged - and overruled (p. 7-8).

During the first wave of feminism, women sought the right to be educated, to vote, and to be recognized as 'persons' under the law. During the second wave of feminism in the 1970's, women began to criticize what had been accepted as 'knowledge' and to develop ways of creating knowledge that were more reflective of the totality of the human experience. In this way, feminists have been instrumental in uncovering patriarchal bias in science and the production of knowledge. What had been purported to be value-neutral, unbiased, and generalizable research was shown by feminist scholars to represent and replicate androcentric values and suppositions that did not adequately capture or explain women's lives and experiences. Worse, what had been presented as 'objective' was now re-conceptualized as the "position of privileged white males" (Hubbard as cited in Reinharz, 1992, p. 261).

### The construction of women by medicine

Feminists have long been critical of mainstream medical science and other traditional health disciplines like psychology and psychotherapy, and the research carried out within them, for pathologizing women, reinforcing gendered power structures in society, and ignoring the social and cultural influences on what constitutes female health and illness (Ussher, 1999).

Medicine is an immensely powerful profession in the Western world. It is built on the epistemological standpoints of positivism and realism and therefore follows closely the 'predict and control' approach of the natural scientific method (Murray & Chamberlain, 1999). Because of its claims of scientific objectivity, and through the rise of anatomy, Medicine appropriated control of knowledge of the body, and therefore power over it. Foucault (1973) argued that the body is a site for the social control of the individual, and issues of power and politics shaped the gaze of the physician.

Medicine has been criticized as being an agent of social control by constructing, through medical discourse, what it means to be a 'woman'. Woman, defined as 'other' in medical literature, was measured against the standard of the male body and found to be not just different, but deficient (Lupton, 1994b). Ehrenreich and English (1978) have described how women were portrayed as sick and incomplete versions of men: weaker, unstable, and a source of infection.

Using the scientific method and technical medical language, Medicine justified defining women as inferior to men on the basis of their biology, and warranted their limited participation in public life. The treatment of the female reproductive body by Medicine provides an excellent illustration of how this profession greatly influenced the place of women in society. The uterus was associated with all female psychological and physical conditions (Ussher, 1999): even as the "*controlling* organ in the female body ... intimately connected ... to every other part"

(Ehrenreich & English, 1978, p. 20). Not surprisingly then, the female reproductive organs became the focus of treatment for any female ill or perceived deviance. Treatments such as leeching, cauterization, or clitoridectomy were routine in the late 19<sup>th</sup> century for disorders such as 'nerves' or hysteria, an inappropriately high libido, or conversely a disinterest in courtship, childbearing or domestic life (Ehrenreich and English; Ussher, 1999). Women of the middle and upper classes were cast in the role of invalids: advised by their physicians to stay at home, see themselves as ill, and retire to bed (Ehrenreich and English). Avoiding 'hysteria' was contingent on women conforming to the social ideal of respectable married life (Turner, 1988). Physicians, as the sole legitimate authority of the human body, encouraged women of the upper classes to assume the role of the frail domesticated, dependent on their husband and physician for care, and therefore largely excluded from the public and economic sphere.

Several reviews of medical and gynaecological textbooks have demonstrated how they were instrumental in perpetuating the oppression of women by Medicine. Scully and Bart (1981) found that women were almost always described as having the sole purpose to reproduce and be maternal; in fact, women who showed no interest in childrearing were labelled neurotic or immature. Martin (1987) not only found that reproduction was noted as the primary role of women, menstruation was described in terms of loss or failure, and the uterus associated with such descriptors as regression, death, and degeneration. Analogous processes in other parts of the body (such as the lining of the stomach) were described by terms such as renewal, production, and protection. She asserts that the negative terminology associated with menstruation denotes the failure of the woman to fulfill her reproductive role. Findlay (1993) as well found that medical textbooks and journals of the 1950's regulated the social world of women by describing what was normal or pathological.

To this day, normal hormonal processes, which occur in every fertile woman, have been pathologized. Menstruation, historically associated with madness (Ussher, 1999), remains within the purview of psychiatric care with the condition 'late luteal phase dysphoric disorder' included in the DSM-IV. Pregnancy, childbirth, and the post-natal period have been positioned as conditions requiring expert medical intervention, with the woman a mere passive recipient of care (Ussher). Menopause, too, is firmly ensconced as a 'deficiency disease' that may be corrected by medical hormonal therapy (Lupton, 1994b), which, until recently, was recommended for an indefinite period into the woman's senior years.

From menstruation to death, the female body remains under the gaze of the physician and requiring care for its most fundamental life processes. Similar care is not provided to men as they progress through normal life experiences. Medical intervention is so pervasive in women's lives, Bush (2000) asserts "medical discourse is now the dominant discourse in controlling women's bodies and ... provides the basis for much of the cultural construction of femininity"(p. 430).

#### Women and medical research

As much as the female body has been the source of much attention by Medicine, there are glaring instances in which women have been wholly or largely ignored in medical research. On the basis of their capacity for pregnancy, women have been excluded from many major clinical trials, such as those for heart disease, AIDS, alcohol and drug use. When women have been included in clinical trials, in cancer research for example, gender differences are not always analyzed (Ussher, 1999). Results from many clinical trials have been unquestioningly extrapolated to women, creating standards of clinical care for women based on the (ideal) masculine body.

In addition to their exclusion as the subject of medical research, women have historically been absent in shaping the agenda as researchers, clinicians and policymakers. This has had a significant impact on the development of knowledge and standard clinical practice for women's health (Ehrenreich & English, 1978). Women's exclusion from the creation of scientific knowledge can be at least partially traced to perceptions of gender differences: a belief system that equated objectivity and science with masculinity (Keller, 1985).

Early feminists recognized that a different way of conducting research was necessary in order to advance knowledge, and that it was important to conduct research in a way that was meaningful for the intended 'subjects' of the inquiry. To merely adopt the traditional ways, and the knowledge created by them, would have largely precluded the perspective of women. As stated by Minnoch:

To a stunning extent, the interests of one half of the human race have not been thought about through history .... If we adopt uncritically the framework, the tools, and the scholarship created overwhelmingly by and for men, we have already excluded ourselves .... Many of those we have don't fit our experiences and were never intended to (as cited in Reinharz, 1992, p. 11).

### Feminist research

Research carried out with a feminist framework is concerned with an analysis of gender as one focal point in the examination of the research problem, along with an examination of social class, race/ethnicity, religion, sexual identity, age and disability as other sources of oppression (Wilkinson, 2003). It assumes that traditional research has been infused with androcentric biases that have excluded or distorted the experiences of women (and other marginalized groups) and have been carried out without an examination of the power relationships existing within a patriarchal society, thereby reproducing and strengthening them. It seeks to give voice to the views of women (and others) by valuing their experience, and in so

doing, ending their invisibility and discrimination. Feminist research does not have particular methods that set it apart from other types of research; it is distinguishable by its theoretical or epistemological standpoint, rather than by its methods (Ussher, 1999).

However, feminist research with women differs from traditional forms of research in two main ways: (a) it respects women's everyday experiences as a legitimate source of knowledge, and (b) it endeavours to conduct research by, for and with women in a way that is empowering to them. The goal of feminist research is to "identify ways in which multiple forms of oppression impact women's lives and empower women to tell their stories by providing a respectful and egalitarian research environment" (Campbell & Wasco, 2000, p. 787).

#### A typology of feminist research

Despite the preceding discussion of 'feminist research', it is not a unitary field. Just as there is no one true feminist theory, there is no one way of doing feminist research. Numerous approaches exist in the literature to describe both feminism and feminist research, each with its own epistemological underpinnings and methods, such as those proposed by Fisher and Davis (1993), Ussher (1999), and Crawford and Unger (2004) to name a few. Wilkinson (2003) proposes a typology of feminist research that includes three broad traditions: positivist empiricist, discursive, and experiential.

Wilkinson's positivist empiricist approach asserts that it is possible to do better, more representative, positivist research using the same traditional scientific methods. It criticizes mainstream health research for not being scientific enough because of biases in sampling, underlying sexist assumptions and inappropriate generalizations.

Wilkinson's discursive approach focuses on the study of talk, where talk is seen as a form of action. Sometimes called discourse analysis, this approach draws heavily on post-modernism.

It holds that individuals involved in the interaction are aware of the actions within their talk, manifested by the conversational practices they use such as agreement, disagreement and identity management. Through talk, the individuals co-construct a moral order reflective of the moral universe they inhabit, thereby promoting socially sanctioned behaviour. Feminist discursive research concerns itself with the study of oppression created and reinforced through talk, and the facilitation of acts of resistance to that oppression. This type of feminist research has not been well used to date in the study of health and illness.

Wilkinson's experiential approach recognises that everyday experiences of women's lives are important sources of knowledge as these have been ignored, distorted or marginalized in traditional health research. It seeks to generate vivid, personal accounts of women's experience by listening to women "speaking in their own voices, expressing their own meanings and concerns" (Wilkinson, 2001, p. 21). In this type of inquiry, individuals are regarded as 'experts' on their own lives, and 'authorities' on their own experience.

#### The underlying epistemology of this inquiry

This inquiry will employ a feminist experiential approach to inform the analysis of the meaning of BSE to women. This approach is derived from feminist standpoint theory and the work of Harding (1983), Hartsock (1983), and Smith (1987), among others. Feminist standpoint theory is based upon post-positivist critical theory (Campbell & Wasco, 2000) and Marxist theory (Hekman, 1997; Hartsock, 1997). It was created in opposition to the dominant, powerful dictates of the rational/empirical approach to knowledge generation employed by science and medicine, among other spheres (Harding, 1997). It challenges the notion of a single external and objective reality that is best explored through traditional scientific inquiry. Standpoint theory critiques 'objective' scientific research as presenting the world from a male standpoint, an

approach that has become confused with absolute truth (Wilkinson, 2001). Rather, it asserts that what is known and what constitutes reality is contingent on the standpoint of the knower and their social context. Standpoint theory recognizes the 'specificities of knowledge' derived from one's multiple positions in relation to gender, sexual identity, social class, ethnicity and the interrelationships among them (Wilkinson, 2001). As a critical approach, it rejects the notion of woman as a 'rational unitary subject' who can be objectively analysed without regard to social context (Ussher, 1999, p. 5).

The position of women in a patriarchal world, and their everyday experiences within that context, provide them with a particular way of seeing the world. By positioning women's experiences as central within the research process, it is posited that fuller, more complete accounts of reality can be generated. Standpoint theory holds that members of less powerful groups can contribute much to understanding social reality (Campbell & Wasco, 2000). Owing to women's inferior position within a patriarchal society, they live within the dominant culture as a member of an oppressed group, with its own sub-culture, and this provides a more inclusive view of the world. By listening to women's voices, issues can be explored and knowledge generated that have been overlooked or underrepresented in more traditional research. Because it produces situated and engaged knowledge from women's own lives it can "articulate a counter hegemonic discourse" (Hekman, 1997), thereby challenging dominant social systems of power. By working with groups of women, standpoint theory can bring group consciousness into being, described by Hill Collins (1997) as a significant contribution of this theory to the feminist movement. She also posits that explicating social power relations is the point of standpoint theory (p. 381).

According to Wilkinson (2001), feminist experiential research is always qualitative, using approaches such as interviews, focus groups, and ethnography to generate vivid accounts of personal experiences (the generation of autobiographical accounts) that are of central importance in understanding phenomena. Although there are various ways to perform analysis within an experiential framework, including constant comparative technique, narrative analysis, and interpretive biography, it is always grounded in the “specificities of women’s lives” (p. 21) as these everyday experiences provide a valuable way of knowing about the reality of women’s lives. A qualitative approach is consistent with the post-positivist critique of the context-free ‘sterile’ approach of traditional scientific health research, with its focus on validity, reliability, and generalizability as the hallmarks of conducting good research and discovering ‘truth’. This approach reclaims women’s experiences, and reports them in textual accounts, complete with their outward contradictions and inconsistencies. In this way, women’s lives are reclaimed and their concerns prioritized. Experiential research provides an opportunity to learn about “a different version of the world, a different kind of truth” (p. 22). The task of the researcher is to encourage the telling of these “hitherto untold stories” (p. 23).

Critics of the experiential approach assert that just by centralizing women’s experiences within the research process, a truer ‘reality’ is not necessarily presented than is offered by other forms of research. As well, it has been criticized for presenting a false homogeneity of women whose realities differ across many axes of diversity. In addition, social constructionists have led the argument that experience does not exist in a ‘pure’ form, independent of the telling of it, but is influenced by the context within which it is told; in essence, the members of the exchange co-construct their reality through their interactions.

To answer these critiques, experiential research, within a standpoint tradition, does not purport to reveal a 'truer' reality than other forms of research, but rather to present a different reality than has been previously presented. Because this form of research is anchored in the everyday experiences of women's lives, it is firmly grounded in their reality, and owing to the diversity of women and their different life paths, it allows for the multiple realities of women's lives to be illuminated. Hill Collins (1997) argues that standpoint theory is essentially interested in historically shared, group-based experiences that transcend individual experiences and have a degree of permanency over time, reflecting the reality of the group. She further points out that it is "the common location within hierarchical power relations that creates groups" (p. 376) and members of these groups have shared histories based on this power structure. In this respect, Harding advocates for 'strong objectivity' which acknowledges the relativism of all knowledge while requiring the researcher to apply a critical mindedness "to determine which social situations tend to generate the most objective knowledge claims" (p. 142). Polanyi (1967) described 'tacit knowledge' as that known to people by virtue of their everyday experiences – knowing that is "of the socially organised ground of our participation in living with others", some beyond consciousness, but no less known (as cited in Smith, 1997, p. 395). It is only with the sharing of experiences through language that this tacit knowledge can become conscious knowing. And it is also through sharing experiences and finding points of common ground and difference that perception of reality is confirmed or changed. Reality is not static and waiting to be discovered. It is an "unstable and dynamic construction that is fabricated, maintained, and modified by people in the course of their ongoing interaction with each other and their environment" (Stringer, 1996, p. 146). As one accepts the variable nature of social reality, one is less concerned with finding the absolute 'truth', and becomes more interested in discovering new

ways to explore and interpret the world. Experiential research provides an opportunity to “unearth the tacit underpinnings of gender” (Smith, 1997, p. 395) and increase our understandings of everyday occurrences and commonly accepted phenomena.

### Feminism and action research

It has been argued that all feminist research is change-oriented research (Lather, 1988; Reinharz, 1992) in that the aim is to create social change for the improvement of the lives of women and other marginalized groups.

Feminists, among others, have become disenchanted with the disengagement and aloofness of positivist research and its inability to explore women’s experiences and life situations (Madriz, 2000). They have criticized the natural and social sciences for being obsessed with instrumental values, such as control and domination, at the expense of the emancipatory values of justice, mutuality, and autonomy (Fox & Prilleltensky, as cited in Murray & Chamberlain, 1999). Feminist research can be seen as a form of resistance to medical and scientific orthodoxy (Wilkinson, 2003).

Action research is a mode of inquiry that is also concerned with social change, but it is not a competing framework to feminism. Greenwood and Levin (1998) describe common issues of concern to both approaches such as a commitment to democracy and social change, a critique of positivism, an analysis of power relations, a respect for the knowledge of the ‘silenced’, a critique of canonical positions, and a focus on transformative praxis (p. 181). Despite the natural fit between feminism and action research, and the use of action research by feminists, there have been only a few systematic attempts described in the literature that link the two perspectives (p. 183). Researchers such as Maguire (1996), Fine (1992), Lather (1991), and Brinton Lykes (1997) have utilized a combination of these two approaches in their research and it is clear that

feminism and action research have much to offer each other. Feminism contributes a demonstrated commitment to giving voice to the oppressed, while action research can offer a variety of collaborative and group process techniques that can effectively advance that end. It has even been written that action research conducted without the benefit of a feminist perspective is absurd (Maguire, 1996) or impossible (Greenwood & Levin, 1998).

### An exploration of action research

The term action research includes the related trends of action research, participatory action research and other forms of participative inquiry (Greenwood & Levin, 1998). What these related forms have in common is a “pragmatic combination of analysis and methods for linking elements of participation, action, and research in concrete situations” (Greenwood & Levin, p. 181). Action research is more than just participatory action for social change; it is a systematic process of inquiry that poses questions requiring the collection and analysis of data, the interpretation of which is directly tested in the field of action (p. 122).

Action research grew out of the work of Lewin (1948), Freire (1970/1993) and Guba and Lincoln (1989), among others. Over 50 years ago, Lewin emphasized participatory research based on client-oriented attempts to resolve particular social problems. Freire, a Brazilian adult educator working with the poor, redefined power away from dominant and authoritative structures in society and towards that which could be created through mutuality and reciprocity. Freire engaged peasants in a critical and liberating dialogue in an emancipatory strategy of conscientization to increase their understanding of the societal power imbalances contributing to their oppression, as well as the ‘hidden distortions within themselves’ that help to maintain it (Henderson, 1997, p. 158). Freire located this dialogue between the oppressed group who

contributed their experiential knowledge of their lives, and the revolutionary leaders who provided a theoretical analysis of their experience.

Starting from this liberatory approach, but extending it, feminists analyzed power imbalances on the basis of gender and blurred the distinction between those with theoretical knowledge (who have more power), and those with experiential knowledge (who have less, p. 159). Feminist action researchers stressed the importance of collaborative and non-exploitative relationships with research participants. Similarly, Guba and Lincoln's book *Fourth Generation Evaluation* (1989) presented a way of doing evaluation based on a hermeneutic dialectic (meaning-making dialogue) that demonstrates respect for all participants involved in the process through their full and informed involvement as partners in the study (Stringer, 1996).

### Participatory research

Participatory research is one form of change-oriented research. It has three core features (1) political action and individual consciousness-raising, (2) democratic and interactive relationships with research participants, and (3) everyday life experiences of participants are a legitimate source of knowledge (Cancian as cited in Reinharz, 1992). In participatory research, the research participants make decisions about the study format, including focusing the question, or they may be involved in data analysis and interpretation, concentrating on issues that are of most concern to them. A key feature of this type of research is the non-hierarchical relationship between the researcher and participants. A power differential would seriously undermine the development of trust necessary for the disclosure of personal experiences that is central to this approach (Campbell & Wasco, 2000). Shared power is also evidenced in research participants' increased ownership over information that is generated. This type of research has been described as riskier than others because the researcher has less control and cannot be specific about precise

outcomes in advance, as much depends on the unfolding dynamics of the research process.

Brinton Lykes has described feminist participatory research as 'passionate' or 'engaged' scholarship (as cited in Reinharz). The researcher and participants are actively involved in the unfolding research process, which has the potential to lead to both individual and group change. Participatory research is consistent with a feminist approach as the emphasis is on change, the lived experience of the research participant is central, and research is conducted in a manner that is respectful and collaborative.

#### Consciousness-raising as an action

An important element of participatory research is the giving of voice to the oppressed or dominated: to hearing the points of view of the silenced (Maguire, 2001). Reinharz states that listening to voices affects power relations by empowering those who are heard (as cited in Maguire). Listening to those who have not been heard, and reflecting on stories that had not previously been shared, can contribute to increased awareness or consciousness among the study participants. Maguire states that "there is a point in a person's evolving sense of self as a knower at which multiple perspectives and diverse opinions are appreciated" (p. 63). Increased consciousness allows one to view reality as contextual and variable. This then allows for the re-examination of tacit knowledge and previously unquestioned 'scientific' research to expose androcentric biases that reproduce a partial and inaccurate view of human experience.

As described by Henderson (1997), consciousness-raising occurs in fairly homogenous groups of individuals who talk about a shared sense of reality. In doing this, they recognize that their individual problems are shared by others and are, in fact, group problems. This new knowledge allows group members to see how they have been shaped by the ideology of dominant social groups, and how they have been complicit in their own oppression. This

increased awareness allows for the reframing of individual problems that may lead to individual or group action for change.

Feminist scholars have long understood the importance of consciousness-raising for changing the material conditions of women's lives, and for illuminating politically unimportant or unspeakable issues such as rape or sexual abuse (Maguire, 2001). Consciousness-raising groups have been held since the 1970's and consciousness-raising has been proclaimed as a uniquely feminist action (Campbell & Wasco, 2000; Reinharz, 1992). And although groups have been acknowledged as the best method for understanding women's lives (Campbell & Wasco), Reinharz decries the paucity of research in the literature utilizing this approach.

The challenge for the feminist qualitative researcher is to develop a perspective that is both grounded in the everyday experience of women but is also critical of the power structures in society (Murray & Chamberlain, 2000). By examining everyday experiences, it is possible to grasp the 'invisible relations' of power and oppression that exert social control over us (Maguire, 2001). Feminist action research endeavours to "connect the articulated, contextualized personal with the often hidden or invisible structural and social institutions that define and shape our lives" (p. 65). A feminist action research design that aims to raise the critical consciousness of its participants has the potential to significantly contribute to knowledge production while at the same time improving the quality of life of those engaged in the process.

#### The phases of the action researching cycle

Curtis, Bryce, and Treloar (1999) have described four phases within the action researching cycle. The first phase involves developing, through reflection, a shared understanding about the focus and boundaries of the issue under study. The inquiry process is captured by the written transcripts of the research interview and used by participants to enhance

their insight into the complexity of the issue. During the second phase, categories or core concepts emerging in the collected information are developed and refined to increase understanding of the issue of concern. During the third phase, participants use the collected information to critically reflect on their current practices. Accepted belief systems and practices are analyzed to determine in what way they are “constraining, distorting or controlling the meaning and value of their activities and the outcomes that are possible” (p. 209). This phase can be concurrent with the first two. During the fourth phase, research reports are produced and new action can be implemented, as enhanced understanding may lead to changed practice. Kemmis and McTaggart (1988) have described this process of group inquiry as a spiral of ‘collective self-reflective inquiry’. This cyclical iterative process of data collection, reflection, and action can occur many times during the research process and each turn of the cycle may result in increased understanding of the phenomenon of interest or more effective action for change.

#### Use of focus group technique in this study

Focus group discussion is a “qualitative research technique used to obtain data about feelings and opinions of small groups of participants about a given problem, experience, service or other phenomenon” (Basche, 1987, p.414). As proposed by Barbour and Kitzinger (1999), any group can be described as a focus group if it encourages and is attentive to the interaction between participants. It is an appropriate method of data collection when the research issue addressed is of concern to an accessible and homogenous group of individuals (Dunne & Quayle, 2001). A group size of six to eight participants is recommended for focus group research (Curtis et al., 1999; Wilkinson, 1998). This small number allows for optimal communication among group members, increasing the likelihood that useful data will be generated.

Focus groups have been described as 'informal' discussions (Beck, Trombetta, & Share, 1986; Wilkinson, 1998). While there may be a general plan or goal for the focus group, including a list of proposed questions to guide discussion, the participants can largely guide the agenda by influencing the topics to be discussed and therefore the phenomena to be explored. In comparison to quantitative research approaches, the role of the researcher is greatly reduced as there is no way to pre-determine how the research process will proceed. The unpredictable nature of a focus group can be stressful and the researcher must learn to deal with the uncertainty inherent in the process. With this method of data collection, it is not uncommon to wonder if any useful data is being generated or if a more direct approach should be taken with the group. The most reassuring aspect of conducting focus groups is that group members will usually guide themselves. A relaxed researcher will allow the group to follow their own line of discussion and, at the same time, encourage their insightful reflection by teasing out similarities and differences in individual's accounts. Group members will usually censor each other for embellishment, over-talking, aggressive behavior, and other challenges encountered by focus group moderators. The researcher therefore does not have to appear as a referee or panel discussion moderator.

Due to the dynamic and spontaneous nature of discussion in focus groups, they can provide a richness of data that is superior to individual interviews or written surveys (Fern, 1982; Morrison, 1999; Ritchie, Herscovitch, & Norfor, 1994). Wilkinson (1998) provides several reasons why focus groups have the potential to produce superior data: (a) There is enhanced disclosure by participants as their experiences are legitimated by others in the group and social desirability becomes less of an issue, (b) participants talk to each other in this data collection method, in their everyday language, which can provide greater access to their commonly held assumptions, beliefs and ways of making sense of their experience, (c) the language of the

researcher is not imposed upon the participants, (d) with reduced researcher control, the participants have more opportunity to develop themes that are of most importance to them which can lead to new and previously unexplored phenomena that extend understanding, and (e) challenges and disagreements between participants provoke the development and elaboration of individual accounts which may lead to a collective understanding of individual experience. For these reasons, the participants may in fact 'forget' they are involved in research and feel free to discuss issues that may not emerge with more formal data collection methods, making focus groups an ideal way to gain access to participants' lifeworlds.

It is important to note, however, that data obtained in focus groups are group data, not individual data. The discussion reflects the ideas that have been shared and negotiated by a group (Berg, 2001). For this reason, focus groups have been criticized as 'situated accounts' (Sim, 1998). The contrived social context of the group can result in ideas being expressed that would not be normal for the participants. The risk of this occurring can be reduced by minimizing the role of the researcher and encouraging an atmosphere similar to a 'rap session' with friends, as recommended by Wilkinson (1998). By doing this, social desirability bias of the participants with regard to their fellow group members and the researcher may be further reduced.

Focus groups recognize that humans are social beings and that reality is created within social interaction. Through everyday activities with other people, common knowledge is created, which in turn becomes part of the ongoing construction of reality. Focus groups provide an opportunity to observe the co-construction of meaning as participants share experiences, pool experiences, compare and contrast them, challenge and negotiate divergent views, seek clarification and encourage elaborate accounts (Wilkinson, 1998).

Focus groups are consistent with action research because they can empower individuals and foster social change (Johnson, 1996). The discovery of common life experiences and the examination of possible causes or contributors can lead to what Freire (1970) referred to as a 'critical consciousness', in which liberation is possible. In this way, focus groups can emancipate individuals and enable them to make changes that improve the conditions of their lives. Perhaps of equal significance is the ability of group members to change the course of the research process. They are not passive subjects following a well-defined pre-determined protocol over which they have no control.

Focus groups are consistent with a feminist framework as they are "particularly suited for uncovering women's daily experience through collective stories and resistance narratives ... that reflect the different dimensions of power and domination that frame women's quotidian experiences" (Madriz, 2000, p. 839). Women have always had conversations with other women as a way to talk out their problems, share their experiences, create solutions, and generally deal with their oppression. Focus groups facilitate communication with and among women, giving researchers access into the shared, and sometimes ignored, particularities of women's everyday lives. While underutilized at present in feminist research, focus groups offer considerable potential to advance its goals and principles (Wilkinson, 1999).

Focus groups are an appropriate way to explore the meaning of BSE to women. Although BSE is an intensely personal activity, the meaning an individual attaches to it can be influenced by their social environment - by their family, peer group and community. Therefore, focus groups, with their inherent social nature, are an appropriate way to explore individual's views of BSE and personal and social factors influencing its practice.

Focus groups have yet to be fully explored in qualitative health research; however, they can contribute much to the social scientific study of health and illness as they allow access to the social context of individuals through the meaning-making interaction that occurs in groups.

The aim of this research study

This study aims to engage women in a cycle of collective self-reflective inquiry to explore personal and social factors influencing the meaning of BSE to them. More specifically, this study will (a) involve women in a series of group discussions over time to explore personal factors related to their practice of BSE, (b) encourage the participants' critical reflection on their practice of BSE in order to discover and explore social factors influencing that practice, (c) explore the meaning of BSE to women within their social context, and (d) explore recommendations for the promotion of BSE to women.

Summary

A feminist theoretical framework has the potential to add much to a research study concerned with women's health. A participatory experiential feminist approach to research is emancipatory for women as it values their everyday experiences, considers them experts of their own experience, and recognizes them as co-researchers in the inquiry. In addition, a group approach to data collection over time, combined with ongoing critical reflection, may empower women to discover and elaborate issues of most concern to them, leading to a critical consciousness of the complexity of factors influencing their health status.

This study is important because it will broaden the debate on BSE from a positivist approach currently favored today. It may provide an avenue to discover personal and social factors, previously unknown or unconsidered, important to women's practice of BSE and the

meaning it holds for them. Most women do not examine their breasts, and this research process moves the discussion beyond the individual level, largely criticized for 'blaming the victim', to a critical analysis of the systemic social factors influencing their choice.

## Chapter V

### Women Talk about BSE – The Method

#### Introduction

This chapter will describe the research method of this study including the overall research design, participant selection, the demographic and biographic characteristics of the research participants, and the strategies used to collect, organize and analyze the information collected.

#### Design

This study uses a feminist participatory research approach to explore in depth the meaning of BSE for women within a society that does not value it. It involved a series of group discussions with two groups of women to explore and critically reflect upon personal and social factors related to their practice of BSE. Consistent with experiential feminist inquiry, women were encouraged to share and reflect upon their everyday experiences as a means to facilitate greater understandings of the phenomena. As co-researchers, the women were active participants in the research process by collaboratively identifying and analyzing issues of concern. This participatory and exploratory process was intended to raise the critical consciousness of women in relation to their practice of BSE.

#### Participants

##### Participant selection

A convenience sample was utilized in this study due to the universal risk of breast cancer, and the relevancy of BSE, for all adult women. Therefore, the author set out to find a large group of women from which a small number of participants could be recruited. Having previously completed volunteer breast cancer-related community work with some members of the Crafters'

Guild (a pseudonym) and learning that it had approximately 125 members, this group was chosen as a potential pool of volunteers. This guild meets on a regular basis in St. John's to craft, socialize, and perform community service. They are organized and have a recognized executive committee.

The Crafters' Guild was an appropriate volunteer recruitment pool because all of the members were adult women and most, if not all, should have been familiar with the concept of BSE. Public health nurses in our province had been teaching BSE for decades and a recently piloted breast screening program had extensively promoted it in this region for the previous four years.

#### Gaining access to participants

A letter was sent to the President of the Guild outlining the purpose of the research and the proposed method of data collection, seeking approval for a short newsletter article regarding the study in their next publication, and requesting attendance at their upcoming general meeting to explain the research study and seek involvement from their membership (see Appendix 1 for a copy of this letter).

The President requested that I attend a meeting of the Executive Committee of the Guild to provide a detailed explanation of the proposed research study and address any questions or concerns. At this meeting, the purpose of the proposed research study was explained as well as the way data would be collected, how the analysis would occur and how the results would be disseminated. They were also informed of the formal consent procedures that would be followed for all participants. A lively discussion ensued about this research study and the executive and committee chairs were unanimous in their support of the research. They invited me to speak to their general membership at their next meeting in the fall and to seek volunteers at that time.

Following approval from the Executive Committee to proceed, a small article was published in their newsletter about the proposed research study in order to generate interest before their general meeting one month later (see Appendix 2 for a copy of the newsletter article).

### Recruitment

Over one hundred women attended the Guild meeting. This research study was a late item on a full agenda. I explained the research purpose, general research strategy (participatory action research), method of data collection (group discussion) and analysis (qualitative), why I was interested in issues related to breast cancer and the proposed timeline. There were very few questions about the study. Women were then asked to volunteer. No women were excluded based on breast cancer history, practice of BSE, age, socio-economic status, race or any other attribute. Sixteen women who were interested signed their names and contact information onto a sheet of paper and provided written demographic information pertaining to age, ethnic group, education level, current work situation, main occupation, and marital status (see Appendix 3 for a copy of this data collection tool). This demographic information was collected so that an informed decision could be made about the selection of discussion groups from one pool of volunteers.

A small written 'thank you' note was published in the next Guild newsletter to recognize the cooperation of the Executive Committee and membership, report on the success of recruitment, and indicate that data collection would begin in four months (see Appendix 4 for a copy of this newsletter thank you).

Following the completion of data collection, a small written 'thank you' note was again published in the Guild's newsletter thanking the general membership and, in particular, the volunteers who participated in the study, for their cooperation and support.

### Participant demographics

Data obtained from the short demographic questionnaire completed by the sixteen women at the time of recruitment suggested that the volunteers were very similar to each other. Most were of English or Irish descent, degreed, employed or retired, professional and married. The ages of the volunteer women ranged from 30 to 62 years and this became the defining characteristic upon which to separate the women into two groups. Of the sixteen women who volunteered, the younger eight were placed in one group (Group A) and the older eight in the other (Group B). The similarity of the women, including their division by age, would work well in group discussions.

By the time data collection began four months later, three women felt they could no longer participate due to a change in personal circumstances (one had been assigned to Group A and two to Group B). The demographic information related to these women is not included in this report, but it did not differ from that of the women who did participate. See Table 6 for a presentation of demographic information related to the seven participants in Group A and six in Group B. In general, the younger women (Group A) were more likely to have a university degree and work outside the home in a professional capacity than the older women (Group B).

**Table 6: Demographic characteristics of participants in Groups A and B**

	Group A	Group B
Number of Participants	7	6
Age range (years)	30-51	52-59
Ethnic Origin		
English/Irish/Scottish	6	6
Other	1	0
Education		
University Degree	6	3
Some College / University	1	2
High School	0	1
Employment Status		
Employed Outside the Home	6	3
Self-employed	0	1
Homemaker	0	1
Retired	0	1
Unemployed	1	0
Occupational Status		
Professional	6	3
Managerial/Administrative	1	0
Owner	0	1
Clerical	0	1
Other: Farming	0	1
Marital Status		
Married or Common-law	6	6
Single (never-married)	1	0

#### Participant biographical information

The following table provides a brief biographical sketch of the 13 participants in both Group A and Group B. The information was volunteered over the course of data collection during the group discussions. In addition to age, profession and marital status, information related to a personal or family history of, or clinical investigation for, breast or other type of cancer is included. Where a participant indicated they had other significant experiences with cancer, this is also included. This information is included because a personal or family experience of cancer may significantly impact on these women's views of issues germane to this study, including how they feel about themselves, their health, cancer, and the health care system.

The information was accurate at the time of data collection. See Tables 7 and 8 for a biographical summary of the participants in Group A and B respectively. The name of each participant has been replaced by a pseudonym.

**Table 7: Biographical information on Group A participants**

Beth	<p>A 30 year old employed post-secondary teacher.            Strong family history of cancer including her mother (deceased at age 52), grandmother, grandfather and great-grandmother.            Her mother's death impacted greatly on her and through the course of the discussions she spoke about her mother's journey with cancer and her experiences as one of her primary caregivers.</p>
Susan	<p>A 30 year old employed teacher.            Strong family history of breast cancer including her mother and grandmother.            Her mother was diagnosed with early stage breast cancer during the time of data collection, which she disclosed at meeting 5.            Her friend's mother had breast cancer and one of her students had an unspecified type of cancer.</p>
Adele	<p>A 36 year old employed teacher.            Strong family history of breast cancer.            Her friend's mother and another friend's aunt had breast cancer.</p>
Madonna	<p>A 42 year old married and employed teacher.            Mother deceased; diagnosed with breast cancer.</p>
Brenda	<p>A 43 year old married, degreed and employed health professional. Has had diagnostic workup for breast cancer.            Close friend died of ovarian cancer; another friend diagnosed with ovarian cancer during the course of the group discussions.</p>
Rose	<p>A 50 year old married and employed teacher and former nurse.            Aunt with breast cancer 40 years ago.            Investigated once for potential breast cancer.            Described her husband's family as being "riddled with cancer". During the course of the meetings, she described her sister-in-law's experience with cancer.</p>
Janet	<p>51 years old; married and employed outside the home.            Feels the medical cancer care received by her husband and father was poor, resulting in late diagnoses.</p> <ul style="list-style-type: none"> <li>• Her husband recently diagnosed with a secondary cancer she felt was missed during its initial work-up.</li> <li>• Her father died within the past year of cancer after an initial (mis)-diagnosis of a different type of cancer.</li> </ul>

**Table 8: Biographical information on Group B participants**

Lynn	A 52 year old married employed teacher. Friend with second mastectomy since these meetings started. Another friend being investigated for a breast lump. Two of her students died this year.
Joanne	A 53 year old married, self-employed business owner. Sister with breast cancer at age 41 and was investigated for a possible recurrence at meeting 4. Has had work up for breast cancer twice. Has had numerous friends and acquaintances with breast cancer - some very recently (at least 11 cases) and other types of cancer. Good friend died suddenly after meeting 3.
Diane	A 55 year old married and retired teacher.
Marion	57 years old; married and employed outside the home. Friend recently diagnosed with breast cancer; knew 2 sisters with breast cancer who died within a month of each other. Friend with lymphoma. Husband died suddenly before the joint group meeting.
Jean	A 58 year old married farm owner. Aunt diagnosed with two breast cancers 40 years ago. Two friends diagnosed with breast cancer in last two years (one just before meeting 3). Close friend died suddenly at age 57 after meeting 2.
Mary	A 59 year old married nurse. Aunt with breast cancer 40 years ago. Has been investigated for a breast abnormality.

### Procedure

#### Ethical approval to conduct research

In order to conduct this study, approval from the university-based ethical review board was essential. This approval was obtained following a formal application to the Human Investigation Committee of Memorial University (see Appendix 5 for a copy of the application for ethical review).

#### Informed consent

Free and informed consent is a process that begins with the initial contact and carries through to the end of the research participants' involvement (Tri-Council Policy Statement,

2000). At the time of recruitment, guild members were notified that they did not have to participate in this study and that there may not be any direct benefit to them for volunteering. Prior to the collection of data, at the first meeting with each group of women, a detailed overview of the research process was provided including the proposed timeline, and methods of data collection, analysis and dissemination. Free and informed consent was obtained from all guild members who volunteered to be co-researchers. Each signed two consent forms and each was witnessed and dated. The consent form followed the guidelines set out by the Tri-Council (2000) and included a statement outlining all major components of the research process. One copy of the consent form was placed in a locked filing cabinet and the other remained with each woman so that she could have information about the study, including my telephone number if there were any questions or concerns (see Appendix 6 for a copy of the consent form and statement).

The group members were informed at the outset that they could decline to answer any posed question or engage in any discussion, or even withdraw from the research process at any time. Participants were assured that the external researcher would maintain confidentiality throughout the research process, and all members were requested to keep all group discussions confidential, which they agreed to do. All members attended voluntarily and attendance was very high, so it was assumed that the women were comfortable with the research process as it unfolded. There were no verbal or non-verbal cues to indicate a desire to discontinue.

#### Data collection

##### Rolling group discussions

Data gathering occurred primarily through (focus) group discussions with two groups of women who were considered co-researchers. Because the women largely determined the issues

to be addressed at each meeting, the term 'group discussion' will be utilized in this report instead of 'focus groups' to reflect the diminished role of the external researcher in this participatory research study.

Over a five-month period, each group met separately five times for approximately 90 minutes each time. There was a final joint meeting to conclude data collection so that the women could meet each other and share their experiences, thoughts, and feelings about the research process. The joint meeting occurred four months after the separate group meetings had concluded. In total, 11 group discussions occurred with these women. The group discussions were conceptualized as 'rolling' because issues raised at each meeting built on previous discussions and informed later meetings.

The research process can be conceptualized as having a beginning, middle and end. See Figure 1 in Appendix 7 for a schematic representation of the data collection process. As stated previously, attendance at the meetings was high. See Table 9 for a summary of the attendance at each meeting.

**Table 9: Attendance at group meetings**

	Group A (7 members)	Group B (6 members)
Meeting 1	All present except Madonna	All present
Meeting 2	All present except Beth and Janet	All present
Meeting 3	All present except Janet	All present
Meeting 4	All present except Brenda	All present
Meeting 5	Everyone present	All present
Joint meeting	Attended by Adele, Beth, Susan, and Brenda (Group A); and Diane, Marion, Lynn, and Mary (Group B)	

The beginning of the research process was critical in securing the trust and commitment of the group members. This was important to reduce member attrition over time and encourage frank and open discussion. Open-ended and semi-structured questions proposed at the outset of

the research process were intended to encourage women to explore as fully as possible their experiences and feelings related to BSE. In order to encourage women to frame the issue broadly, the questions encouraged women to explore issues related to health, cancer, BSE, and being a woman (see Appendix 8 for a list of questions proposed at the outset of data collection).

The research problem in this study is that there is a poor understanding of the meaning of BSE to women within a society that does not value it. In order to explore this phenomenon in some depth, and to empower women through the process, data collection occurred in a collaborative holistic iterative process. In-depth dialogue (also called 'learning conversations') was the main vehicle for knowledge generation. Activities to spark discussion were planned for each meeting but the participants were encouraged to freely explore issues related to BSE that were of most relevance to them. There were many potential sources tapped to generate discussion including: (a) Messages they received from family, friends, the medical community and other health professionals, (b) educational materials related to BSE, and (c) media items such as billboards, magazine articles, TV commercials. Each group meeting continued until the conversation naturally faded.

Initial data analysis occurred as a continuous ongoing process with data collection. Using thematic analysis, recurring ideas and concepts were identified by the researcher after each meeting and presented to the participants (sometimes informally) at the next meeting (analysis is discussed in more detail later in this chapter). This was done to ensure they were consistent with their experiences and feelings, to encourage further reflection, and to inform ongoing data collection. Without breaching confidentiality, issues raised by one group were sometimes shared with the other to allow for a more comprehensive exploration of the research problem by all participants. In this cycle of systematic inquiry, the participants clearly took a lead role in

defining issues relevant to their practice of BSE. Data collection continued until each group felt they had fully explored all relevant issues related to BSE and that new knowledge had been generated which reflected their experience. Table 10 provides a brief description of the activities undertaken with both groups of women over the nine months of collaborative data collection and analysis.

**Table 10: Summary of activities at each group meeting**

Meeting 1	Explanation of the study; consent forms completed; quantitative data collected by questionnaire; journals distributed; getting acquainted; general exploration of issues
Meeting 2	Presented a summary of the quantitative data; invited readings from their journals; presented some general ideas from Meeting 1 with both groups
Meeting 3	Invited readings from their journals; presented 13 general themes gathered through review of first two meetings with each group; taught BSE; asked them to discuss with their female family and friends why they do or do not do BSE (Group A); Asked them to notice images of women in the media (Group B)
Meeting 4	Invited readings from their journals; discussion of images of women in popular magazines; discussion regarding their family and friends' practice of BSE; distributed BSE educational pamphlet
Meeting 5	Invited readings from their journals; concept mapping; discussion regarding if and how BSE should generally be promoted; all women given a copy of the 13 themes for further reflection
Meeting 6 (Joint meeting)	Further reflection on concept map and how generally to promote BSE; discussion of the impact of the process on participants, re-collection of quantitative data by questionnaire; request for voluntary journal submission; social event to aid closure of the research process

#### Other methods of data collection

In addition to group discussion, there were alternate forms of data collection. The women were informed they had the option of an individual interview with me if they so chose. These were offered in case any woman wanted to share information in a more private format. One woman asked for an individual interview after the joint (final) group meeting. She could not attend the last meeting and wanted to let me know the impact the group meetings had on her. She was interviewed one month after the joint meeting.

### Journaling

All women were given a small journal at their first meeting and invited to use it throughout the research process to record their thoughts after, or in between, meetings. Women were informed that although they would be invited to voluntarily share from their journals at each meeting, they were to be considered their private property. Women were also informed they could provide their journal to me at the end of data collection if they wished to have them included in data analysis. While some of the women did use their journal between meetings to aid their reflection, none of the women volunteered their journal to me at the end of the data collection process. I also kept a journal to record my reflections on the unfolding research process.

### Field notes

Field notes were used only once. This occurred when an interesting conversation commenced at the end of one meeting after the tape recorder was turned off and the women were leaving. The essence of this exchange was captured in field notes, which were distributed to women at the next meeting to ensure I had accurately documented their discussion.

### Memoing

Memos were employed during the transcription and analysis process. These jot notes were written in the margins of the transcript or in a journal kept throughout the research process and helped to identify hunches, isolate contradictory data items, and clarify emerging ideas.

### Quantitative data

Quantitative information was collected by a short questionnaire about the women's knowledge, attitudes, and behaviors related to cancer, breast cancer, and BSE (see Appendix 9 for a copy of the questionnaire). The questionnaire was created by the external researcher, contained only closed questions, and was administered at the beginning of the first meeting with each group and at the final joint group meeting. The purpose of this questionnaire was to assist in detecting a change in the women's knowledge, attitudes, and behaviours related to cancer, breast cancer, and BSE, and to stimulate discussion on the issues raised by its questions. While the questionnaire was unable to demonstrate a change in the women, largely due to the small number surveyed, it was very useful in sparking discussion among the women, as reflected in the results section.

### Setting

The meetings were held in a location of the groups' choice. The first meeting for each group was held at the staff lounge at my workplace. This is a well-known educational facility attached to a rehabilitation hospital. The staff lounge consists of living room furniture, including standing and table lamps. Overhead lighting was not employed during our meetings so that a more relaxed environment could be created. In the same room, a kitchen area provided a convenient place to provide a small tea for the women. It was proposed that we could meet elsewhere, including their own homes if they wished, but the women in both groups chose to have all their meetings in this room. The women were encouraged to do their crafting during our meetings. At each meeting, the appropriateness of this setting, including the comfort of the participants gleaned from both verbal and non-verbal cues, was assessed. This setting worked

well for the group discussions. Despite this, the joint group meeting was held in my home, as I wished to thank the women for their participation by offering them a small reception after the meeting was concluded.

The individual interview occurred at the individual group member's home, at her request. Some family members were present from time to time, including her daughter-in-law, who participated in the meeting.

#### Data management

The group discussions were audiotaped and transcribed verbatim as soon as possible after they occurred. The women reported they were comfortable with the recording process. While a transcriptionist created a first draft of each meeting, each transcript still required numerous hours of careful editing while listening to the audiotape to correct errors in conversation (despite her superlative work) and attribute individual speakers to text within the transcript. When several women talked at once, as often occurred, this task became more challenging and important. At the completion of this process, I was comfortable with each transcript.

To ensure confidentiality, no identifying data that could be traced back to the individual was recorded in any transcripts or in the final report. Participants were identified by a number. The tapes were kept in a locked filing cabinet without any identifying labels. Only the researcher, transcriptionist, and thesis committee members had access to the data. Information collected during this study will not be used in any other research project without consent of the research group. Group members were informed that results, without identifying data, might be published or presented orally.

## Collaborative data analysis

Research using focus groups are generally analyzed using qualitative analytical techniques (Wilkinson, 1998). In this study, thematic analysis was employed to assist in understanding and interpreting the data collected. There were various stages in the analysis of data and the group members, as co-researchers, were actively involved in a cyclical process of data collection and analysis, one informing the other, until a reasonable interpretation of the meaning of the data could be obtained.

### Phase 1: Temporal mapping – Identifying the pieces

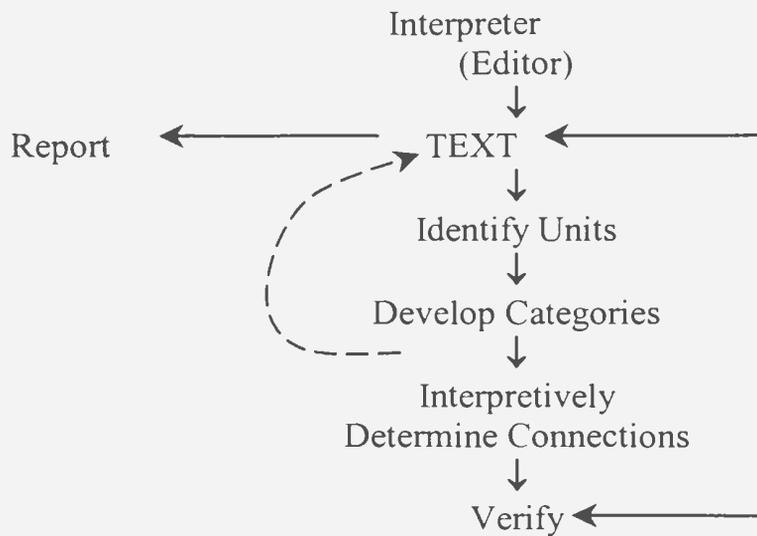
The first step in developing an understanding of the meaning of BSE to women involved having them explore, through ‘learning conversations’, personal and social factors they felt were relevant to their practice of BSE. To make sense of this information, a technique called temporal mapping was employed. Denzin suggests temporal mapping as an approach to assist groups to formulate descriptive accounts of their situations (as cited in Stringer, 1996). The purpose of temporal mapping is to describe the problem (issue of concern) and its context. Thematic analysis of the written transcripts of the women’s discussions by the external researcher assisted in identifying the key components of the issue. The transcripts of the first two meetings with each group (four transcripts in total) were utilized in identifying the components of the temporal map.

### Thematic analysis

Thematic analysis allows for the “direct representation of an individual’s own point of view and descriptions of experiences, beliefs and perceptions” (Butcher, Holkup, Park, & Maas, 2001, p. 474). It is an appropriate method of analysis for qualitative data derived from semi-

structured interviews (Kelley, Swanson, Maas, and Tripp-Reimer [1999], as cited in Butcher et al.). DeSantis and Ugarriza (2000) define a theme as “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experiences into a meaningful whole” (as cited in Saunders & Byrne, 2002, p. 220). In this way, a theme can provide coherence to an assortment of seemingly unrelated experiences or phenomena and can therefore aid in the organization and interpretation of data. The analysis is grounded in the sense that the data is anchored in the everyday practices of individuals as they live their lives. Thematic analysis allows the researcher to remain close to the data and be sensitive to the themes as they emerge and are refined, while more broadly seeking insight into the meaning of individual or everyday experience.

The specific analytic technique employed in this study has been described by Crabtree and Miller (1992) as an editing style of analysis. Using this technique, the researcher naively approaches the textual data without a pre-conceived template of codes. It is a bottom-up or inductive approach that is guided primarily by the data. The researcher makes interpretations (observations) of the text through multiple readings. Reflection on the emerging interpretation informs further reading of the text, which leads to deeper understandings. Codes are created, applied to the text, validated and revised as analysis progresses. In the early phase of the data collection and concurrent data analysis, pre-suppositions and pre-conceived notions from the literature and the external researcher’s own experience were bracketed as much as possible with the aid of journaling, memoing, and reflection.

**Figure 2: Editing Analysis Style**

Analysis began with listening to the audiotape of each meeting, reading (and re-reading) the verbatim written transcript, and writing notes (memos) in the margin. The memos helped to identify concepts that were recurrent in the data and added contextual information such as tone of voice or laughter that provided further meaning to what was said. Recurrent concepts identified in the memos were organized into categories. Data captured within and between these categories were compared, refining and redefining them to ensure they reflected the emerging data. Category reduction helped to ensure that the most important concepts were identified. The refinement of categories occurred across the first four transcripts. These categories became the components of the temporal map.

The temporal map components were presented to each group of women in their third meeting to validate their relevance and accuracy. The temporal map helped facilitate further data collection. By capturing the key issues discussed by the women and reflecting those back to them, both new and elaborated accounts of their experiences were shared. This stimulated thoughtful discussion that was critical in constructing the problem and its context.

## Phase 2: Concept mapping – Putting the pieces together

Concept mapping recognizes that there may be many relevant factors contributing to an issue of concern. A concept map is a schematic representation of an issue, illuminating the interrelationships between its significant elements. In this study, the concept map provided an accessible record of the women's collective conceptual schema related to the meaning of BSE and could be reflected upon to deepen understanding.

In this process, women in each group were asked to organize the components of their temporal map (written on individual index cards), into a pattern or diagram that was meaningful to them. The index cards were placed on the wall and women organized them into clusters, indicating what were believed to be sequential or interrelated components. Both groups of women created their own concept map.

The group discussions allowed the women to co-create the schematic representation, taking into account the experiences and perceptions of all. It occurred in the fifth meeting with each group so participants had ample time previous to this to reflect on the components of the temporal map, to discuss issues, and share experiences that were meaningful to them. This led to an examination of BSE with great depth and breadth.

The concept mapping exercise was chosen because it could be emancipatory for the women in two ways. Firstly, it provided an opportunity for the collaborative analysis of issues related to BSE practice. Because the women were constructing these maps themselves, they had more control over, and input into, the analytic process than would have been afforded by other, more traditional, textual analytic techniques. The women were able to scrutinize their schema, discuss it, disagree over it, and ultimately change it until they were satisfied with its representation. Secondly, through exploring the relationships between components of the

temporal map (in essence the context surrounding BSE), they could identify elements of their own personal experiences common to others in the group and discover broad social issues common to women that influence the meaning of BSE for them. Through this process, the women could better understand the complex and deeply rooted forces influencing their lives.

### Phase 3: Extended thematic analysis - Understanding the pieces

Once the temporal map components were developed and organized by each group of women into a concept map related to BSE, the external researcher began a more in-depth analysis of the data, comprised of over 700 pages of text. The analysis served two purposes: (a) To develop a greater understanding of the temporal map components and concept maps developed by the women (one for each group), and (b) to explore the data for evidence of a raised consciousness among the women, an indication they had changed during the research process.

To more fully understand the two concept maps, the eleven transcripts were analyzed using thematic analysis as previously described. Informed by feminist theory, a continued reading of, and reflection upon, the text, combined with coding for themes and subthemes, augmented the analysis until a deep understanding of the account was developed (Miles & Huberman, 1994). As well as being grounded in the transcripts and the experiences of the women's lives described therein, the analysis at this stage of the research process was also informed by selective sampling of the current literature related to cancer and women's health.

To discern any change in the women as a result of their participation, the research process was broken down into three sequential phases: The beginning, the middle, and the end, as previously described.

### The beginning

The beginning of the research process incorporated the first meeting with each group of women. The verbatim transcripts of these two meetings were analyzed to determine the major issues of concern to both groups of women at the outset of the study. Themes, and corresponding sub-themes, were identified for both Group A and Group B. These were conceptualized as the subject position of the women at the beginning of the research process and are presented in Chapter 6.

### The middle

The middle of the research process included the second to fifth meetings with each group of women. The eight corresponding transcripts were analyzed to gain greater understanding of the meaning of the thirteen components of the temporal map, and the concept map itself, for these women. Through continued reflection on the text, the temporal map components became clearer. Excerpts of the women's discussion that illustrated the essence of the meaning for each temporal map component are presented, along with the concept map for each group, in Chapter 7.

### The end

The joint meeting with both groups of women marked the end of the research process. The transcript of this meeting was analyzed and compared with those from the beginning phase to determine if and how the research process had changed the women's consciousness in relation to BSE. The results of this analysis are presented in Chapter 8.

### Increasing credibility of research findings

In qualitative research, the credibility of research results relate more to the trustworthiness of findings than a measure of their validity and reliability, as is frequently discussed in quantitative research studies. Care to increase the trustworthiness of the data will help ensure the resulting knowledge generated makes sense (fits the substantive area), is recognizable to the reading audience, has the potential to be applicable to other contexts, and will help describe, explain and interpret the practice of BSE. This study utilized four approaches to increase the trustworthiness of the research findings: reflexivity; triangulation; thick description, and member checking.

#### Reflexivity

In qualitative research, the researcher is the 'instrument' (Brody, 1992). Qualitative researchers acknowledge they are involved with their participants in the research process and that they bring their own life experiences, assumptions and beliefs into the data collection, analysis and reporting of results. What they see or choose to interpret in the data, and how the data are interpreted, is influenced by their personal framework. In fact, using the researcher's personal experience, or even starting from their personal experience, is a distinguishing feature of feminist research (Reinharz, 1992). For some feminist researchers, puzzling or troubling experiences become a 'need to know' and a motivation to conduct research to understand phenomena. Feminist researchers often write in the first voice, and present an explanation of their relation to the subject at hand in a preface or post-script, to indicate their engagement in the process and subject matter at hand. While personal bias cannot be avoided entirely, it can be minimized by researcher reflexivity: essentially an ongoing reflection on themselves and how

their values and views may bias the research process. In this study, reflexivity was achieved by stating my socio-historical location (Murray & Chamberlain, 1999) in the preface, and through personal reflection on, and journaling of, my thoughts and feelings throughout the process.

### Triangulation

Triangulation (Flick, 1992) can refer to using different research methods, theoretical perspectives, or participants within a study, or collecting information over a period of time. In this study, the following approaches to triangulation were utilized: (a) Using different participants - two groups of women were engaged in the same research process at the same time, (b) collecting data at different times – the group discussions occurred over a period of nine months, and (c) using a combination of research methods – the women were involved in group discussions as well as journaling. Prolonged engagement with both groups of women built trust, helped to identify personal and social issues of most concern, and limited the potential for superficial examination of phenomena.

### Thick description

Thick description (Geertz, 1983), a term often used in reference to ethnography, is an important concept because what we often need to comprehend about a particular event or phenomenon may be perceived as background information. Including detailed accounts of what has been observed (thick description) allows the researcher to perceive broader, more abstract interpretations from the analysis of minutiae. In this study, documenting extended segments of conversations among the women, and copious amounts of them, serves to enrich the interpretation by firmly grounding it in the multiple and varied experiences of the women's everyday lives, as described by them. Thick description of what they discussed allows the

women to ‘speak for themselves’; as well, it exposes the ways in which the women negotiated their conversations, and conceptualized amongst themselves, the meaning of BSE for them.

### Member checking

The ongoing engagement of the women in the research process ensured that they validated the data collected and the resultant iterative analysis. This occurred during the emergence of themes (temporal mapping), their organization into a schematic diagram (content mapping), and in the final analysis and interpretation of results. This latter activity involved a verbal presentation of findings to the co-researchers after the external researcher had completed the interpretation. As a smaller example, field notes generated after one of the audiotaped meetings had ended were circulated to the group participants at their next meeting to confirm their accuracy.

### Placement of external researcher in the text

I have placed myself in the text of this research report as appropriate to indicate my engagement in the research process. However, I was less involved in some of the discussions than the other group members, as I wished them to take the lead in exploring and discovering issues and experiences of relevance to them related to BSE. In the three ensuing chapters of research results, I refer to the group participants as ‘they’ when I had limited involvement in the conversation, and ‘we’ when I was more actively involved. The term ‘external researcher’ is utilized to emphasize the active role of the women as co-researchers.

### Notation on the presentation of research results

Owing to the importance of providing ‘thick description’, long excerpts of the women’s conversations are included in the presentation of research results. These excerpts have been

edited by necessity to decrease the length of the final report and provide increased clarity to the information presented. Symbols are utilized to differentiate between pauses in conversation and information deleted from the transcripts. Please see Table 11 for these and other symbols (and their intended meaning) incorporated into the research results.

### Summary

This chapter has described the participatory action research design for this study including the use of convenience sampling to select participants, group discussion to collect information, and thematic analysis to develop a greater understanding of the meaning of BSE to women. The following three chapters will present the research findings according to the three phases of the research process: the beginning, the middle, and the end.

**Table 11: Symbols utilized in research results**

Three dots (...)	A pause in the conversation
Hyphen (-)	A swift change of thought
Empty square brackets [ ]	Data excluded
Italics	Emphasis of the speaker
Italics in brackets ( <i>italics</i> )	Descriptive notes of the conversation (e.g., tone of voice, laughter) and explanatory information inserted by the external researcher
Question mark (?) to indicate speaker	Speaker could not be identified

## Chapter VI

### **Women's Views at the Beginning of the Study- The Subject Position of the Women**

Group A: Women's subject position in relation to breast cancer

At the first meeting with Group A (the younger group), the women were asked to bring up any issues they felt were important in relation to BSE. The women required no prompting and easily began discussing issues they felt to be relevant, reflecting on their life experiences as they illustrated or stressed a point. The resulting conversation was very broad in scope and highlighted the women's desire to take care of their health in relation to breast cancer and their perception of the challenges they encountered in trying to do so. In this way, this discussion illuminated their subject positions in relation to breast cancer at the outset of this research study.

Perception of 'reality' is influenced by an individual's subject position. While not a fixed identity, a subject position determines the way one understands the world and reacts to it (Hardy, Palmer, & Phillips, 2000). It is influenced by the dominant discourses in society and the material conditions of one's life, including gender, and affects which aspects of experience are attended to. Theorists such as Foucault (1973) assert that a limited number of positions exist within discourses from which one can speak and act and an individual must assume one of these subject positions in order to have a voice (as cited in Hardy et al.). As discussed in Chapter 4, women have occupied a subservient position to men in society and in the bio-medical sphere. Evidence for this subject position can be found in women's language, which in turn reinforces their position. The consciousness-raising approach employed in this study will enable women to become more aware of their subject position so that they can begin to challenge it.

In various ways, the women discussed how vulnerable they felt in relation to breast cancer; they were aware of the seriousness of the disease but did not have a clear sense of how to reduce their risk. They explored feelings of uncertainty, powerlessness, fear, frustration, bewilderment, and being overwhelmed (among others). It is this expressed vulnerability that characterized how the women were feeling at the outset of this study. However, they were not passive; they took the opportunity to reflect upon their collective experiences in an attempt to more fully understand their subject position in relation to breast cancer and how to change it.

Challenges highlighted by these women in relation to breast cancer included the quantity and conflicting nature of information related to BSE (and other aspects of women's health), the array of potential external risk factors that cannot be controlled, and the quality of health care. These challenges, along with the women's expressed desire to care for themselves, form the basis for the themes and sub-themes identified in the first meeting with Group A. These are presented in Table 12.

**Table 12: Themes identified in the first meeting with Group A: The subject position of women in relation to breast cancer**

Themes	Sub-themes
Lack of knowledge despite much information	How to do BSE What to look for Meaning of a breast cancer diagnosis Risk of HRT Usefulness of mammography
At risk despite self care	Gender Family history Fate Cell biology, the physical environment, and the unknown Social environment
Non-confidence in the health care system despite seeking reassurance	Poor medical care Wanting to be reassured Need to be vigilant
Seeking control	Importance of self care Importance of a positive attitude

But cancer is still lethal
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### Lack of knowledge despite much information

The women expressed concern they did not know how to do BSE or do it well. They indicated they had read material or were taught how to do BSE but did not do it properly, did not know what normal breast tissue was, or when a medical opinion should be sought. These gaps in knowledge existed despite many sources of information about breast cancer in our society including pamphlets, magazine and research articles, physician teaching, and stories from family and friends.

### How to do BSE

Adele volunteered that she did not examine her breasts because she did not know how to do it properly. She felt that BSE was a special technique and she had not looked into it seriously.

Anne: Have you ever examined your breasts?

Adele: Not properly because I've seen the brochures and things but I've never really looked into it very seriously. My doctor done an examination before - a long time ago - but since that [ ] sure, like I touch my body but I'm not doing a proper examination. I just figured that if there was something wrong I'd know.

Anne: How do you think you'd know if there was something wrong?

Adele: Well, I guess I would feel something. I mean you just assume but I know that's why there's a special technique they use for the examination.

### What to look for

Several women expressed that they did not know what normal breast tissue felt like and were therefore uncertain about how to detect an abnormal breast change. Some of the women described their breasts as having some type of perceived abnormality such as tenderness or lumpiness, or as 'feeling funny'. Uncertainty about these findings caused various reactions in the

women in relation to BSE including their choosing not to do it, feeling anxious while doing it, or in some cases, feeling sufficient 'panic' to seek a medical opinion.

Janet indicated that she performs BSE very quickly because it causes her to be fearful. She related her anxiety to conflicting information she had read about the significance of tender breasts, which she considered herself to have.

Janet: I do self exam but I find I'm scared when I do it. I'd like to get over that fear. Like I'll do it and I'll do it very quickly and I'll ... oh my God! It's over with now! I would like to become more comfortable with doing it [ ] There are conflicting things too. For years, they say if it was tender or sore you have nothing to worry about.

Various: Yeah, right.

Janet: And I have tender breasts. And then I read an article by a doctor who says that's not true. It can be something if that's the case. You're at peace of mind and then you're not.

Brenda reported hearing inconsistent messages about what would constitute a significant breast lump. Given her cystic breast tissue, she wondered if doing BSE would even make a difference, even though she reported doing it. The mixed messages about what to be concerned about has caused her to occasionally become 'panicked' enough to seek the advice of her physician. She expressed a tension between 'freaking out prematurely' versus attending to a potential change early, as widely recommended. She became very reflective as she wrapped up her thoughts by stating that it is the 'lack of clarity' that is really difficult.

Brenda: There's a lot of conflicting information too [ ] oh well, if it's sore and tender it doesn't mean anything or, oh no, even if it's sore and tender, it can mean something. If it's a hard lump, then that means something. Well, no, if it's a soft lump it could mean something. Well, no, if it's a soft lump, it could mean ... you know, and I have I guess what they refer to as lumpy breasts so ... and plus I also tend to have cysts anyway. So part of it for me is like I do it but most of the time I am thinking to myself - crap shoot - it could be something or it could not be something; and then it's like if I get anxious enough and panicked enough, I go see the doctor so there's that ... what should I say - that lack of clarity - that I think is really difficult [ ] But hey, it's a hard lump and a hard lump is supposed to mean something you know. I think it is that tossing up between freaking out prematurely versus attending to something that could be...

In many instances during this first group meeting (and those to follow), Adele expressed the opinion that it was very important for individuals to take care of their health, make the right lifestyle decisions, and have a positive attitude. However, with regard to BSE, she expressed conflicting feelings. On the one hand, she would like to take control of her breast health as she felt that one would know their own body better than anyone else would. But she also acknowledged that she too felt unsure about how to differentiate normal from abnormal breast tissue. This uncertainty has caused her anxiety; in fact, like other women, she too used the word 'panic'. The negative feelings caused by doing BSE have discouraged her from doing it, even though she believes in self care. She "almost" preferred to have her doctor examine her. She recognized the dichotomy in her feelings.

Adele: I almost feel like I'd better have my doctor do it; but on the other hand, you know your own body and everybody is different [ ] But I know like when I've tried to do it myself, where I don't really know, it feels kind of funny and there's like different texture, I guess, and things like that. Mmm, 'is this? ... it's like this' - mmmm - kind of lumpy, you know - 'I guess not - no, it's the same on this side'. Okay. And then I'd rather not do it, I guess, because you panic and why worry yourself - all these opposite thoughts.

### Meaning of a breast cancer diagnosis

The copious amount of information in our society related to breast cancer has created confusion among women. Adele expressed the sentiment that she is not even sure what all the information about breast cancer really means for her. After all she has heard from magazine articles and others' stories, she wonders how concerned she should be. She indicates she is left with more questions than answers.

Adele: There's so much out there in the city and you read and you read stories in magazines and I guess most people have cases in their families and well it's like 'am I supposed to be really worried about it or is it good to be paranoid about it and' ... all these questions! (*chuckles*)

### Risk of hormone replacement therapy

Some women expressed confusion about what course of action to take with regard to HRT. Rose related the conflicting messages she had heard from others with respect to the risk of breast cancer with HRT and how difficult it is to assimilate this information in a meaningful way. In addition to not yet knowing whether or not to take HRT, she was bewildered about why there was so much ‘hype’ about menopause now in comparison to her mother’s generation and what could be done about that. Janet points out that despite the written information circulating about HRT, the number of women taking it and the encouragement she has received from her physician, the research is not yet conclusive. Similar to Rose, she felt quite fearful about having to make that decision as well.

Rose: I find her (*family physician*) very supportive and she’s not trying to sway me one way or another - just educate me, and I appreciate that. But, you know, you hear this, ‘this could increase your chances’ and somebody else says, ‘well, look, after the age of sixty your chances increase a little bit more with every decade’. You may ... you’re sort of a little higher at risk and a little higher at risk. So by the time you’re 85 - if you live to be that long, you might get it, you might not. Should hormone replacement be sort of thrown out the window because of that? There’s an awful lot of things to look at. I mean I would prefer not to do anything that put me in that risk category anyhow; but then on the other side you look at hormone replacement, oh that doesn’t seem to come from it so you think well ok, I’m in this category. Well, I think I’ve got a pretty good chance of not having this because of family history, so maybe I’ll go this way so I’m vacillating right now. I don’t know if I’m ready to make that decision yet.

Brenda: Do you want a broken hip or breast cancer?

Various: Yeah, right. You know. [ ]

Rose: All of these things are coming up. And then I look and say here's my mother - 86 - who really has never been very ill at all in her life [ ] She has never had anything [ ] she went through menopause [ ] She didn't go off the wall. She didn't do anything weird. And, you know [ ] well, my friends' mothers were exactly the same way and *there's all this hype about us (whispered)*.

? I know.

Rose: So, what do we do about this?

Janet: I feel the same as you. I'm in that same position. Like my mother went through it and our grandmothers went through it, and they didn't have any hormone replacement therapy [ ] I've read some articles on it and, you know, the research on hormone replacement therapy is not even going to be conclusive until the year 2007; and all of our doctors are saying 'Go on it! Go on it!' There's nothing to worry about. All my friends are on it. I'm scared to death of it.

### Usefulness of mammography

Rose brought up a recent research study that questioned the usefulness of mammography. She felt angry that one of the few things women could do to control their risk of breast cancer was now being criticized. She described the conflicting evidence as being provided and debated by others, separate from her and possibly from all other women. She wondered if men were creating these debates about issues related to women's health and if they would just provide paternal pronouncements to 'the ladies' about their conclusions and tell them not to worry. She described the current academic debate and media attention as a 'war' that is going on around them. Rose expressed disbelief, frustration, and confusion. From this vulnerable position, she wondered what, if anything, could be done to improve women's health.

Rose: ... Another thing too, you know, you hear these different studies. Just a little while ago, one really made me angry because some group - I can't remember where - but they came out and said, okay, 'mammograms are a waste of time'. Okay? It really upset me because I thought, hey, now we've got something that can help us here, along with breast self exam - I'm for it - I think it's a good idea. But to hear ... and I ... my first question was, are these people all men? I'm sorry! I'm not what I'd call a gung-ho feminist or anything but it really bothered me because it's quite easy to turn around and say, 'okay ladies, this is not going to help anyhow. Don't worry about it'. And I thought, you know, that's not really fair. And then there were a whole other group of people that said, hey wait a minute - *so there's a war going on out there but it's all about us and what's going to help us here?*

### At risk despite self care

The women spoke about the importance of a healthy lifestyle (e.g., diet, exercise, rest, doing BSE) in reducing their risk of breast cancer and other illnesses. They not only acknowledged, but embraced, the important role the individual plays in protecting their health. However, they also discussed various factors influencing their risk for breast cancer over which they had no control such as their gender, cell biology, family history, fate, the physical and social environment, and other yet unknown factors. The women began to question the importance of self care within this context and the extent one should feel responsible for their health status if there are so many factors out of their control. They also discussed the fear they felt because they could not control their risk for illness despite self care.

### Gender

The very fact they were women was identified as a factor. In the following quotation, Brenda discusses her fear in relation to being a woman and the ubiquitous risk of breast cancer associated with just having breasts.

Brenda: I mean I'm petrified of having breast cancer. [ ] It's that sort of omnipresent ... if you've got breasts, you can get it.

### Family history

While filling out the questionnaire related to cancer at the first meeting, Beth reflected on the question about her perception of the likelihood that she would develop cancer at some point in her life. She based her perception of risk on her strong family history of various types of cancer. To her, it was very likely that she would be diagnosed with cancer but she did not want to acknowledge this perceived risk. On the likert scale provided for that question, she ticked '50/50' instead of the next box on the scale, '*it is likely that I will get cancer*'.

Beth: I mean ... I put down 50/50, but in reality ... I don't know. my mom died of lung cancer at age 52. My grandfather had skin cancer. My grandmother had breast cancer. Great-grandmother had stomach cancer. My sister has a mole disease [ ] and I'm sitting here going, I'm just a ticking time bomb! [ ] I really was going 50/50 or you're getting it! *(laughter)* It was like I can't tick that box!

### Fate

Adele and Beth talked about the role of fate in getting breast cancer or any other disease.

They felt that everyone is due for some type of misfortune; that it is pre-ordained and something over which the individual has no control.

Adele: You know something is going to happen to you out of all the things that are out there - breast cancer and many other things - it's almost like okay, what am I going to get and when is that going to come [ ] It's almost like you're ... it's something that you owe or that you're due for and then just -

Beth: What's your lot in life? What are you going to get, your karma *(agreement from women)*.

### Cell biology, the physical environment and the unknown

Brenda questioned the importance of personal health choices and how much one should feel responsible for illness, as if it were a consequence for doing something wrong. While Adele acknowledged it is one perspective to compare illness to an indictment for poor lifestyle choices, all the women reflected on the myriad of other factors in the environment outside personal control such as cell biology, the physical environment, and the unknown.

The women expressed anxiety related to not understanding the process, or knowing the health impact of, recent technological advances such as genetically engineered foods or pesticides. They feared for their own health and that of generations to come. Rose reflected back to her childhood when she felt people had more control over their environment. There is a sense that the women felt they had less control now about these issues.

Brenda: And I guess that brings up a really interesting issue about the degree to which we take responsibility or see ourselves as responsible for illness if we get it. I mean ... because I guess that's one perspective - is that if you get cancer, it's because you didn't do something right as opposed to, hey, sometimes cells just mutate and you end up with cancer despite all of the right things, you know, so ... [ ]

Adele: Because I understand that is a part of it when you get cancer or whatever illness - well, I'm guilty. I did this. I didn't do this.

Brenda: So, I guess, just you saying that just triggers in me the thought that how much control do we have and when is it ... it's like, well, there's that unknown factor that, despite all our good intentions - not smoking and eating healthy and exercise and all that.

Rose: And our environment, I think, is going to play more of a role in anybody's physical well being right now and we just don't know what's affecting us. There's a big discussion now about genetically engineered products. [ ]

Rose: It's just a little bit scary. I thought that was a great idea until I began reading a little bit about it. [ ]

All together: It's so sad! What's going on here! Yeah! Scary.

Rose: Like, I feel as if we grew up in a less engineered environment [ ] I mean people grew and produced a lot of their food anyhow and they didn't have all these pesticides but my own children are being exposed to it and their children are going to grow up totally surrounded by it and I wonder what that's going to do to them.

### The social environment

The women also discussed the effect of the social environment, in addition to personal health choices and the physical environment, on health status. They talked about the difficulty in maintaining personal balance within a society that is very fast paced and competitive. The women talked about how hard it is to slow down and care for oneself even when one is aware of how unhealthy their lifestyle is.

Brenda and Rose expressed feeling overwhelmed by factors in the social environment. Brenda wondered if doing BSE would make any difference at all given our unhealthy culture.

Rose stated she feels anger toward 'the whole society' that is driving the unhealthy fast-paced social environment, but is powerless to change the situation.

Brenda: And, maybe that's part of the lack of doing BSE's as well; it's just that sense of what the hell difference does it make [ ] Because I mean sometimes it can be overwhelming when you think of all those things and it's like what – *I'm going to do a breast exam - like that will make a difference* [ ] But it's not a healthy culture. It's like, you know, the way we work, the things we eat - all of those things. I mean I think health is in us too but if you work in a job that's in an air-tight building and you're expected to put in 8 hours a day in an airless box and you have a family and other commitments so that you're not getting exercise. You're not getting out and working. You're grabbing food on the run. It's like all of that health goes [ ]

Rose: Sometimes I get really angry at ... not just me or my friends or [ ] but the whole society - the way we have geared ourselves to be maniacs about work and time and losing sleep and worrying and competing and [ ] you know, I mean, we're killing ourselves! We're really killing ourselves and we're not teaching our children any better. What's going to happen with a couple of generations down the line? Like, you know, are we just going to be on automatic pilot all the time - just going here, here, here and here and there's going to be no time for ourselves.

Brenda: You know, it's always interesting to me - is everybody feels that way. [ ]

Rose: I often thought I'd like to just stand up and scream - stop!

#### Non-confidence in the health care system despite seeking reassurance

The women expressed concern about the quality of health care they and their families were receiving. At the same time, they expressed a strong desire to seek out medical care and reassurance. In recognizing the inadequacies of the health care system they were reliant upon, they stressed the importance of individual vigilance, although the usefulness of that was questioned as well.

#### Poor medical care

Concerns raised by these women related to poor medical care stemmed from experiences they or their family had within the health care system. They included cursory examinations,

physician error, poor communication with physicians, and inequities within the health care system itself.

Janet talked about a clinical breast examination she was given by a gynecologist that she felt to be brief and incomplete; she even recognized that some components, like axillary palpation, were omitted.

Janet: And the other thing for me is like I saw my gynaecologist today and she did a breast examination and it's a riot. It's a total riot! You know, it's not good enough.

Anne: How long was the exam?

Janet: The breast exam?

Anne: Yes.

Janet: I'd say five seconds (*laughter*). It's true. [ ] and then the doctor said, lift up your bra, and I did, and it was just that quick. There was no ... nothing up in the armpit or ... it was just very, very quick.

In reference to physician error, Janet talked at length about the care her father and husband received for cancer. Her father had died within the past year "through an error with the doctors". She related that when he was diagnosed with his initial cancer, the doctors missed a concurrent cancer, the treatment of which eventually killed him. In addition, her husband had been diagnosed with cancer four months previously. Janet felt that the report of an investigational scan had not been read closely enough, resulting in a missed secondary cancer. This second cancer had been picked up only after Janet kept waking up at night feeling uneasy and finally asked her physician to pull the report again so she could read it herself.

Janet: But the only reason they found it was because I had uneasiness inside of me – an intuition – that I asked. It had gone on for a couple of months and I just wasn't feeling good about the two tests he had; and when they were brought out, there it was. It was just put in the file.

Another example of inadequate medical care discussed by the women was poor communication by physicians, both in terms of withholding critical information or in delivering information in an insensitive way. Beth brought up two instances of a physician withholding information in relation to her mother's terminal lung cancer. In the first instance, Beth recounted that it was only after her mother's death that the family was told her primary cancer had already metastasised to her heart when she was first diagnosed. They had previously been told 'they got it all'. Beth attributed her "distrust" of the medical system to this withholding of information. It also left her with the view that a cancer diagnosis for her would be lethal and that she would be very fearful if she were ever diagnosed with it. Janet agreed with her that she should be afraid.

Beth: Anyway, when she finally died, Dad spoke to one of her doctors [ ] and he told us when they took out (*the primary cancer*) the first time, there was cancer in her heart. It was everywhere! And they didn't even tell us! They didn't tell her - nothing! And I mean I have such distrust in the medical system because of that and just things like that that I know if I got cancer, I'd be like 'oh my God, my number is up! That's it!' I'm terrified! Terrified!

Janet: And you should be terrified.

In the second instance, Beth recounts that her family was not told she was dying until the end stages of her mother's life. And when they were informed, it was done abruptly in the hospital corridor while they were on their way to the cafeteria. The insensitive way they were informed of her mother's terminal prognosis added to Beth's terror of getting cancer. Beth expressed a concern about "this kind of attitude" displayed by the attending physician.

Beth: I remember when my mom was in the hospital, like she was dying. We had no idea that she was dying, honest to my God, and ... we don't know these things anyway. I remember ... me and my dad left her room - we were going downstairs to get a sandwich and ... walked in the hall, her doctor was there. He walked up to us and he said, 'where are you going?' [ ] he looked us straight in the face and said, 'you know she's dying, don't you'. We just nearly collapsed on the floor! And it's this kind of attitude that's like if I ever got breast cancer, lung cancer, whatever, I'm ... I'm serious ... I'd freak! You have no idea! Like even just thinking about it is ... is ... it raises my blood pressure, just even thinking about it.

Brenda also admitted to a distrust of the medical system because she did not feel confident it had the capability to adequately diagnose and treat breast cancer. She expressed fear that if diagnosed, her cancer would metastasize in spite of modern technology, without her physician's knowledge, and be ultimately lethal.

Brenda: I guess also there's kind of this inherent distrust in the medical system because I guess I imagine myself going in and having a lumpectomy or something and then they'll say, you know, we got the lump and yet I know that it's already somewhere else in my body by then. It's like it's already in my liver [ ] waiting in my liver or waiting in my lungs or something like that and so even if they say, we got it all and you're better. I have this sense that I know it's just like a time bomb [ ] It's lurking, yeah, because I guess I feel like I heard that happens so often that on the one hand I think, hey people survive breast cancer but there's really a part of me that thinks, no, once you've got it, it gets you in the end.

Another concern the women expressed about medical care was related to inequities existing within the health care system, based on who you are, and whom and what you may know. Janet associated finding an error in her husband's medical workup with having personal contacts in the system and knowing some of the terminology. Brenda agreed, stating she was infuriated by a presentation made by a nurse at an oncology conference who admitted that her personal contacts made a difference in her care.

Janet: You know, we had a few contacts who knew a little bit, and some of the lingo; but anyone who just doesn't know - not a clue - I mean they wouldn't even ask. They would just take the doctor's word: this is the results and never ask, right (*agreement*). So ... I don't know ... it's so scary. It's just so scary (*agreement*).

Brenda: ... It seems to be if you don't have contacts or if you don't have someone who can advocate for you in the system [ ] (*in reference to the nurse's presentation*) But you know, it was all about who...and she acknowledged that it was all about who she knew, what contacts she had, who she could get to advocate for her and it was infuriating because if you're not part of that system, it's like you're chopped liver!

Janet: It's true [ ] But people don't realize what's going on. People don't realize [ ] How many mistakes are being made that people just don't have a clue about.

### Wanting to be reassured

Even though the women spoke of perceived inadequacies in the health care system, they expressed a profound desire to seek and receive medical reassurance. Rose responded to Susan's comment about "panicking" when she did her BSE and making an appointment to see her physician. Rose stated that it was desirable to have someone else tell her she was fine; that she could then stop worrying.

Rose: I think that's a good idea really, that you're doing that. It's better [ ] I think I would I do that too. At least then you have your peace of mind someone else is going 'that's ok, don't worry', you know.

Susan made the point that women will seek a medical opinion for potential breast changes and be reassured by their physician's assessment, even though the examination may not have been thorough. She relayed a story about her friend's mother whose breast cancer may have been missed in previous clinical breast examinations. This possibility scared her.

Susan: I think you've raised a good point too that a lot of people go and they get these like 5- or 30- second examinations and because you've gone to a doctor and they say, 'oh everything feels fine', then it's okay. And I'm just ... in the last six months, one of my friends I grew up with - his mother has been diagnosed with breast cancer and one of the things she said when I went to see her [ ] 'I don't know. I always got an exam when I used to go for my pap smear or for whatever' and it was kind of left at that and that kind of set a trigger off in my mind again that I got a ... you know, a bit of a scare, and I thought 'is it an effective examination [ ]?'

Brenda succinctly described the dichotomy between wanting to take care of oneself and also wanting the reassurance of a physician. She told the story of a young journalist who died of breast cancer. When her lump was discovered, her physician told her she was too young to get the disease (she was in her twenties) and to go overseas as planned. When she was finally diagnosed, it had metastasized and she died within six months. Brenda was greatly moved by this woman's death and described it as "pointless". She speculated that the journalist may have struggled with wanting to take care of herself on the one hand while feeling relieved to give

responsibility for her health to her physician on the other. The women strongly identified with the desire to be reassured when seeking medical care and their relief when they have been declared well by their physician, even though they knew that physicians sometimes made mistakes.

Brenda: I remember when they announced it on the radio; I just sobbed because it was so pointless. [ ] I guess she felt like she was trying to take care of her health but I think sometimes it's easier to give a little responsibility to a physician or something and then, you know, feeling bad about how she didn't follow that up.

Adele: If you suspect that you might have something wrong and then you go and check with someone just to know it's okay - you don't want to believe there's a possibility of cancer.

Rose: Yes, exactly. We want to be reassured, don't we? (*agreement from women*) [ ]

Janet: It is not always the case though.

Brenda: What? No.

Janet: That the doctors say you can be fine and then not be.

Brenda: Yes, but you want to be reassured so you'd rather believe that.

Beth: Yeah, there's one part of you when the doctor says you're fine, you're like 'whew!' - you know what I mean?

### Need to be vigilant

Given that the women were aware of the inadequacies within the health care system but were still dependant upon it for reassurance, they agreed they had to be vigilant over the health care they received. Janet cautioned them to be very careful to detect potential medical errors.

Janet: So never take anything for granted. If you have a test done, ask for it in writing. If you can't understand it, get someone to read it for you - but there's a lot of errors being made. A lot.

Various: I agree. I definitely agree. Yeah.

However, while the women agreed there was a need to be vigilant, they also questioned the ability of the individual to fight the health care system where they perceived all the key stakeholders would stick together. They expressed feeling like victims, having little recourse to improve their situation, and not without incurring negative personal repercussions such as poor care or a damaged reputation.

Janet: We as a society let that go, you see. We do let it go! [ ]

Brenda: It's a very hard system to fight because ...

Janet: You can't fight it.

Brenda: Everybody sticks together.

Janet: You can't fight it.

Adele: So what do you do?

Janet: You really can't fight it there.

Adele: So it's just being victims of the health care. [ ]

Janet: There's nowhere to turn. There really isn't. There's nowhere to turn. You can't go complain. You just ... they just won't [ ]

Brenda: Well, if you do make a fuss, then you get pegged as that loony person who's ...

Beth: Yeah, the upstart.

Janet: So if I kick up a fuss now about my husband, will I compromise his care?  
(*agreement from women*)

Janet: That's a fear, isn't it?

Rose: But that's an awful way to have to feel.

### Seeking control

There were many times throughout this first group meeting that the women voiced feeling fearful, confused, powerless, uncertain and other expressions of vulnerability in relation

to breast cancer. However, despite these feelings, there were also instances in which the women were actively trying to find ways to increase their control of the situation: most notably by taking care of themselves and having a positive attitude. It is remarkable though that the women returned to their discussion of what a cancer diagnosis would mean to them at the end of their meeting. In this discussion, the lethality of cancer was stressed; that the fear associated with cancer in general is related to the perception that it is ultimately terminal. So, while the women endeavored to find ways to reduce the risk associated with breast cancer, the underlying context of the disease was death, and this was very frightening to them.

#### Importance of self-care

Throughout this first meeting, Adele stressed many times the importance of taking care of one's health by making prudent lifestyle decisions and having a positive attitude. She spontaneously shared with the group the reason she volunteered for the research study was that she was hoping to understand why she did not examine her breasts even though she was aware of its importance, had a family history of breast cancer, and felt that she should. Attending these meetings was a strategy Adele chose in order to do something about breast cancer.

Adele: Well, personally [ ] I hope that will get me to do BSE because I do not do it. I know it is important but I just don't do it - I don't know why. So I am hoping I get that out of it, and you hear different things, I guess, related to it and I know in my family there's a lot of cases of breast cancer so I think that I should do something about it, but I know I'm not so I'm hoping that will get me to start.

In reference to Janet's discussion of her 5-second clinical breast examination, Adele stressed the importance of knowing one's own body in order to detect a change as early as possible, as no one else would know their body better. Although she did not do BSE, she articulated well a rationale for doing it.

Adele: Nobody else like yourself to know your own body and from what you were saying, sounds like you should know your body very well so then when there is a change you know, whereas when you have a stranger who has never touched you before, you know they don't know what your breast feels normally so how are they supposed to know.

Rose agreed with Adele that self care was important. She spoke about the need for individual decision-making around health issues. While still vacillating in her decision about HRT, and feeling stressed about hearing differing opinions, she recognised that ultimately she had to be the one to make the choice and live with the sequelae. Other women agreed that making decisions about health was an individual responsibility, albeit a stressful one.

Rose: I know. I guess it comes down to ... it really has to be an individual choice and you just have to say, okay, either 'I'm going to do this thing and accept the consequences' or 'I'm not going to do this thing and accept the consequences', and come to a decision. Like I'm still vacillating ...

Adele: You have to make a decision, no matter what you do.

Various: You do! Yeah. [ ]

Rose: And who do you listen to.... It comes right down where you're going to have to do what you're going to do [ ]

Adele: I'm after reading a lot lately about books that talk about taking care of yourself, being healthy. It all comes down to you do what feels right. [ ]

Rose: We seem to be all stressed out about it.

Late in the meeting, Adele asked what could be done to increase individual control over health. While she had emphasized the importance of self care throughout the meeting, she now seemed to consider the impact of external forces upon the individual, such as the amount of information available and the quality of the health care system.

Adele: It's like what can we do to be in control of that ownership of our health and our body and just ask the right questions and know what to do when? ... because I guess sooner or later, you *do* have to go see the doctors even though people...

### Importance of a positive attitude

In addition to taking care of themselves, the women also discussed the value of a positive attitude about being diagnosed with and surviving cancer. In spite of their fears related to cancer, they stressed the importance of not letting negative thoughts or pessimism take over.

Adele discussed the questionnaire regarding their knowledge, attitudes and behavior related to cancer. While forming an opinion on her risk for cancer, she differentiated between what she thought might happen (there was a “pretty good chance” she would get cancer) and what she hoped would happen, choosing to think positively instead.

Adele: ... do you think you'll have cancer or hope it will be or what I actually think. it's two different things. [ ] How likely do you think it is that you will develop cancer at some point during your life? So you know the statistics and everything and say, well, I guess there's a pretty good chance but I don't want to think that way - positive attitude! *(chuckles)*

In relation to surviving cancer, Adele discussed how she used visualization to help her cope with her perceived likelihood of getting breast cancer. She talked about picturing herself well again post-treatment, while not actually thinking about the treatment phase at all.

Adele: When I think about breast cancer - I just picture it because I know it's a very possible thing that I'll get breast cancer - and then the whole treatment or whatever is just a complete blank and then it's just after. After, I just get on with it and life goes on. You're good now and you appreciate it; but it's like there's that gap there you don't think about.

While Beth acknowledged she was “terrified” of getting cancer, she did not want to have, or be seen to have, a pessimistic outlook towards it.

Beth: And it's not a defeatist attitude, don't get me wrong.

Janet: I know.

Beth: It's not like I'm saying I'm going to get it and I'm going to die and that's it and I'm ... you know.

But cancer is still lethal

The women's strategies to reduce their risk of breast cancer by taking care of themselves and having a positive attitude were juxtaposed against their comments that cancer was lethal.

The following two comments were made towards the end of the group meeting. Beth's comments about the terminal nature of cancer are in keeping with her earlier statements that she was terrified of getting cancer. The following statement was made in relation to her mother's cancer experience. She recalled sitting with her mother during one of her chemotherapy sessions and intuitively knowing that her mother would not live to see their plans to fruition.

Beth: ....and I remember sitting there thinking, 'there's no way in hell you're going to see where I'm putting my furniture'. I was right. And just having done stuff with her like that, that I know if I had breast cancer, lung cancer - whatever - I would freak! If I had breast cancer, I'd be like, cut it off! Get it out - now! Not next week! Now! Find a scalpel! Get it off! ....

On the other hand, Adele's comments on the lethality of cancer are in stark contrast to her numerous comments throughout the meeting that she would be healthy if she made the right choices. The following quote provides a good summary of her statements with regard to staying healthy.

Adele: And then you wonder what it does to your health to worry, like for so long until you get cancer or whatever and I just take care of myself and sleep well and everything else. I'll just be healthy and I'll be alright.

However, at the end of the meeting, Adele stated that surviving breast cancer would be a miracle. She attributes some of this sentiment to the state of the health care system.

Adele: The word cancer to me is like a death sentence; and if you can survive it, you're like really lucky. You are like a story to print in a magazine - I mean, against all the odds and you made it. I know there are some types that are very treatable but you have to get it early and I mean there's a waiting list...

### Subject position of Group A

At the outset of the research process, the women in Group A expressed vulnerability in relation to breast cancer in three ways: (a) Feeling they did not have enough information or understanding about breast cancer and breast screening, related to a plethora of conflicting information in society, (b) feeling at risk despite their efforts to care for themselves, related to a large number of factors outside their control, and (c) not feeling confident in the health care system, related to poor medical care and inequities in the care provided. However, despite this subject position and their perception of cancer as lethal, the women were committed to taking control of their breast health by continuing to care for themselves and maintaining a positive attitude.

### Group B: Women's subject position in the world

The first meeting with the women of Group B began spontaneously as one of the members entered the room and commented on a TV show she had recently seen where women were described as being 'size zero'. This set the tone for the ensuing discussion. and even while the purpose and method of the research study were explained to the members of Group B, and they were filling out their short questionnaires, the women were discussing how 'woman' was portrayed in our society. Not surprisingly, discussion related to women's subject position in the world dominated the rest of this meeting. In various ways, the group members discussed how frustrated they felt about the way women are represented and treated in society. This was expressed in feelings of anger, bewilderment, confusion, sadness and incredulity.

Like the members of Group A, the women drew on their day-to-day experiences to inform their discussion of BSE. Various phenomena were highlighted by group members including the sexualization of women's bodies and how this influences the way women are

treated in society, the social standard for female beauty, and feelings of shame associated with the female body. At the end of the meeting, as the women were exploring possible reasons why women do not examine their breasts, they reflected on their preceding discussion, and stated that it was a complex issue touching on something “inner and unidentified”. See Table 13 for a listing of the themes and sub-themes identified in the first meeting with Group B.

**Table 13: Themes identified in the first meeting with Group B: The subject position of women in the world**

Themes	Sub-themes
Sexualized children	Women as sexual property Women as children
Trivialized but at risk by Medicine	Minimizing women’s agency Minimizing women’s risk
The ideal androgynous body	Beauty is size zero The quest to be thin
Shameful female body	Menstruation is dirty Touching oneself is wrong
BSE is a complex issue	Older women are not worth it Something inner and unidentified

#### Sexualized children

The group members talked about the contradictory place women occupy in our society, such as the glorified object of male sexual attention, while at the same time holding little social power in legitimate public roles traditionally occupied by men. In other words, valued for both their mature sexual characteristics and their underdeveloped place in society. Their limited social power is more characteristic of children than adult women.

#### Women as sexual property

The women spoke of the female body as the property of men, and their breasts as the dominion of the entire society. In the first excerpt, the group members discuss the dress Jennifer Lopez wore to the Academy Awards. It appeared to be two swatches of sheer fabric that met at

the navel. The women felt that her male partner at the time was proud of her revealing dress because she was displaying his property.

Mary: Some of these dresses they are wearing, some of these openings where...

Lynn: Absolutely.

Mary: There's barely anything there.

Anne: Do you mean Jennifer Lopez?

? She's just one of many.

Diane: Was that a dress?

Marion: She was on TV last night and someone asked her 'is that a dress?' 'That's a dress', she said. She asked her boyfriend if it was a dress...

Diane: And he told her it was a dress.

Marion: She said, 'what do you think of this?' He said, '*now that's a dress*' and she wore it.

Joanne: Of course she did because he wanted people ... he could see and he wanted everybody else to see the skin that he owned.

Joanne brought up a news item of a billboard campaign for breast cancer awareness that had gotten pulled because of public outrage. The campaign featured women with mastectomies. Joanne questioned why this type of representation would be offensive to the public. The women easily articulated the view that women's bodies could only be seen in public as sexual objects, and were liberally portrayed as such in the media. They felt that a reminder of the reality of breast cancer would disrupt the fantasy of the sexual female body.

Joanne: Yeah. It's like the ads they were going to put up in America on breast cancer and they had photographs of women who had their breasts removed and there was an outcry, and I'd like to know why there was an outcry [ ]

Mary: But I guess that's facing reality, isn't it -- that's really what it was about - and it was just not nice.

Joanne: And women *cannot be* portrayed as anything but size zero (*agreement*).

Diane: Yeah, Barbie dolls.

Mary: But, I mean you know, with women's breasts glorified all over the place and why show a woman without. I mean, you know.

Joanne: It's just too stark.

Diane: That's right... A billboard of two breasts would be just dandy [ ] A woman with two breasts is just dandy.

Joanne: But minus one? ... What is this? It's a hint of reality ... It puts women or it removes women from that fantasy world that objectifies women ... Being sexy and feminine and everything - everything that we are supposed to be.

Diane: That's right.

Joanne admitted she had often wondered about the rationale for the outrage over the billboard. Diane wondered if it was related to the societal objection to breastfeeding in public; that it is not socially acceptable to present the female breast in any way that is not sexual. As well, the women discussed how breastfeeding was not even encouraged when they had their children.

Joanne: But it really bothered me. I thought about it several times like even driving in the car and seeing a billboard and thinking 'wonder why they wouldn't put up those'.

Diane: ... I'm wondering would this be related in any way to the objection to women breastfeeding in public? If breasts are anything other than a sexual object [ ]

Joanne: Which they are ...

Diane: It's not going to be permitted so you can't use them for nourishment, which is after all what they're there for.

Marion: That's what they are there for – originally [ ]

Joanne: Exactly, and that's how you get pregnant in the first place. [ ] So which comes first and why do we have to remove one from the other?

Diane: There is that dichotomy.

Joanne: Well, I breastfed all my four boys; and when I did back 32 years ago, I was the only woman on the floor who was breastfeeding ...

Mary: Yeah. It certainly wasn't encouraged.

Lynn: I had a doctor come in and tell me that I probably couldn't produce enough.

### Women as children

The women discussed that despite being glorified for their obvious adult female sexual characteristics, they were often treated as children. They were not expected to participate fully in the world and were not encouraged to experiment beyond their social boundaries. There were several instances provided by the women from their experiences that exemplified this. In the first instance, Joanne reflected back on the initial foray of women into the broadcasting business. Her mother was a pioneer on CBC Radio but was restricted to discussions about fashion and recipes. When women were finally assigned to the news, it was thought of as "cute". The group members agreed that the portrayal of women in the media at that time reinforced the traditional roles of women in society, and that other representations of 'woman' were not permitted.

Joanne: It's like what can you compare it to? It's like when women first read the news on TV - [ ] It was kind of a cutesy thing to be. It was a new thing for us. It was still in that cutesy kind of genre, (*agreement*) shall we say, but then she got kind of actually to do some news coverage and it became more popular. [ ] My mother was on CBC for years doing women's ... a Women's Broadcast it was called and it *had to be* recipes and fashion because that was what women were interested in, right?

Jean: That was women's work

Joanne: And this whole concept of what is the woman's role ...

Marion: Whether it's in this role.

Joanne: And if [ ] interested, you had to fit into this little slot or whatever.

The women discussed examples of how, even today, women are not taken seriously in the traditional male sphere and are not expected to take on or handle responsibility well. They shared

experiences from their lives, and those of their family members: Joanne owns her own business but it is continuously attributed to her husband; Jean's sister is a building contractor who is often ignored on site when deliveries are made, as the bearer of goods searches for a male to take responsibility for the delivery; and Lynn spoke of her experience of being ignored and patronized in the hardware store.

Joanne: The perfect thing is ... like I own my own business and my husband works for me in the summertime [ ] every time we do anything together in the business, people always refer to him.

Jean: Him.

Joanne: And people always say to him 'oh, you have this business - you and your wife have this business?' - and he says 'no, actually, my wife has the business. I work for her' (*laughter*) ... but it's always that way.

Jean: My sister is a building contractor. She builds houses, you know, and people come up to her ... and there could be a little fellow there about 10 years old and it's him they go to, bypass her sort of thing and that, you know.

Diane: When they do that, what's her response?

Jean: She's says 'I'm the one who ordered this cement or hardwood floors, not him. Me'.

Lynn: It's that way when you walk into a hardware store too.

? Oh yeah!

Lynn: A woman in the lumber store - any of the big lumber stores - all the men get served first and then they pat you on the head and say, 'now dear, what would you like?'

Diane: That's right.

Upon reflection of the way that women are still being treated in society, they discussed how slow public perception changes, even their own. Physicians were male when they were having children. Today, even though medical school graduates are at least half female and there are many female physicians in practice, there is still that assumption that a physician is male. Joanne pointed out that it is difficult to change what has been socially instilled.

Joanne: Let's say the word, doctor - when you hear the word doctor, you don't automatically think male or female. Most people still today - if you say, 'oh I'm going to see the doctor - Dr. So-And-So - or I went to see Dr. So-and-So' - 'what did he say?'.

Mary: Oh yes, you still think of it, 50% of the classes now are female and you still automatically ... think.

Joanne: Because we're geared that way. [ ]

Mary: And there were only male gynecologists. [ ] and now there's more female than male ... there's more of a ... at the time when I was having children, there was only male (*agreement*).

### Trivialized but at risk by Medicine

The women explored their relationship with their physicians and their feelings about the health care they have received. While discussing their personal experiences, they acknowledged that women have been simultaneously patronized and put at risk by Medicine.

### Minimizing women's agency

Lynn discussed how she has felt patronized in her encounters with male physicians: that they did not communicate with her well, or even ask her to provide her illness narrative, while telling her that 'everything will be fine' and prescribing medication. The group members agreed that historically women have been trivialized by their physicians. However, they explored whether this was a function of physician personality, or if it was more indicative of the power wielded by, and accorded to, the profession of Medicine in society, a profession traditionally male-dominated. While Joanne expressed the view that both male and female physicians could provide excellent care, Mary felt that the female physicians with whom she has worked were different than their male counterparts and developed more of a partnership role with their female patients.

Lynn: Well, Anne, the only reason I have her is that [ ] if I walk into her and say, 'I'm not feeling right', she will say, okay, 'what are you doing?' - not, 'now dear' - which I find a lot of them ... when I had male physicians, quite often, they're just so bloody patronizing and, you know, it's 'now, now' and, you know, 'things will be okay'. She will stop and say, 'okay, what's going on? What are you doing?' And she doesn't give pills very easily. [ ]

Joanne: But there are female doctors that are patronizing too because I've encountered them.

Mary: I think that's more personality perhaps.

Diane: Although there probably are more male just because of an age function ... older doctors (*agreement*). [ ]

Joanne: I think a lot of the older doctors, that was their role. They were put into ... they were there to take care of you, to cure you, to set you right and that was the job that they tried to fulfill; and if it made them paternalistic, it was probably a function of the role.

Lynn: Yeah. They were all Marcus Welby.

Diane: They had secret knowledge and ... it was society – gave them - allowed them or created the role for them and they performed it beautifully! (*laughs*) They took it over. I suspect that younger male doctors will not [ ] I suspect it wouldn't be quite as prevalent among the younger male doctors. I don't know that.

Mary: I find that the female gynecologist or obstetrician that I know are more into preventative rather than just ... you know, like when they're talking, they're letting you make the decisions and they give you the information about hormonal replacement therapy and encouraging you to go forward to the breast screening clinic and things that the others didn't do over the years (*agreement*) ... I worked with a whole lot of them so I'm familiar with the trends - change - a different kind of - and I can see a change, a change for the better.

### Minimizing women's risk

In addition to feeling trivialized by their physicians, the women felt the health risks of common 'female' treatments were minimized, placing them at further risk. To illustrate this point, Joanne shared her feelings regarding a tubal ligation she had several years previously. She described her anger about not feeling fully informed of the invasive nature of the operation and the recovery time needed for the procedure. She was told there was "nothing to it" and then

experienced a difficult six week recovery, During that time, she wondered why she had put herself through that and why her husband did not have a vasectomy, a far less involved procedure.

Joanne: It was also the same time when I had my tubes tied. *I was so angry about that* after I had it done and found out how miserable I was going to be for six weeks. [ ] I was ready to kill any man that ever walked (*laughter*) [ ]

Diane: You were given a choice ... but were you pressured into it -

Joanne: I don't know what it was. It was just I had passed the stage where I should have children. My kids were older. I had a business. It was the sensible thing to do and I was told there was nothing to it *and Jesus Christ (whispering)* ... I really was. I'm not angry now but at the time [ ] But having said that, the more I thought about it - why couldn't he have the vasectomy. Why did I have to, *why did I put myself through that?*

The women discussed how Joanne's experience was not unique and that there were, in fact, serious risks associated with a tubal ligation. Diane described a recent newspaper article where a woman had experienced severe adverse effects from the procedure. Lynn felt that the attending physician's response was cavalier and insensitive, seemingly conveying that these risks were just a matter of course. The group members also remarked that women have been put at risk for decades, especially in relation to birth control, even when less invasive procedures for men were available.

Diane: Did anyone else read the ... [ ] an article about a woman who had an operation for a tubal ligation and then ... That out of every 10, I guess we can call them sterilizations, two are vasectomies and eight tubal ligations. But the tubal ligations are much more dangerous (*agreement*).

Anne: She lost both arms and both legs.

Diane: Both hands [ ]

Lynn: Doctor went to Vancouver and he said: 'well, that happens'. That was my impression on reading it.

Joanne: Now, you can't believe everything you read.

Lynn: I was appalled at the same number you were appalled at ... and I thought 'it's really odd - we could have a tubal ligation and they wouldn't want to get it snipped'. [ ]

Marion: It was the women's duty to have it done, for the women to have it done.

Lynn: And we did, we went on the pill, we took all of those risks with the pills ... especially the early pills. And there were a lot of risks.

The ideal androgynous body

In addition to discussing how the female body itself is sexualized, and the central role of the breast as a symbol of this, the group members explored how women's beauty is being portrayed in society. According to popular media images, the current standard for female beauty is to be ultra-thin, ironically with very little fat or breast tissue: in fact, to be androgynous or male-like.

Beauty is size zero

Joanne was quite concerned about the reality show "Who wants to marry a millionaire". It was this program that sparked her question 'What *is* it with size zero?' as she walked into the room at the outset of the meeting. She was very concerned that size zero was listed as an asset for the contestants who were competing to be chosen to marry the millionaire: that it would send a damaging message to women that zero was the size to be to marry well or be valued. She wondered if size zero also sent a message to women about their worth or perceived worth.

Joanne: The female image or *the female's impression of the female* image. Size zero. Do you want to marry a millionaire? (*laughter*). Size zero ... what does that tell us? That we're nothing? [ ] Sends women a very, very significant message that size zero is the size to be if you want to get chosen by a multi-millionaire (*agreement*). Not for our age group, we're past that but for the younger age group. [ ] And if you don't conform, you're out! [ ] Did she have to have a pretty face and be intelligent and speak well and everything. No - she had to have the perfect body image... two breasts too.

The women also spoke of other popular television shows and magazines that featured women who were extremely thin such as “Ally McBeal”, the women on “Friends”, and “People” magazine. They commented that these women all looked alike, and all looked androgynous. Beauty was no longer the full and voluptuous body portrayed by Marilyn Monroe (who would now be considered overweight), but a waif with no breasts. Joanne commented that Twiggy had this look, as well as the slim and firm shape modeled by Jane Fonda, indicating that this standard of beauty has been a long time in the making.

Joanne: I think her size (*Ally McBeal*) is giving women - young women especially - a terrible message. [ ] And if you look at some of the other programs that young women are watching - like ‘Friends’. They all lost 20 pounds.

Diane: They`re all the same size.

Joanne: They all have the same hair color. I can` t tell one from the other. [ ] And then they decided ... “People” magazine, which is a very popular magazine for young people in particular, and they did an article on weight. Ally McBeal is in it as an anorexic and she defended her position that she isn` t and ... all this kind of thing and [ ] they`re using Marilyn Monroe and somebody else said, ‘oh God, if I was as big as she was, I`d make away with myself basically’, or words to that effect. And in some article they did a - in the same magazine - they did a whole article on anorexia and then you turn one more page and they said, ‘oh, look at so-and-so, she`s really slobbering on the weight’.

? Give me a break. Give me a break!

Mary: To us it doesn` t matter because it doesn` t mean anything; but to the young people that are growing up ... thin is in and everything else is unacceptable (*agreement*) ... but in the meantime, these very, very thin people like models you see on the runways and the shows ... I mean they don` t have breasts! [ ]

Joanne: True. But, you know, I have a theory on that too (*laughter*). The majority of fashion designers are homosexual and they pick women that look like boys.

Anne: Interesting theory.

Mary: Yeah, that`s true.

Anne: They are pretty androgynous these days, the models. [ ]

Diane: Well Twiggy, we all know about her.

Jean: Yeah, she was our generation.

Joanne: Someone should have been taken out and shot her. Jane Fonda was another one. She should have been hung dry and quartered. Imagine 50 years old trying to look like they're 16! (*very loud laughter*).

### The quest to be thin

The women discussed how they and their friends endeavored to stay thin and achieve this standard of beauty through diet and exercise. Joanne talked about how foolish this seemed to her at age 46, when a friend of hers died. She stated she then stopped caring about maintaining her 'ideal' weight. This standard was both self-imposed and encouraged by husbands.

Joanne: Women should be allowed to be comfortable with yourself. And not always striving to be - dieting and dieting. I remember from the time I was 13 years old until I was 46. I can tell you the day I gave it up. If I went to a 130 pounds, I thought I was huge! Huge! I was always trying to be a 110 pounds and I thought that I had to be. I really did! And then a friend of mine, who was always dieting too, and we used to joke and say when we are 65 and get the pension, we're going to live at Tim Horton's and have all the bowties and we'll eat whatever we like ... and she died and that was a real wake-up call for me [ ] And I said, enough of this! I don't care! I stopped dieting and I went from a size 8 to 18. [ ] But it took that. And I mean, I did ... I had a husband that insisted that I stay thin.

Various: *Oh!!!*

Diane: Now this is another story.

Joanne: If he saw me at that cookie there tonight, he'd say 'you don't need that'.

Marion: Well, my husband does the same thing and I say to him 'look at yourself'. I know what he's trying to do - get me to watch it.

Anne: I agree because Tony is the same way with me. [ ] there is a pressure to stay thin. And I feel that very much.

Joanne: I have a friend who walks two hours every day ... because she afraid she's going to gain weight. *Terrified!* [ ] I used to go to Aerobics classes, I used to work out. I never went to bed without doing my exercises, for years.

Even though group members acknowledged that the pressure to remain thin was influenced by popular representations of women in the media, and was imposed by both themselves and their husbands, they wondered for whom exactly women were trying to maintain this standard? Perhaps not to feel better about themselves or to be more physically fit, but for public consumption. Jean talked about an acquaintance of hers who worked out of her home with her husband.

Jean: ... in their home they have a business ... and she is absolutely gorgeous ... you can't tell her age. She's probably in her early 40's or something. She musn't eat because [ ] and I think to him it's very important for her to look because there's a lot of people coming back and forth to her house, you know. She's just gorgeous. [ ]

Mary: But then you wonder if she's happy or is that what she's doing because he wants her like that ... comfortable or to be just on display? People who are always done up, are they doing that for themselves? [ ]

Various: I know people like that ... who are you doing this for? [ ] I guess when people are like that all the time that you ever see them, like who are they doing it for?

### Shameful female body

There were two ways that the women expressed shame in relation to the female body. The first was their discussion that menstruation was to be kept secret; neither menstrual blood, nor feminine sanitary products, could be seen. The second was that touching oneself was not appropriate and was not discussed easily.

### Menstruation is dirty

The women talked about various ways they handled menstruation so that it was kept hidden, as if it were both secret and repulsive. 'Secret' was conveyed by the way feminine products were handled: by not asking their husbands to buy them; by not having them out in front of children; by sneaking them into the house. 'Repulsive' was conveyed by the way blood

was handled: by not letting it be seen on clothes or in media ads; by burning soiled feminine products; by not letting soiled clothing mix with other laundry or soak in the sink. As the women said, violent blood is okay for television but menstrual blood is not. In this exchange, the women were talking all at once.

Joanne: You know something ... how many of you ... *I shouldn't be telling all this (whispering)* ... How long did it take you to ask your husband to go to the drugstore and buy *Tampax*? [ ]

Diane: Well it didn't matter about asking. It was... *(laughter)*

Joanne: Oh, you never asked?

Various: No ... no ... I never asked ...

Mary: Not that he wouldn't do it. I'm the one who's - [ ]

Joanne: ... I was walking down the hall and my husband said, xxxx. *get that nightdress off (whispering)*. *It's got blood on the back of it;* and I turned around and said, *it's blood xxx. Not shit! (laughter)* ... And my mother came down and my boys had a package of *Tampax* opened and they were using the tubes for [ ] and she was appalled that I would even have them anywhere in front of them and I said 'mother, I gave them the directions to read when they were old enough to read because I didn't want them to grow up thinking this was something secret, bad, dirty, abnormal'. [ ]

Various: ...use a blue strip... blue ink... *(in media ads)*

Diane: To go on diapers too...blue is a neutral color.

Joanne: What is it? When are they going to show real blood?

Diane: Never.

Joanne: Only when they shoot someone.

Diane: That's right [ ] not going to broadcast that all over the place...

Anne: Oh I see! They don't use the right color.

Mary: No... a little drop of water on the pad...

Lynn: A lot of men film these. [ ]

Joanne: I mean when we were girls - and I'm sure you'll remember this: pre-*Tampax*. [ ] They came into the house in a brown paper bag and you couldn't ... I mean, heaven help you if you left one around or if you had one with blood on it that was wrapped up, you always had it wrapped up, right (*agreement*); and if you left it on top of the toilet box while you were washing your hands... You couldn't put in the wastepaper basket. You couldn't flush them down the john. *You had to take it and burn it (laughter)* ... and my thing was, *why? Why* do we have to do that?

Anne: If you had blood on your panties, what would you do then? Throw them out?

Joanne: No, you washed them in cold water with Sunlight soap right away.

Anne: Could you hang them in the bathroom?

Joanne: No (*said very quietly*) [ ] We were lucky - we had a dryer ... *we never let it go in the laundry like that*. It would *never* go in the laundry like that. *No*. It would never go in the laundry bin. [ ] And that's something else men don't know how to deal with. I mean you take the pants and you stick them in the sink and soak them in cold water cause they've got blood on them and my husband comes in and looks in the sink and goes, 'oh my God?!' (*laughter*).

Various: I mean, what is it? ... isn't that funny! Isn't that true!

### Touching oneself is wrong

In this brief interchange, Joanne asked the other women if BSE was somehow related to touching oneself, with the implication that touching oneself was shameful. Dianne admitted that she did not know if her young adult daughter examined her breasts, because she had not asked her. Diane wondered aloud why she had never discussed this with her daughter, and felt this meeting might provide a good reason to bring the subject up.

Joanne: Like for our age group too, does it go back to touching yourself? [ ]

Diane: I don't think [ ] are younger girls going to have a different attitude toward their body? ... My daughter doesn't do it, I don't think ...

Anne: You don't think she examines her breasts?

Marion: Who's this?

Diane: *My daughter (softly)*.

Marion: Did you ever ask her?

Diane: No, I'm just thinking that.

Marion: What age group is she?

Diane: She'll be 23 tomorrow.

Marion: She's in the age group where she should be, you know.

Diane: Or maybe this group, actually - this focus group will give me a good ... yeah. Because she was asking me where I was going [ ]

BSE is a complex issue

Towards the end of the meeting, the group members reflected on all the issues previously discussed and how they were related to BSE. Recognizing that most women do not examine their breasts, they wondered if it was because women do not feel they are worth it, and if this feeling grows stronger with age. They agreed that BSE is a very complex issue that could not be easily explained or understood and that it was something very personal.

Older women are not worth it

Joanne remarked that she is doing BSE less now than when she was younger. She made an analogy to wearing nail polish and conjectured that women who do not wear nail polish do not take care of themselves. Diane reflected on this and remarked that young women take enormous amounts of time on their general appearance, while older women generally do not - perhaps because they do not feel worthwhile. Joanne agreed, stating that Diane's query was touching on an essential issue of how women relate to their sexualized public image and do not feel they are worthwhile if they do not measure up.

Anne: Believe it not or I think all of this has to do with breast self-examination.

Joanne: I do too.

Anne: Do you?

Joanne: Because it's all part of why we don't. Why don't we examine our breasts?

Jean: Yes ... a good question.

Joanne: I mean why ... gee, I should be doing this every month and I was really good when I was younger because I remember my doctor saying the obstetrician is going to do that, examine your breasts when you start your period or just after your period so you do it every month, just remember that and then you do it. And I did, for years [ ] let it go on for longer and longer [ ] and then you kind of get to the point where you think, gee... [ ]

Anne: You don't examine your breasts if you don't wear nail polish?

Joanne: Because the women who don't wear nail polish are the women who don't take care of themselves. [ ] We don't spend that time on ourselves. Do you know how long it takes to put on nail polish? [ ]

Diane: I was thinking about the same thing, Joanne, earlier when you were first talking about some of these things and I think a lot of it has to do with maybe we think we don't have the time or we're not worth it or this isn't important – we're not ... like focusing on ourselves is not important. *But I'm thinking as you're were talking about this* - as someone who taught a lot of young girls - who obviously *do* spend a lot of time on their hands and on their hair and their make-up - *flawless* and I'm thinking, well, does this mean they will spend more time and they seem to be much more comfortable with their bodies [ ]

Joanne: I think the most interesting comment was yours, Diane, do we think we're worth it. You know, are we ... I think that's a *very essential* question. Are we made to feel if you don't conform to that certain level image there, are we made to feel like we're therefore not female enough, not - [ ]

Diane: Which comes right back, Joanne, to your billboard. A woman with one breast off is not worth it.

Joanne: Exactly ... should not be seen

Something inner and unidentified

Finally, the group members discussed some of the common reasons women give for not doing BSE including fear, lack of time, denial, and seeking other forms of screening. While

Diane does not disagree with these reasons, she contends that BSE is more complex than this – that it is touching something “inner and unidentified” in women.

Mary: Do you think that most women because they are so well informed now about self breast examination, why is that I wonder that they don't? ...

Joanne: - *breast examination because it can't happen to them.*

Mary: Oh, I know that. That's the main reason why they don't do it regularly, all the time a routine and saying like ...

Joanne: Denial?

Mary: And the doctor does it and says everything is fine and you have the mammogram and everything is fine...

Anne: I still don't do it every month. I mean I have every reason in the world to do it. [ ]

Joanne: I know. I have a sister who has a breast off to cancer and I still don't...

Mary: But is it because we're afraid of what we *may* find [ ]

Joanne: Yes, I suppose ... but yet, no - I don't know...

Diane: It's not that simple because we would never get in our car and go driving. [ ] If you were worried about what *may* happen...

Anne: For me it's about making the time.

Diane: I feel it is more complex than that.

Joanne: It's very time consuming [ ]

Anne: For me, I guess... I examine women's breasts, I teach breast self examination. I am *adamant* about women doing BSE. I can do my own breasts - They're not large - in five minutes, tops, so for me there's no excuse whatsoever.

Various: No excuse for any of us... no...

Diane: It's much more complex than that. Somehow it's touching something inner and unidentified.

### Subject position of Group B

At the outset of the research process, the group members expressed frustration at the way women were portrayed and treated in society. In particular, they were concerned that: (a) Women are treated like children in society while simultaneously being valued primarily for their physical sexual characteristics, (b) women are put at risk by Medicine at the same time that their concerns are trivialized, (c) the standard for female beauty is an unattainable male-like body, and (d) the female body is considered shameful. At the same time, the women took the opportunity to reflect upon these issues and wondered by the end of the meeting if BSE was associated with profound feelings of self-worth.

### Summary

At the beginning of the research process, through examining their everyday experiences, both groups of women expressed feelings of powerlessness in relation to the issue of BSE, albeit in two different ways. For Group A, this was demonstrated by their statements of feeling vulnerable in relation to knowing how to protect themselves against the threat posed by breast cancer, a disease they know to be lethal. On the other hand, members of Group B expressed frustration related to the inferior status of women in society, in comparison to men. That both groups were discussing BSE is an indication of the myriad of issues associated with the act of examining one's breasts. While members of Group A focused mainly on personal issues related to BSE, the members of Group B were clearly examining broader social issues that impact upon that practice. As indicated in the study purpose and objectives, an exploration of personal and social factors related to BSE is important in order to more fully grasp its meaning to women. This will be explored in greater detail in the discussion.

Highlighting the subject positions of the two groups of women is important in order to understand how they felt about BSE at the outset of the study and how they may have changed over time as a result of participating in the group discussions. It also illuminates the diversity and complexity of issues related to BSE practice which will be described in greater detail in the next chapter.

## Chapter VII

### **Women's Views at the Middle of the Study- The Women Reflect on BSE**

#### Introduction

The purpose of this chapter is to present the results of the women's discussions and collective self-reflections in their second to fifth meetings. Over this four-month period, they had ample opportunity for both personal and group reflection, which enabled them to identify and more clearly understand personal and social factors influencing their practice of BSE. The result of this collective action was the development of temporal map components and their organization into a concept map that can increase understanding of the meaning of BSE for these women.

#### The process

As discussed in Chapter 5, temporal mapping can assist groups to formulate descriptive accounts of their situation by describing the issue of concern and its context. Thematic analysis of the first four transcripts (the first two meetings with each group) by the external researcher identified 13 components in the temporal map. In order to increase the validity of the components for these women, the wording used for each component was consistent with the words and expressions used by them in their discussions.

During the third meeting with each group, the 13 components of the proposed temporal map were presented to the women for their validation. This was achieved by writing each component on a separate index card and distributing them among the women. Each of the women took turns reading out their index cards. One component at a time, they discussed its relevancy, often citing related experiences they had had. Each woman was given a copy of the

temporal map components on index cards so they could take them home to reflect on them in private and at their leisure. During this meeting and for subsequent meetings, they were encouraged to reflect on and redefine this conceptualization of the phenomenon through their journaling and group discussions.

Only one theme was questioned: 'Mistrust in the medical / health care system'. During their third meeting, some members of Group B indicated they were uncomfortable with the wording used in this component, even though they agreed with its general meaning. They elected not to reword it at that time. Upon further reflection during their fifth meeting, the women agreed the wording was appropriate and it remained unchanged. It is significant to note that none of the components of the temporal map were added to or changed in any way through the remaining group discussions, indicating their reasonable representation of the context of BSE for these women.

The temporal map components are presented in this chapter in their original wording and punctuation, even though the external researcher, on further reflection and analysis over a period of years, would have liked to modify the wording and composition of some components. This is to maintain the integrity of the analytic process carried out collaboratively with the women as co-researchers.

This chapter will provide excerpts from the women's discussions to add depth and clarity to the meaning of the temporal map components for these women. For most components, at least two excerpts from the transcripts are provided for illustration (generally one from each group of women). There are more lengthy excerpts provided for two components ('Responsibility: BSE for finding it / diagnosed to fight the battle' and 'Female Beauty = Beautiful. slim, 2-breasted, youthful') because the women in Groups A and B respectively identified these as being the

overriding or general context of their concept map. The concept map for each group will be presented at the end of this chapter.

In order to provide some clarity to the temporal map, it is presented within an organizing framework. The 13 components were deemed to be related to three major issues: cancer, being a woman, and the health care system. The rest of this chapter will follow this organizing framework. See Table 14 for a listing and brief description of each component of the temporal map.

**Table 14: A temporal map of key issues related to the meaning of BSE**

<b>Cancer</b>	
No control / no guarantees	Cancer diagnosis and survival is unfair and outside of individual control.
It's everywhere – fate; lotto / roulette; karma; environment	Cancer diagnoses are prevalent and without any discernible pattern leading one to believe multiple factors, including individual fate or karma, plays a role.
Once diagnosed – never free; lurking; invader in the body	Cancer is never truly cured; once diagnosed, it is an unpredictable silent threat dwelling within the body.
Cancer = death, pain, loss	Cancer is associated with physical pain, loss of time, personal attachments and goals, and death.
Conflicting information	It is difficult to know how to prevent or reduce the risk of breast cancer due to the presence of so much conflicting information.
Responsibility (BSE – for finding it; diagnosed – for fighting ‘the battle’)	The responsibility women feel to find breast cancer early (if doing BSE) and to survive breast cancer well (if diagnosed).
<b>Woman</b>	
Sexism – our doctors; the hardware store	Attitudes and practices prevalent in many social spheres that influence women's identity and behaviour.
Menstruation is dirty / bad / secret	Social messages portray menstruation as shameful, repulsive and something to be kept hidden.
We don't value ourselves	Women find time to care and nurture

	others but not themselves.
Human condition: We make bad choices	The tendency of individuals to make lifestyle and disease-related decisions inconsistent with dominant health advice.
Female beauty = beautiful; slim; two-breasted; youthful	A prevailing and widely promoted ideal of woman that is defined narrowly as very slender, young, and sexual.
<b>Health Care System</b>	
Denial of death – scientific breakthroughs; increasing technology	Increased scientific information and technology is changing the way health, illness and death is viewed.
Mistrust in health / medical care system	Uncertainty related to medical policy and recommendations for breast screening, and dissatisfaction with experiences of patriarchal medical care.

The temporal map

Cancer

No control / no guarantees

The women talked about the uncontrollable and unfair nature of cancer, and breast cancer in particular, in terms of who develops it, and who survives it. They discussed factors outside of individual control that may affect cancer risk, such as those within the human body and in the environment.

During the second meeting with Group A, the women talked about ‘undeserving’ individuals they knew who did “everything right” in terms of lifestyle choices to prevent cancer, or treatment choices to survive it, but still found themselves diagnosed or dying. They spoke of feeling anxious knowing there is only so much individual control one has over cancer, and the difficulty of predicting or understanding who will get the disease, and who will survive.

Madonna summed it up by saying that anyone, even themselves, could get cancer.

Rose: I think what disturbs me most [ ] it's always the friend or the mother of a friend who did everything right and still ... like maybe even three or four months after it was detected and everything was done, the person is pretty dead (*agreement*). You know, like it's still upsetting. You still are never sure of that thing. You try and do everything that's right but there's always somebody you know who just didn't make it even though they did all the right things. That disturbs me more than anything. And I know there's nothing we can do about it. A lot of it is, as you said, the type of cancer and how people react to the different types of treatment and things like that. That's the part I don't even want to think about sometimes.

Susan: All my experiences with cancer have been in people where they shouldn't have gotten it. You know, they led healthy lives and almost, I guess, what you were saying, Rose - they did everything right and the family history really wasn't there and they got it and they weren't survivors.

Adele: I guess we just have this mentally [sic] of you get what you deserve. You know someone who smoked all their life and yet they're very healthy and they live very, very long. Somebody who never smoked and they get lung cancer or ... you know, that's not right. That's just not fair ... It's your genes. There's a part, I guess, that you can't control. I think we talked about that last time. You want to do everything right and be healthy and yet you feel that there are some factors that you cannot control and I guess you feel a bit powerless facing that. [ ]

Madonna: What it comes to is the fact that you see so many people with cancer you see so many people ... and you say, 'oh God, they' ... you know. 'Why did? ... I could end up with cancer or I could end up with anything' ...

During the second meeting with Group B, the women talked about a variety of environmental factors that may increase their cancer risk including genetically engineered and otherwise chemically treated foods, pesticides, growth hormones in the food chain, cleaning fluids, and synthetic fibres. This discussion brought up similar concerns to those raised by the women in Group A during their first meeting.

Mary: - we eat is so chemically treated ... Now they're genetically engineering the food, which is [ ]

Lynn: ...And they're making them not just pretty broccoli flower, which seems to be a perfectly logic ... they're making them ...

Various: Disease resistant ... that's what it is ... it's something else ...

Lynn: Disease resistant and long lasting and so they're changing the actual nature of the plant - [ ] as opposed to pollination.

Marion: That's why I say, what we eat causes a lot of it.

Anne: We are what we eat.

Marion: I agree with you. [ ]

Joanne: But I mean I'm more concerned with all the chemicals in our lives ...

Mary: All chemicals that they use to spray all the food that we're eating - the pesticides ...

Anne: The growth hormones to cows.

Various: Yes, and all that stuff.

Mary: It's not put on ... you know, not just picking up things that are coated with chemicals but the chemicals that go into the growing. It's almost like genetically engineering, isn't it? It's the same thing. They're putting all these pesticides onto ... grow better plant food that will be resistant to disease.

Joanne: It's all the cleaning stuff that we use, the synthetic fibres that we have that we breathe in from the carpet that we're walking on ...

It's everywhere = fate / lotto / roulette / karma / environment

Both groups of women talked about the high number of women they knew diagnosed with breast cancer. There were at least 27 documented cases cited by the women during the course of the group discussions. Joanne listed so many people she knew in the second meeting that she said, in reference to cancer, "it's everywhere". This component of the temporal map is similar to 'no control / no guarantees' in that one cannot predict with any certainty who will be diagnosed with cancer. However, it is different in that it stresses the high prevalence of the disease among their family and friends, and conjectures about the role of fate or karma in its diagnosis. The women in Group B even conjectured that one might unwittingly increase their risk of cancer by thinking about it too much or participating in screening activities.

In the following excerpt from the second meeting with Group B, Joanne described how afraid she felt when she was in the waiting room prior to a recent mammogram. She felt like she was participating in a lottery or game of roulette and that she might have increased her chances of being diagnosed just by being there. Her use of the term “sitting duck” emphasized her feelings of helplessness to control her risk for breast cancer. In the fourth meeting, Joanne again referred to potentially increasing her risk for breast cancer by talking and thinking about it too much. She worried she might be more likely to be diagnosed because she was participating in these discussions. She compared a breast cancer diagnosis to a lethal attack when she used the term “line of fire” to describe her perceived increased vulnerability. Also in the fourth meeting, the women discussed the tension they felt when doing BSE; fear that one might find a breast cancer because they were “looking for something”. Diane referred to this dilemma of wanting to do BSE, but being afraid of increasing their risk, as “approach avoidance”.

Joanne: Well, I started writing the day I had my mammogram.

Diane: It was the turning point.

Joanne: I just wrote it down because I thought, now I must write this down, because I was really ... I got there - all of a sudden I was really afraid.

Mary: Was that your first one?

Joanne: No. And I said ‘this is ridiculous’. I mean ‘why am I feeling this knot in my stomach, feeling really nervous about this?’, sitting with all these other women and it’s almost like you’re waiting for ... it’s like a lotto. Is your name going to be the one to be drawn type of thing.

Mary: Roulette wheel, right - spinning.

Joanne: Yeah. [ ] I wrote down then about all these women - *(gives a list of six names)* - all having breast cancer and just a comment that it’s fearful ... *(reading)*: ‘It makes you feel like you’re a sitting duck, waiting - waiting for your number to be called’.

During the fourth meeting, Joanne reiterated her fear of increasing her risk of breast cancer by talking and thinking too much about it.

Joanne: I'm starting to become paranoid about it now. It's like we're talking about it too much. I'm thinking about it too much, being involved in it too much and is that now going to put us right in the line of fire? *(laughs)*

Also in this meeting, the women talked about increasing their chances of being diagnosed with breast cancer by doing BSE.

Joanne: I'm nervous about it, I have to say. It's still a little frisson, you know. that fear that you just might come up against something. There is definitely ... you know, you're looking for something. [ ] That you don't want to find. [ ] You know; and I can't get beyond that.

Lynn: It's not hidden treasure.

Diane: No. It's approach avoidance, isn't it?

Joanne: It is.

Once diagnosed - never free, lurking, invader in the body

The group members discussed how cancer is never perceived as being fully cured; once diagnosed, women live with the risk of recurrence every day for the rest of their lives. They described cancer as being an "it", an unpredictable silent threat dwelling within the body that could strike out anywhere, at any time, regardless of the treatment received.

During their second meeting, the women in Group A discussed how cancer, unlike most other illnesses, could stay hidden within the body for years. Brenda talked about losing trust in your body once diagnosed with cancer. Although she acknowledged that the body is not a separate entity from one's consciousness, she described it as becoming vulnerable and fallible and letting 'you' down.

Brenda: And the other thing is too [ ] the other thing I think that we also touched on last time is my view of it is that there's no guarantee that it's not already somewhere else so,

you know. I find a lump and they take off the whole breast and it turns out it's in my liver or whatever already so ... you know ... [ ]

Rose: Oh! I'd want it gone! There's the sense of it lurking. My mother spent 10 years after she had breast cancer - even though she was very strong all the way through it - she would always say 'that's the cancer back'. When something would go wrong, 'that's the cancer. It's back' ... [ ]

Diane: That's the thing - you're living with it after - even if you're healthy, it's always on your mind [ ] you know, you had cancer. It was in your body. You know, it's like an invader. It's in there somewhere. Maybe there's a little trace left. You must think about it every day, you know. How do you go on and say, nothing is wrong with my life and not think about that?

Mary: No one can give you a guarantee that cancer is gone. No matter how they treat you, they can say 'okay, we have you in remission' but they cannot say to you 'it is gone; you will never have it again'. You might never! [ ]

Brenda: - but I think when your body - I guess the way I think of it is - when your body lets you down, I think somehow that ... you never get that trust back [ ] Yeah, and maybe that's sort of talking about your body like it's an alien but I think that your sense of being vulnerable and fallible, that is hard to overcome.

During their second meeting, the women in Group B also talked about the ability of cancer to function in a subtle or sinister way, both at first diagnosis and for many years later. For example, they talked about the ability of cancer to travel in the body through the lymphatic system to affect distal sites. Mary talked about a woman who had a bilateral mastectomy and a bilateral oophorectomy and still had a recurrence of the same cancer 25 years later. Note that in part of this discussion, the women talk all at once and finish each other's thoughts.

Joanne: And the other thing about cancer is that nobody seems to know they have it until you've got it - it's too late or so far advanced you've got a 40% chance of survival or you got ... it seems to be such an insidious ... [ ] Is it true that once you've had cancer, your chances of getting it again are increased considerably? [ ]

Diane: Because you often hear of someone who has one kind and ...

Marion: Yes, and they develop another -

Diane: Five years later it just -

Marion: It resurfaces -

Diane: It's seemingly unrelated but -

Mary: Another part of the body entirely. [ ] You always live in dread that it'll return or you'll find another lump. [ ] But I know a person who had breast cancer [ ] this was probably 28 years ago [ ] and had ovaries removed and, you know, all this ... and had her breast removed - both of them - and everything. And she did really, really well; but 25 years later, she developed a lump under her arm, you know, and then died from it. [ ] It's interesting, isn't it? But they said it was exactly the same type of cancer that she had originally. [ ] And so many times it travels through the lymph nodes and appears somewhere else.

Cancer = death / pain / loss

The women talked about the way they associated breast cancer (and cancer in general) with physical pain, loss of time, personal attachments and goals, and death. Both groups of women talked about individuals they knew who refused to seek medical care for an obvious breast cancer, or waited until it was extremely advanced. The women wondered if fear and denial of death were associated with this behaviour. They also talked about the influence of the media in supporting this association as news reports often stress the number of individuals who die of cancer, as opposed to the majority (in most cases) who survive.

During the second meeting with Group A, the women talked about the losses associated with cancer such as time with children and grandchildren, and time to achieve goals and bring future plans to fruition. After they had discussed this at length, Brenda remarked that it was telling they were meeting to discuss BSE and breast cancer, but had spent substantial time on death.

Rose: I think what bothers me more about dying than the actual thing is I'm not going to be here. I'm going to miss my children. I'd like to be around a little longer. I'd like to see grandchildren if they're coming. That would bother me [ ] what I think I'm going to lose. [ ] It's just the sense of loss that you feel like you'd like to be here to see life go on in its next generations and that sort of thing. I thought of that and I think the loss I would feel

would be time, I suppose - time to do the things you want to do - things you want to see accomplished.

Brenda: But I think it's interesting just from a process perspective that this ... the focus of this is about breast self exam and about breast cancer and we're talking about death. I think that they really are interconnected in our minds (*very softly*). That's kind of telling about we feel about that whole issue.

During the third meeting with Group B, Joanne talked about a woman who had a lump in her breast for four years but refused medical care. She had two close family members who died of breast cancer despite receiving medical treatment, and felt that treatment for her would not make any difference. The women discussed how often cancer is still thought of as a death sentence, and that those who have it will die.

Joanne: Well, I'll tell you another instance of that. She's dying now and she knows she's dying but she has had a lump in her breast for four years that she knows about [ ] but her mother and her aunt - they both died of breast cancer. They had had surgery done; and once they had the surgery done - you know, the doctors thought they had gotten it all - and they died quite quickly after it. So she felt - when she found the lump - well, that's it. I've got breast cancer and my mother died and my aunt died. They went and had the surgery done. They died within months of the surgery. 'I'm not going to do anything. I'm going to die anyway. I'm just going to live my life out'. And that's exactly what she has done. [ ]

Anne: Who has the card: Cancer equals death? [ ]

Marion: It's true.

Joanne: Not always. It certainly equals pain and it can mean loss of parts of you. It doesn't necessarily mean death but it often does.

Mary: But I think anybody who hears the word that they have it, right away, automatically, thinks they are going to die from it

Joanne: It's a death sentence

Mary: Yeah, it is. It's a death sentence. There's no doubt about it because you can't see past it. [ ]

### Conflicting information

The women discussed not knowing how to prevent or reduce the risk associated with breast cancer because of the presence of so much conflicting information. This phenomenon was discussed earlier in Group A under the theme 'lack of knowledge despite much information'. The following excerpts provide two brief additional examples of conflicting information causing confusion and anxiety in women.

In the fourth meeting with Group A, the women discussed how difficult it is to know if there are abnormal changes in their breasts because of the lumpy nature of breast tissue itself. Madonna spoke about feeling lumps in her breast and her physician telling her there were no lumps present and that she did not, in fact, have lumpy breasts. Madonna is confused about the discrepancy between what she knows to be true, and what her physician is telling her. She is not certain how to interpret her BSE in light of this conflicting information, so she does not feel BSE is of benefit to her.

Madonna: But it's still always that thing of when you do it, you say, 'okay, it all feels lumpy to me'. I don't know [ ] every time that I do remember to do it, I always ... after I say, 'well, that didn't tell me anything' [ ] I thought I felt about ten different lumps but I mean it was everywhere. Everything felt lumpy. [ ] You know, my doctor - my family doctor - tells me that - she says my breasts are not lumpy - you know, that it's not - they feel lumpy to me! I mean. I don't know, that feels like lumps to me! (*agreement*) [ ] this doesn't feel lumpy? My legs don't feel lumpy. My breasts feel lumpy. [ ] - it's not like an arm or a leg. If there was a lump on my arm, I would know it right away but I wouldn't ... it's different; and I don't feel it's doing *it* - not doing me any great deal of good because I'm ... you know.

The women in Group B discussed the changing nature of information related to breast cancer prevention and treatment. Although not included here, the women spoke about the internet-generated warning related to the increased risk of breast cancer with anti-perspirant use, calling it an urban myth. As well, they discussed recent recommendations to eat soy protein to

reduce menopausal symptoms and breast cancer risk. As Joanne stated in the second meeting 'every week it's something different'.

In this excerpt taken from the fourth meeting, Joanne is talking about her sister who is living with breast cancer. At the time of her treatment, adjuvant chemotherapy was not recommended for her based on her cancer staging; however, she acknowledged that now it would be recommended. The women stated that it is difficult to make treatment decisions because of the variable nature of medical evidence over time.

Joanne: But see, she had the breast off at a time when, I guess, if it hadn't gone to the lymph nodes, which it hadn't; and when they sliced it, it was contained far enough away [ ] they felt that she would be fine if they just took the breast off. Now they're - and fairly recently I think - the new thinking is that you do the chemotherapy anyway. So ...

Diane: You know, my God, it's ...

Mary: You don't know what to do.

#### Responsibility: BSE for finding it / diagnosed to fight the battle

The women talked about the responsibilities associated with breast cancer: These included doing BSE "right" in order to find the cancer as early as possible; and for not only surviving breast cancer and its treatment, no matter how difficult, but doing so with a positive attitude. The following section includes two excerpts for each dimension of responsibility; although lengthy, it provides meaningful insight into the meaning of BSE for these women.

#### For finding it

During the fourth meeting of Group A, Madonna talked about a negative experience she had the only time she consulted with a physician about a change in her breast found during BSE. Even though this was 14 years ago, she stressed how embarrassed she was to hear from the physician that she was doing BSE 'wrong'. She has never since sought a medical opinion for a

suspected abnormality and doubted that she would in the future. Previous to this encounter, she had successfully been able to differentiate normal from abnormal breast tissue, but described her reaction on this occasion as ‘panic’.

Madonna: And I guess first when I sort of took it on that I was going to do the examination and that kind of thing - it was way back, it was before I got married - and I thought I had found this lump. Of course, I panicked and I went right off to the doctor [ ] and I was so embarrassed because she just said, ‘oh, how are you doing the exam?’ and then ... you know, I explained. ‘Oh’, she said, ‘you were doing it wrong’ and, ‘oh, there’s nothing there’ and it was ... I was right embarrassed by the whole thing. I said I think if I found something, I don’t know if I’d go back. [ ] And that was the only time and, like I said [ ] I didn’t find her very comforting [ ] lots of time I think I feel something but I keep saying ‘oh, it’s just lumpy. It’s just lumpy’ - and that’s it. Just pass it off. [ ] It was like, ‘oh, you’re just doing it the wrong way. This is the way you should be doing it’ and ‘that’s nothing, don’t worry about it’. And that was the end of it. It was like, ‘okay’ (*sounding acquiescent*) - and I left.

Anne: What a message, you know – ‘you’re doing it the wrong way’.

Madonna: Yeah. That was her exact words, I think and that was like 14 years ago or something.

During the second meeting with Group B, the women discussed the responsibility they felt for finding breast cancer as early as possible when doing BSE. They recalled conversations with family and friends in which they stated they had no problem seeking health care, including having a CBE or mammography, but they did not want to do BSE; they did not want to ‘deal with it’ or ‘take the chance’ by doing it. This was related to not wanting to feel responsible if their breast cancer was not found early, and not wanting to face the questions they would ask themselves, such as if they had done something wrong.

Joanne: And they also agreed that they don’t mind if their doctor examines them or if they’re examined by somebody else because *they* find it. They’re not responsible for finding it themselves.

Anne: Really? Well, that’s interesting.

Joanne: Isn’t that interesting. [ ]

? I feel the same

Joanne: Yes! ... But the younger girls were saying [ ] ‘well, you know, it would be great if there was somewhere where you could go on a regular basis and have somebody else examine your breasts for you, you know’ [ ]

Anne: But I’ve never read that before that women don’t want to find it themselves because then they’re responsible for it.

Lynn: But I had a friend say the same thing and she - last spring - went through finding a lump and having a biopsy and the whole bit [ ] and she said ‘I haven’t done it since because I don’t want to find anything now’. She said ‘I did it once. I found it once. Thank you. That’s it’. [ ] It wasn’t cancer. [ ]

Joanne: So I found that quite interesting [ ] that this group of young ... and there were what - six, seven, eight young women who all said, ‘yes! Wouldn’t that be great if there was someplace we could go and [ ] have your breasts examined and somebody else would find it and you wouldn’t have to do it’. And it is! - it’s that thing about having to take responsibility for finding your own ... [ ]

Lynn: I don’t know why she decided that. She said she just simply doesn’t want to find anything. She doesn’t want to take the chance. [ ] I would imagine she’ll go back for her mammogram but she will probably not do a breast self-examination for a while. She sees her doctor regularly but she’s certainly not going to - [ ]

Diane: But that’s what we’re hearing with some of these women - comments of some of these women. [ ] Then I’ll be responsible if I find it. [ ]

Mary: Why didn’t I find it sooner? or ...

Joanne: Why didn’t I find it sooner? ... what was I looking for? ... what did I do wrong? You know, it’s like the mother of the child who has the cancer and they think, why didn’t I feed him differently? What did I do? What could I have done?

### For fighting it

The women also discussed the tremendous responsibility associated with surviving cancer (and its treatments), no matter how difficult it might be. In this excerpt taken from the second meeting with Group A, Rose talked about helping a family member through her cancer treatment and how important “fighting” the cancer was. She wondered if she would have the

same attitude and personal will to “fight” if she found herself diagnosed with cancer: if she would be able to endure the required treatment.

Rose: - so I went on and spent three or four days with her in hospital right from recovery room right through and I thought ‘boy, you know, if there’s any way we’re going to get her through this, it’s certainly going to be getting her to fight this all the way’. [ ] But I also thought ‘I don’t know if I’d have the energy to fight like that if it was me’. and that’s crossed my mind so much. [ ] ‘God, is it worth this?’ - because I saw what she went through and in those days - this was almost 30 years ago - and the radiation that she had ... that was pretty rugged stuff in those days. And chemo – (*agreement*) it was really rugged stuff - and it just wasted her away.

In addition to feeling the responsibility to overcome breast cancer successfully, the women also discussed how admirable it is to see individuals maintain their positive attitude or zest for life in spite of life’s travails. In this conversation taken from the fifth meeting of Group B, Diane and Joanne discuss two different women who are friends of theirs who had breast cancer. Although their full discussion is not included here, they talked at length about the admiration they felt for the way their friends had overcome their cancer and other life challenges, as if they were talking about the same person. They often finished each other’s sentences. They described the characteristics of a role model for breast cancer including a woman who survived – without dwelling on it, without being morbid, by doing her best, and by being fun and positive through it all.

Diane: Well, she doesn’t deny it. I mean if it comes up, she’ll talk about it. She’ll talk about other women that were on the floor with her who had it worse, had it better, didn’t survive - whatever; but it just ... she also lost a son. At 30, her son died of an aneurysm and it’s just ... she just doesn’t dwell on it. You get on with your life.

Joanne: Exactly.

Diane: You do the best you can. You live for today because you never know what’s going to happen to you, but you’re not morbid about it; and she is the most bubbly, fun, gregarious, socially outgoing, poised, groomed person that you could meet. She’s had grief in her life but she sort of ... deal with it and go on. [ ]

Joanne: And I have ... my friend is exactly the same, but she has had a child die with spina bifida. She's had so many miscarriages in her life. She's had a sister die from cancer. She's had her husband die from cancer. [ ] She's had her breast off herself. She's had to have a knee replacement. [ ] and I love her - I have to say - because she's always up and positive. She's positive about what *you* do. She's hard on herself but she's the most ... and she's ... like she's just great! I just find her to be ...

Diane: I mean there really are role models ... she volunteers [ ].

Joanne: Yes! I was just going to say... [ ] But they really are exemplary people.

Marion: Yes. So she has the right attitude.

Diane: She has the right attitude [ ]

Joanne: Oh absolutely! [ ] And she's always got this laugh and ...

Diane: It's not a 'woe is me'.

Woman

### Sexism – Our doctors / the hardware store

There were many instances where the women discussed how the perception of woman in society influenced their actions and how they felt about themselves. The women explored their personal experiences where they felt their place in the world as women was established, reinforced or questioned, and how they negotiated a place for themselves within this social structure.

In the first excerpt taken from their third meeting, the women in Group A described occurrences in the business world, in their professional life, and within the school system when they had experienced discrimination based on their gender. Madonna talked about an experience she had in a wholesale plumbing business where she was waiting in line for service but was not certain she would be treated fairly by the customer service representative. She recalled coaching herself to be assertive in the presence of so many men even though she felt intimidated. Both

Susan and Madonna had experienced sexism in the school system where their ability to perform their teaching duties were questioned because they were women. They described their feelings of frustration, anger, and ultimately resignation at having their professional role repeatedly questioned.

Madonna: That's funny because I was in a plumbing, wholesaler place [ ] with these big contractors, these big, you know, guys - I'm in there and I looked around and I said 'now, am I going to stand and just wait and wait and wait because all these guys just come barreling in the door?' [ ] I thought I'm going to be here forever if I just don't go and right down here and sort of catch this guy's eye so that's what I did and I got served next, the other guys were just standing around. But it was just that I sort of ... 'ooh, am I going to be intimidated by this or am I just going to get in here and ask for what I wanted?' and I did that. Which I was pleased [ ] It was a bit intimidating, I must say.

Susan: I did my graduate work in administration. I'm a teacher. [ ] one of my courses I had to do - the whole notion of discipline came up and I was one of two women in the class and then there was eight men, so there was ten of us; and one of the men actually just point blank looked at me and said, 'as a woman, do you think you're going to be able to like say handle a junior high for discipline?' [ ]

Madonna: I was asked that in an interview for a high school position.

Rose: Is that right?!

Madonna: 'You're female and you're not very big; how would you handle a situation where you've got two 16-year-olds that are, you know, 6 foot?' [ ]

Anne: How did that make you feel? What was your initial reaction to that?

Susan: That sort of came when I was half way through my program so my initial reaction to that was sort of 'oh, here we go, someone is making a comment again'. But I remember when I was starting out in the program, I used to get really frustrated - you know, that people - because you're a woman - assume that you couldn't handle stuff like that. [ ]

Madonna: It angered me.

Susan: Yes, yeah. [ ]

The following interchange is taken from the third meeting with Group B. Lynn recounted an experience her friend had in which she was encouraged by her physician to have

her second breast removed for a potential cancer as “she did not need it”. Lynn asserted that this comment was related to the recent death of her friend’s husband and her age of 65 years. The women indicated she would have been particularly vulnerable to this message because it was from her physician. After the breast was removed Lynn’s friend felt very upset over the loss of her second breast and the impact of that on her perception of herself as a woman. It also later became known that the cells were only pre-cancerous. At the end of the meeting, the women acknowledged that it is not only in the medical system that women are treated differentially to men, but also in business, politics, and the legal and religious systems. Marion indicated at the end how the discussion helped her to make the association between sexism in Medicine (of which she was aware) and the way women are treated in other social spheres.

Lynn: Since we started these meetings, I had a friend that has had her second breast removed and two things occurred with that: One was, less than a year ago she lost her husband and a number of years ago, she lost the first breast; and when she went in to see the doctor, his comment was, well ... it was a mass - they weren’t sure if it was malignant - and he said, ‘well, we might just as well - with your history we might just as well take it; you don’t need it anyway’. And she bought that, because she called me soon after and told me. She said, ‘well, I guess I really don’t need it’. However, just before our last meeting, she called me because she was very, very upset and her current perception is that she is no longer female. She decided she did need it. [ ] She’s 65, lost her husband; of course, she doesn’t need the other breast. What the heck! I found that ...

Joanne: Just insinuating that is enough to make you think that you’re useless, doesn’t it? .

Lynn: I found that appalling. [ ]

Joanne: That’s too bad ... If she had said that herself, that would be different.

Lynn: That’s correct.

Joanne: But for somebody else to say it to her ...

Jean: And especially, a doctor, I suppose.

Lynn: Especially the doctor - and then when she did talk to me on the phone, she said, ‘well I guess I don’t need it, you know, because after all ...’

Mary: I've been told.

Lynn: Yeah. I've been told and ... [ ]

Joanne: But, I mean, you have to look at society per se. How have women been treated, period.

Anne: Oh yeah, the medical is not special.

Joanne: It's not just the medical system.

Lynn: No.

Joanne: It's everything. It's the business world.

Anne: It's the legal system.

Joanne: It's everything.

Anne: The religious structures.

Diane: Don't get us started on that (*laughter*).

Joanne: Don't go there.

Marion: ... politics. [ ] It was interesting because while Lynn was talking first, I was looking at my card and I said, yup - sexism by doctors. What this one has to do with it, I don't know - a hardware store. Think about it.

Menstruation is dirty, bad, secret

As previously described in the first meeting with Group B, the women discussed how social messages portrayed menstruation as shameful, repulsive and something to be kept hidden.

Group A also discussed the negative connotations associated with menstruation. In the following excerpt from their third meeting, Adele talked about how the young girls she has taught would never speak to her about their periods, even if they were feeling ill at school; menstruation was always kept secret. This reminded Brenda of the TV commercial that advises women not to take their purse to the bathroom because "people would know" they were

menstruating. Similar to Group B, the women also brought up the blue color used in ads for feminine products. The women remarked that red would never be used as it is considered 'dirty' and 'gross'.

Adele: Like I know some of the girls in my class - they must have their periods, right. [ ] They would never come and tell me, you know, 'I'm not feeling very good; I have my period'. They would never say anything like that to me.

Brenda: But have you seen that ad on TV now that says -

Madonna: Oh yes, about going - yeah, don't take your handbag.

Brenda: Don't take your purse -

? Oh that's horrible isn't it!

Brenda: But, you know, just that whole thing of advertising - I mean, it just blows me away. They get up there on television and they take this tampon or this pad or whatever and they're like pouring blue water onto it.

Various: What's with that???? [ ]

Brenda: When you think about it ... it's so sad.

Adele: It's the same blue liquid they use with diapers.

Madonna: But it's always blue (*agreement from women*).

Beth: It can't be red or pink - forget it!

Anne: I can't believe this (*jumble of voices*). This blue liquid came up in that discussion *with the other group* - that they can't show blood.

Various: It's dirty ... or anything that looks like blood ... it's gross ...

### We don't value ourselves

The group members discussed the tendency of women to be nurturing and caring of others, while not necessarily caring for themselves. They talked about how busy women are

trying to meet multiple demands, often not taking time to do the things they need to do for themselves.

During the fourth meeting with Group A, magazine articles and television ads were explored to examine how women were represented in the media. I read a description of the changing roles of men and women as they age, which was printed in a popular magazine. It is apparent from this description that women were expected to be, first and foremost, the primary caregiver to family (both children and parents), while men were expected to achieve business and social success, while secondarily having the responsibility of a family. Women were repeatedly cautioned to take care of their health in order to be able to meet all their demands. Men were described as being more settled and successful with age. The women agreed with my interpretation of the article and related it to their own lives. Janet stated that men were generally more self-centered while women were socialized to put everyone else's needs before their own.

Anne: I read this a while ago now but I just saw some interesting parallels, if you will. This is called 'The Stages and Ages of Health'. Okay, 'women aged 25 - lucky you. You're probably pretty healthy without trying too hard but don't take your good health for granted'. [ ] 'Men aged 25, you're in your prime - young, strong, healthy and at your peak physically and sexually'. I think that's ... you know, to me it was a bit contradictory. 'Women aged 35 - you're busy juggling the demands of career, marriage, children. Too often there's no time for you, but take care of yourself'. But 'taking care of yourself will make you feel better and give you more energy to meet those challenges. Men aged 35 - you're quickly acquiring new roles and responsibilities at work, with your family and in your community. If you keep taking care of your health, you'll be much better able to handle additional demands on your time. Women aged 45 - you're the sandwich generation, bombarded with demands from your children, teenagers' - it's always centered on the family - 'and the needs of your own aging parents'. [ ] 'Men aged 45 - you're consolidating your career, family and social activities. You may feel less driven to achieve and more settled with your accomplishments. Women aged 55 - you're free of many of the worries of your younger years - child-rearing, fertility, climbing the corporate ladder. Keep taking care of yourself so you can enjoy more years ahead. Men aged 55 - you've reached the physical and emotional maturity that should bring you increasing levels of satisfaction'. [ ]. To me it just seems like he was going to be accomplished and have the corporate and she was going to have the family and *then* the work.

Adele: She's going to have a lot more on her plate too than the man did, didn't they? - like the women had the children and the men was like maybe a little bit of family and ...

Rose: Mostly you're progressing through your career, eh?

Adele: Yeah. He seems to have an easier time.

Janet: I think men were more self-centered, you know what I mean - did more for themselves as opposed to us women. Like we put everybody else first instead of nurturing ourselves.

Adele: I guess we're raised as being the caring ones (*agreement from women*). But then again, there's differences, right, with that, but I guess in general.

Janet: Yeah, in general.

During the third meeting with Group B, Joanne described a conversation with her physician in which he asked her what would make women take care of themselves. Her recounting of their conversation included a reference to the tendency of women to "get after" or tend to the needs of their family members, but to put off meeting their own needs. Lynn pointed out the card Joanne was holding: 'We don't value ourselves' as a possible explanation, which prompted Joanne to wonder if the popular refrain of having no time was an excuse for her to not take care of herself.

Joanne: You know, one of the things my doctor did say to me [ ] 'What is it?' He said 'what do we have to do to get women to take care of themselves?' I said 'you're talking about me now, aren't you?' 'Well we know you only come for the immediate cure - an instant cure' - but ...

Marion: I think we're all like that.

Joanne: 'What is it?' he said [ ] 'you can get after ... say to a woman now - you haven't had a pap smear done in a year. It's time for you to get your pap smear done. Oh, I can't have that done today. I'll come back for that. Next time they come back - look, you haven't had your pap smear done. Oh my God, they say, I forgot about that; and then finally, they'll come in and they say, well, I'm here. Let's get it over with. You know, it's like it's a big deal. Like, what is it?' It's true, isn't it? [ ]

Lynn: Isn't that on your next card?

Joanne: On my card? We don't value ourselves ... Do you think that's the answer?

Lynn: I don't know.

Joanne: But what is it about that? And the same way with the ... you know, like this mammogram - I mean I haven't had a mammogram done in four years; and even though when I had the last one done, it showed a calcification and I had it removed surgically, it still took me four years to get around to getting another one. Why? I've been asking myself this question. I've been told to examine my breasts and I haven't done it. [ ] When I put my feet on the floor, I'm going for it. I'm flat out going! It's crazy! And I use that ... do I say to myself? - Do I use that as an excuse to? ... you know, can I not find the time? I find the time to - .

Mary: You're always told that you make time. [ ] For the things that you want to do, you make time.

Human condition: We make bad choices

Both groups of women talked about the tendency of individuals to make lifestyle or health-related decisions that are inconsistent with dominant health advice. These decisions are made in relation to both the prevention of, and care for, disease states. The members of Group B referred to this phenomenon as "the human condition". While it is applicable to both men and women, in the case of BSE, it is applied solely to women.

The women in Group A discussed how individuals negotiate with their bodies to keep working in the present with the promise they will take better care of themselves in the future. Adele referred to the questionnaire they had filled out in the first meeting, in which the majority of respondents stated their health was 'good' but not 'very good' or 'excellent'. She surmised that most people responded this way because they knew they were not taking the best care of themselves to protect their health. Brenda felt it would take substantial time and energy to significantly change one's lifestyle. Rose agreed, but then questioned why she felt that way and rhetorically asked "why can't we make time for ourselves?"

Anne: But I think we negotiate with our bodies all the time, don't we? (*agreement from women*). I mean you push yourself and you say 'oh, let me do x, y, and z and then I'll lie down or I will eat better tomorrow and I'll exercise'.

Rose: Exercise is the thing. 'Oh, oh, oh - if I can get through this year, this summer I'll walk more' (*laughter*).

Adele: Yeah, I guess deep down you know you're not treating your body as well as you should. Most people aren't and that's why we put 'good' for health. We didn't put 'excellent' or 'very good' because most of us [ ] you know, we're not as well as we want to be or we should be (*agreement*) [ ]

Brenda: Takes a lot of time and energy though. [ ]

Rose: But I was just thinking the same thing. If I was going to focus on getting my body in gear, I'd have to stop work because there's not enough time. I can't ... that's stupid to say that, isn't it? – Really, when you say it. Why can't we make time for ourselves?

The women in Group B talked about the same tendency for people to make choices that are in apparent conflict with their health. Specifically in relation to diabetes, the women discussed the “perverse” nature of some affected individuals to make “wrong” dietary choices, skip medical appointments, and play with their insulin even while aware of the associated risks. The women referred to this common “Russian roulette” lifestyle approach as the human condition.

Diane: I wonder if that's just with breast cancer. I'm thinking of friends who have diabetes and who almost deliberately make wrong dietary choices. You know, if there's something healthy and there's something that's not healthy and they know which they should have, they'll go for the cheesecake every time without fail. [ ] And deliberately make these choices. [ ]

Lynn: And I've seen a lot of people that do that - or they don't go in for their vision checks and they run into problems with diabetic retinopathy.

Joanne: We're a perverse society. People are perverse. [ ]

Mary: It's the human condition [ ]

Lynn: And they play with their insulin levels even if they know that it's going to affect, possibly, their vision (*agreement*). [ ] He says, you know, when he's taking the meds he

doesn't feel quite as good as when he isn't. [ ] So he says 'sometimes I've been known to play' ... he also drinks - and he counsels other diabetics.

Joanne: That's like playing Russian roulette in a way.

Lynn: Yeah. It is, but people will do that.

Female beauty = beautiful, slim, 2-breasted, youthful

The women in both groups talked substantially about the popular images and representations of women in our society. As previously summarized from the first meeting with Group B, the women talked about the extremely slender, almost androgynous woman, as the standard of female beauty and the breast as a physical symbol of that beauty. The women talked about the high number of media messages urging weight loss and the difficulty with letting go of the slender ideal. As well, they noted the negative connotations and sequelae associated with being overweight, such as being labeled as "sly" and being shunned by others. Finally, some of the women shared experiences of women with breast cancer who exhibited anger related to a perceived loss of womanhood after mastectomy.

During the second meeting with Group B, Joanne talked about the frequent messages in women's magazines directing women to lose weight and reap the inevitable rewards, such as having a better life.

Joanne: - and every week it's how to lose weight. [ ] Every single women's magazine known to woman says, lose 10 pounds, get a better life. Lose 10 pounds, get a better man. Lose 10 pounds, get a better job. Lose 10 pounds ... (*laughter*)

At the end of the next meeting with this group, I introduced two magazines to the women that we would discuss at the following meeting. The women joked about the many messages that were prominent on their covers related to losing weight.

Anne: We'll look at some of these (*magazines*) next week and look at how women are portrayed in the media. How does that sound? [ ]

Lynn: That means we're going to have to sit and look at thin and emaciated, underfed women.

Joanne: Is there anything on the cover on the magazine about losing weight?

Anne: Yeah – 'Bye, bye bagels'. 'Food ruts that make you fat'.

Joanne: Oh, there you go – 'Lighten up!' [ ]

Marion: 'Summer body jumpstart'.

Anne: 'Lighten up'... 'Seven day eating' ...

The women in Group A also discussed television ads that promoted what they perceived as an unhealthy way to lose weight in order to reach the largely unattainable goal of 'size zero'. They spoke about a prescription drug promoted over American networks that will cause weight loss but may also cause liver damage.

Adele: As a society, we don't promote health really. I mean like you look at the way people eat and there's this commercial ... this commercial I saw recently - can diet - or it's a product and zero comes up. Did you see this one? [ ] 'Zero is the number of calories you allow yourself some days. Zero is the size of dress that you' – [ ] Okay, and it comes to zero-zero; and then they say about how this is not healthy - blah - and then you see this woman lifting weights and she's thinking this product and *that's healthy* and then she loses weight. [ ]

? Oh my God!

Adele: It must be American because then they give like the side effects on the bottom.

Madonna: Big long list. Side effects of diarrhea. [ ] This could cause liver damage.

Beth: Yeah, yeah, it's great. You'll grow another head but you'll be thin.

During the fourth meeting with Group B, Mary talked about her long period of dieting in the hope that she would feel better with some weight loss. She also highlighted how difficult it is to reject the thin female ideal, even when one is very elderly. She spoke about the disapproval her Mother (who is 87) felt over the "chubbiness" of her younger sister (who is 85). Her mother

could not understand why her younger sister would not want to be thin, even though she had not been for at least 60 years.

Mary: I've dieted on and off for eight years. [ ] I'm always thinking if I could lose ten pounds, I would feel better. [ ] But like my mother is 87 and her sister is 89 and she's got one who is 85 and she gets on to me sometimes for half an hour about this - this 85 year old. 'Oh she's ... so much weight' and every time she calls the other one - who is the little thin one - says - and mom weighs 105, you know, and she'll say 'my God, did she take off any weight?'. 'My dear', she said, 'you'd think now at her age that she'd want -'. I said, 'Mom, be quiet. She's alive. She's healthy. She's 85. Let her eat what she wants'. 'Oh, she just eats everything. She's short and she's chubby.' [ ] - and I said, 'Mom, she's always been that since I can remember'. 'Go on, don't be so foolish! She used to be so thin'. I said 'Mom, yes - before she was married'. 'Yes' she said 'before she married'. I said 'Mom, that's over 60 years ago, you know, before she was married'. She got this fixation about weight. I said 'leave her alone. She's happy'.

Also at their fourth meeting, the women in Group B talked about the negative connotations and associations that are sometimes made about individuals who are perceived as overweight. Joanne spoke about a teacher who labeled "fat girls" as sly; while Mary spoke of her husband's experience in a post-secondary institution where his overweight students had a more difficult time getting hired than their slimmer classmates, even if their qualifications were comparatively better.

Joanne: And I can tell you another ... a teacher who commented about fat girls who ... 'well, you know how it is with fat girls'. [ ] 'They're sly. They're always the ones who cheat' (*sound of disbelief*). 'They're this and that and everything' and I say what's fatness got to do with any of that? [ ]

Mary: My husband taught at XXXXX for 30-odd years and, you know, he'd be preparing the students to go out for job interviews and he used to often say that some of my best students - real gems, smart as anything - but he said they had a little bit excessive weight; and he said, as sure as anything they'd go out for an interview - nothing that they did wrong but he said, you know, it was their appearance. Even though they dressed nicely and they were primed for it and they were excellent, they never got the top job.

Both Lynn and Joanne had the occasion to observe separate high school graduation dances in the weeks previous to the fourth meeting. They witnessed young girls who were not very slender both shunned and ridiculed by the other girls.

Joanne: But they were all starving. The ones who were chewing gum were the little skinny ones because they were all starving to death, poor little things. [ ]

Lynn: There were some big girls there and the other girls [ ] were talking about these girls with the weight on and, you know, 'look at them. Just look at them! God, they're' ... and one of the words that they used for it ... like gross. 'Aren't they gross?'

Joanne: And they're condemned outright because they have weight on. [ ] - but this reference to personal shape that people have no compunction whatsoever about making on the most personal level. [ ] Yes, and all the little skinny girls get together. You know, they would all sort of run and throw their arms around one another and 'you look so gorgeous'.

Anne: The congratulations club.

Joanne: The congratulations club [ ] 'Aren't we beautiful?' ... 'Don't we outshine all the others?'

Both Brenda and Rose talked about anger they saw expressed by women who had one or both breasts removed. During the third meeting of Group A, Brenda shared an experience she had with her roommate who had a mastectomy. In apparent frustration, she threw her breast prosthesis at Brenda shrieking that she no longer felt like a woman.

Brenda: Yes. But I remember coming home late one night. She was sitting up drinking and I don't remember what happened but she ended up freaking out and I remember her reaching into her blouse and taking out the prosthesis and flinging it at me and saying 'that's all I am!' - or something like that; but I mean it was really ... it was that whole thing about - 'I don't feel like a woman anymore. I don't know who I am anymore. This is what I am - this piece of foam rubber!'. It was ... It was ... I was terrified. I was almost thirty and it was like horrifying for me. I moved out shortly after.

During their next meeting, Rose shared an experience she had as a student nurse with a female patient who had just had her second breast removed. The woman would walk around the hospital floor with the top half of her body exposed. Rose felt the woman was angry and defiant over the loss of her breasts. She stated previously that when they asked the woman to return to her hospital room she told them "it doesn't matter anymore".

Mary: Yeah, she had these gorgeous silk pajamas - [ ] and she just walked around as if it was a man because she had both her breasts off and the scars in those days ... they were

really huge and ugly and blue and one was more recent than the other [ ] but I think she was very angry. [ ] I think she was trying to prove something [ ] I think it was the thing that shocked me most right through my training. Never forgot it. I never forgot her face and her attitude. It was almost like you could see the chip on her shoulder. She was almost swaggering down, you know. It was really amazing. I never saw anything like it afterwards and I had never seen the like before.

The health care system

Denial of death: Scientific breakthroughs / increased technology

The women in Group B talked at length about the impact of increased scientific information and technology on how we view health, illness and death. In their second and third meetings, the women explored how we have come to believe that we can and should remain healthy indefinitely, that all illnesses should be curable, and that we may even be able to avoid death altogether if we just figure out the science associated with living well. Joanne remarked that while death was an accepted part of their parents' and grandparents' lives, we are now almost affronted by illness and death.

Joanne: Our generation in particular has taken on this quest for health, this quest for longevity, this quest to live forever, this quest for eternal life, for eternal youth. You know, you talk to older people - like my mother-in-law who's 91 years old - and she says, 'well my sister Margaret died when she was 19; and when I was young, I didn't understand why she died but as I got older I came to terms with it'. Or mother had six stillbirths or my grandmother's greatest boast was I had nine children and they all lived. [ ] It was part ... death was much more a part of life then. It's almost like shock to us now. It's almost like, well, we're doing what we're supposed to be doing. We're taking the vitamin C, we're eating the fresh fruit. You know, we're doing it all and people are still dying! (*laughter*). I mean, what is wrong here?

Various: What's the problem? What's wrong with us? ... Yes. [ ]

Diane: And up until, I would say, the Second World War, we didn't think that way in North America either. I think it has to do maybe with prosperity. I think it has to do with the explosion of scientific information - and not just information but scientific improvements in *technology*. [ ] Technology, right, that we can turn around - we can cure some kinds of breast cancer. We can operate and we can replace heart valves. We

can do by-passes. [ ] This is just one more thing. If we put enough money in it, enough time in it, we can just solve this because we can solve everything else.

Joanne: We'll work it out. We're going to live forever!

The following excerpt is also taken from the third meeting of Group B. I had relayed my experience with a provincial screening program in which the emphasis was becoming increasingly strong on technology to detect breast cancer early at the expense of BSE and CBE. I indicated there had been numerous discussions at the provincial and national level to eliminate both of these components of early detection at the breast screening clinics, so that all resources could be focused on mammography as the sole screening technique. Later, I shared with the women the way I taught BSE while with this program. Diane expressed bewilderment that health professionals would not support a technique that had the potential to find breast cancer early without the aid of expensive technology, especially in the current climate of fiscal restraint. She described her realization as "chilling" that the medical profession would choose technology over teaching individuals how to care for themselves. She stated that this paternal attitude robs people of a sense of self-responsibility for health and choice to which they are entitled.

Diane: And you say that ... let's go back to what you said earlier, that doing that procedure on a regular basis would have or has a really high probability of locating lumps.

Anne: If you have a lump in your breast that can be felt ...

Joanne: That's the trick, isn't it?

Anne: I really feel that you will find it.

Diane: And then it seems to me so peculiar then that health care professionals would be dismissing that kind of procedure because it would seem to be in this day and age when we've run out of money for the health care system - this is free. The training isn't free but the procedure is free.

Lynn: And you can train a whole lot more people a whole lot easier than you can pay for equipment.

Diane: It just seems to me to defy logic. [ ] I still find this attitude that you ... with the medical profession and I find that ... I find it chilling and I find it mystifying. It's like saying, well, let's not teach the public about nutrition. Let's just go ahead and put all these whatever ... we'll rely on technology and we'll add it to their food to ... we won't give them any sort of role to play. [ ] You know, it's ... it's really quite bizarre when you stop to think about it.

Lynn: Well then, you know, it's an attitude of they will take care of us and I don't like it either.

### Mistrust in the health / medical system

Women's mistrust of the health/medical system was related to two issues: Their difficulty in understanding the rationale behind some health care policies (such as those related to mammography and BSE) and a questioning of whether methods of remuneration influenced policy; and their experience of patriarchal health care from physicians.

In this excerpt, taken from the second meeting with Group A, the women expressed frustration with inconsistent policies related to mammography depending on political climate and funding models (inter-provincially and between Canada and the U.S.). They also discussed not being taken seriously by their physicians because they are women, and essentially having their medical complaints associated with their menstrual cycle. Several references were made to feeling that a physician had "patted them on the head" when they sought medical care. Brenda, a health care professional, postulated that this was a widespread problem for women and stressed that women need to be vigilant to ensure they receive good care.

Rose had been discussing a friend of hers who was told by a physician she was too young to get a mammogram even though her mother had breast cancer and she had a palpable lump in her breast. The women started to question the policy on mammography screening, and why it differed from one place to another.

Madonna: I think in Canada it's 45 and in the U.S. they take 40; and as it happens, the cardiologist has said to me, 'as far as I'm concerned the only reason why they say 45 in Canada is because of the cost of it and in the U.S. everybody is paying for it anyway so they say, go when you're 40'.

Brenda: But in B.C. I think it's 40 or 30 - 35 or 40 anyway, one or the other.

Susan: But, you know, it's funny you'd say that because we have a history of breast cancer in our family and my sister ... well, she has been in the U.S. now for two or three years and she was told here because she's 35 and they said, 'you're too young; don't worry about it' and stuff, and when she went for her first check-up when they moved down there, her doctor ... you know, with the family history we have, was quite surprised she wasn't sent for one by the time she was in her late 20's or 30's. Well, this physician said there really isn't any kind of an age thing so I've often wondered, like [ ]

Brenda: I had a client about a year ago - a woman who came in hospital having lost her uterus and most of her bowel because of cancer; and she had gone back to that specialist so many times and they kept saying it was irritable bowel [ ] we can't allow ... we can't allow the medical profession to trivialize our concerns and just fob us off with a pat on the head. [ ] I think if you're not a very assertive person or you don't even know what to ask for, I think that's very frightening when you think about what that means for health care (*agreement*). [ ]

Adele: ... and you feel like you have to be educated yourself before you go in there and have your little note pad. [ ]

Susan: Well, I had an experience this week. I believe that more than ever what we talked about last month. I had an experience yesterday and today with the doctors [ ] I've just been having severe headaches and migraines [ ] Went to another doctor at the clinic and I was basically getting prescriptions for Toradol and Atasol and, you know, it was just ... 'you're under a lot of stress at work' and you know 'it's your period' and everything else and I kept trying to explain to this doctor that the pills weren't helping and I thought it was something else [ ] and in the last couple of days, I've [ ] found out that I have TMJ and that's what caused all the headaches [ ] But I went through this with this other doctor patting me on the head like you said and saying, 'oh, it's just this and it's just that' and I was like, 'no, I live in this body. I know it's not that'.

Anne: It's your stress - it was work; it was your period.

Rose: That's really trivializing, isn't it - to put it down to women's problems. (*agreement from women*) [ ]

Brenda: It happens all the time. I would suggest that there is not one female who's got to the age of 40 or 45 who haven't had an experience like that with a physician.

Also during the third meeting with Group B, I shared with the women some of the rationale provided in the literature as to why women should not be taught BSE, such as the resultant increased number of ‘unnecessary’ visits to the family physician for ‘normal’ changes. Lynn wondered if this perspective was predominantly male, or medical, in which case technology may be more favored over a traditional hands-on approach. They also questioned the physicians’ motivation as well by wondering if remuneration for reading mammography films might influence their perspective.

Anne: And we need to keep telling women to examine their breasts.

Diane: Who says that? ... you said there’s some question about whether women should be taught about self examination. Who raises the question that it wouldn’t be a good idea?

Anne: Well, I’ve gone to ... I’ve been at many meetings here - senior policy level meetings, at national meetings of radiologists, surgeons, policy makers, nurses - and was very concerned about what I felt to be a shift in breast screening towards technology and a shift away from women knowing their own bodies and the health aspect of ... breast health - and helping women to feel comfortable about themselves and, you know, it would be said at almost every meeting I went to, say in 1996 and ‘97 - which is when I started to do research on it - that ... and written in lots of academic articles and a big debate - should we be teaching women how to examine their breasts and all of the controversy around it - for instance, women get hysterical; they don’t know what they’re looking for.

Joanne: Excuse me. Repeat that first one again. Huh! [ ]

Lynn: You heard it right.

Anne: Women are anxious anyway; they’ll run to the doctor every second week - [ ]

Lynn: Pretty damn patronizing, isn’t it? [ ]

Diane: And none of those concerns address the issues that you have just said - that women do find the majority of lumps. That sort of glosses over... [ ]

Lynn: Is the push coming boys with toys. You know, is that a male doctor, medical practitioner point of view primarily or is it a female ... are the nurses saying that as well or is ... you know what I’m saying?

Anne: Well, nurses generally are trying to push for the comprehensive approach.

Joanne: I think it's ... but it's a way of making the dollar.

Mary: That's the bottom line.

Joanne: That's the bottom line. It has to be.

### Concept mapping

As previously stated in Chapter 5, the concept map provides an accessible record of the women's collective conceptual schema related to the meaning of BSE for them and its examination can deepen our understanding of this phenomena.

During the fifth meeting with each group, the women were asked to organize the components of the temporal map (on individual index cards taped to the wall) into a schema that was meaningful for them in relation to the issues relevant to BSE. To prompt the women in Group A, they were asked to look at the components and put them into some kind of logical order indicating overarching issues and or relationships between components. The concept mapping exercise with Group B began with the following question to prompt discussion: 'What are the factors that influence women's practice of BSE?'.

With minimal further encouragement, both groups of women organized and re-organized the temporal map components into clusters. They labeled them, indicated perceived interrelationships, and gave their maps an over-arching title to reflect the general context of BSE for them. Despite several rearrangements of the temporal map components, overall there was little disagreement within each group of women about their placement. Where disagreement did occur, the women reached consensus through discussion. I facilitated the concept mapping exercise but participated little in the creation of their maps. This was especially important in the creation of the second map, in order to avoid biasing the process by introducing ideas from the

first group. The concept maps created by the two groups were very similar, validating the data collection and analysis to date. See Figures 3 and 4 for a copy of the concept maps created by Groups A and B respectively (these figures can also be found in Appendix 10). Along with the presentation of each concept map, excerpts are provided from each group's discussion to indicate how they performed the concept mapping exercise. The excerpts will illustrate how, through discussion and consensus building, they organized the temporal map components into clusters with interrelationships, labeled the clusters and their overall concept map, and engaged in reflection during the process.

### Group A

#### The creation of the concept map by Group A

The following discussion gives a brief illustration of how the members of Group A collectively constructed their concept map. The first excerpt demonstrates how the women organized most of the temporal map components into two clusters of concepts; one pertaining to being a woman, and the other to cancer. They also indicated a reciprocal relationship between 'human condition' and 'we don't value ourselves'.

Brenda: Well, there's some of them that belong - that seem to me they could be grouped together - like 'it's everywhere' sort of goes with 'no control/ no guarantees' - or could go; but it's fate - (*agreement from women*).

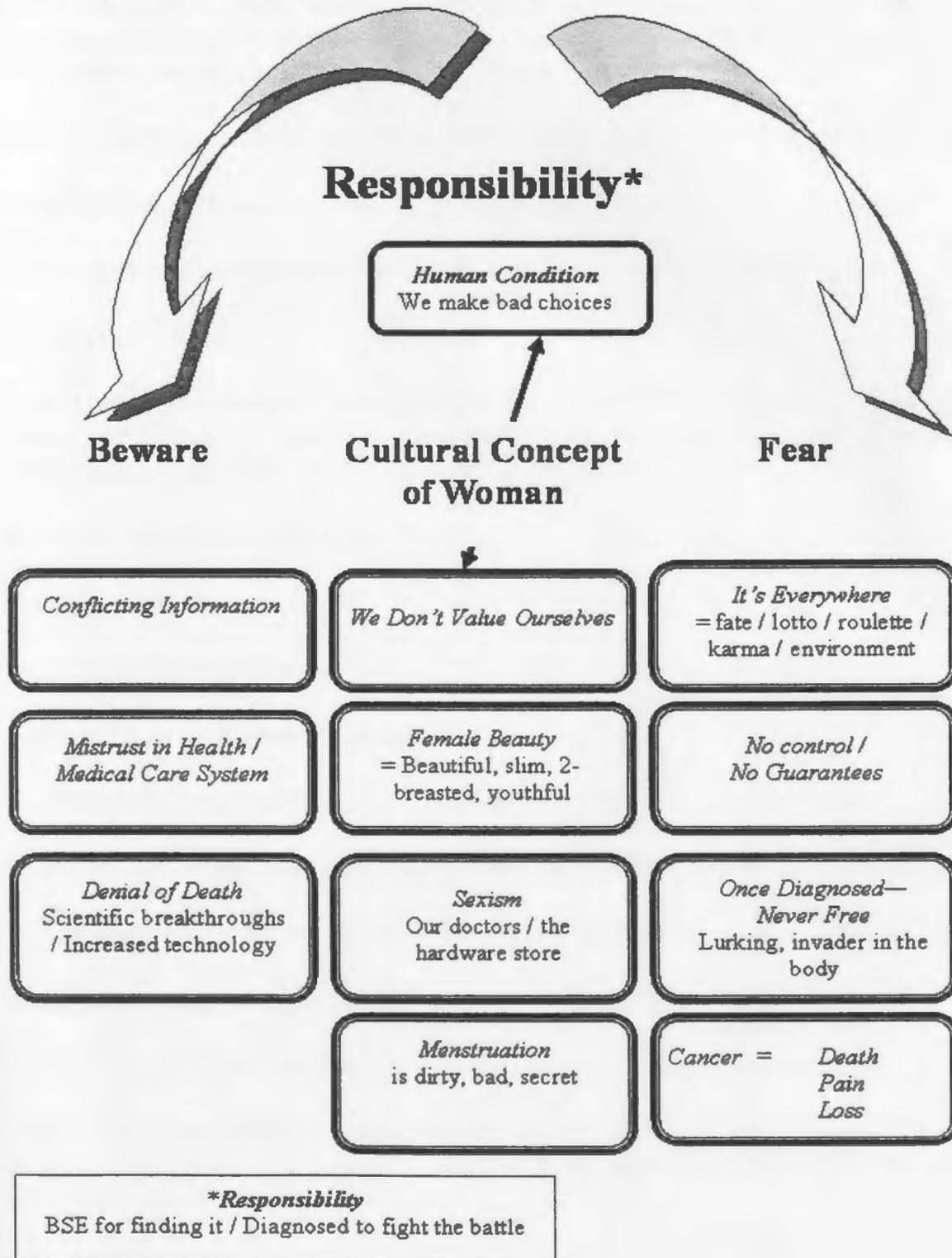
Adele: And then there's some that seem to go with or like female condition - like the one 'female beauty', 'sexism', 'menstruation', I guess. I don't know if there's anything else there that could go with that?

Brenda and Janet: Well, 'we don't value ourselves' (*agreement from women*). [ ]

Anne: You all seem to be fairly comfortable with that? (*agreement from women*)

Brenda: Also, that 'once diagnosed' kind of goes with this ('it's everywhere' column) because you're never free, it's lurking - invader in the body - kind of with 'no controls', 'it's everywhere' ... (agreement)

Figure 3: Concept Map of BSE created by Group A



Beth: I think maybe the 'we make bad choices' - it kind of goes with 'we don't value ourselves'. I don't know if it necessarily fits in with all the rest of them but I find there's a bit of a tie between that - over on the left: 'the human condition, we make bad choices'.

Anne: Maybe like this ...

Beth: Yeah, like ... yeah! Like I find those two things kind of go together because sometimes we make bad choices because we don't value ourselves. Sometimes we don't value ourselves; we make bad choices - you know.

In this excerpt, the women suggested ways to label a cluster of temporal map components they felt were related to being a woman. Rose reflected on issues discussed in previous meetings, such as the influence of patriarchal values and the media. The cluster was eventually labeled 'cultural concept of woman'.

Rose: I think for 'we don't value ourselves' ... I think a lot of that, to me, seems to come from social pressures - society's views and maybe the male-dominated view or the advertising - whatever - but I think perhaps, you know...

Beth: Kind of cultural ideas.

Rose: Cultural ideas.

Beth: Cultural/social ideas.

Adele: Female ... the female image.

At times, the women clarified and negotiated the meaning(s) associated with the temporal map components as they created their concept map. In the following discussion, Beth suggested that 'responsibility' was the overarching theme for their concept map. Rose shared her perception of the meaning of 'responsibility' with the other group members. Brenda put forth a different interpretation of the component, based on her memory of the discussions.

Beth: I kind of feel that the one card that's left ['responsibility'] is kind of like the big heading. You know, you've got ... *(the card is being moved to the top of the map)* yeah, almost like that.

Rose: Intellectually, that's what we know we have to do but all these other things maybe ... you know, interfere with us actually taking responsibility - you could look at it that

way maybe - you know, because we have a lot of other things that we have to deal with there.

Brenda: Although I seem to remember when we had that discussion - well ... and that was my feeling anyway - was that I didn't want to have that res ... it was sort of the responsibility was a burden (*agreement*). It was like, you know, if I didn't find it, that was my fault. If I didn't look at everything on the Internet and everything, like that was my responsibility. I didn't actually see that as a good thing.

Finally, Rose reflected on the concept map at the end of the exercise and remarked that it was reflective of the collective contribution of the group members.

Rose: ... these issues are issues for all of us in one way or ... and we all have contributed something there and, you know, whether we agree with everything or not, I think we're all ... we all have a feeling for what's up there. It's part of all of us. (*agreement from women*)

## Group B

### The creation of the concept map by Group B

The following excerpts provide a sample of the discussions that occurred in Group B while they were organizing their concept map. In the first example, the women were clustering the concepts they felt were related to being a woman. The women reflected on the discussion in the previous group meetings as they put these components together.

Anne: 'We don't value ourselves' under 'women'?

Diane: Under the 'sex ...', well, where would you put that? It might be a stand-alone.

Lynn: I don't know. I think that is part of the 'female beauty'.

Diane: We meant it as part of that.

Lynn: That's exactly ... yeah - because it's in there with 'menstruation is dirty, bad and secret'. It's all part of ... that probably ... yeah, I seem to recall - it was being done. It was all part of if you weren't pretty enough, if you weren't ...

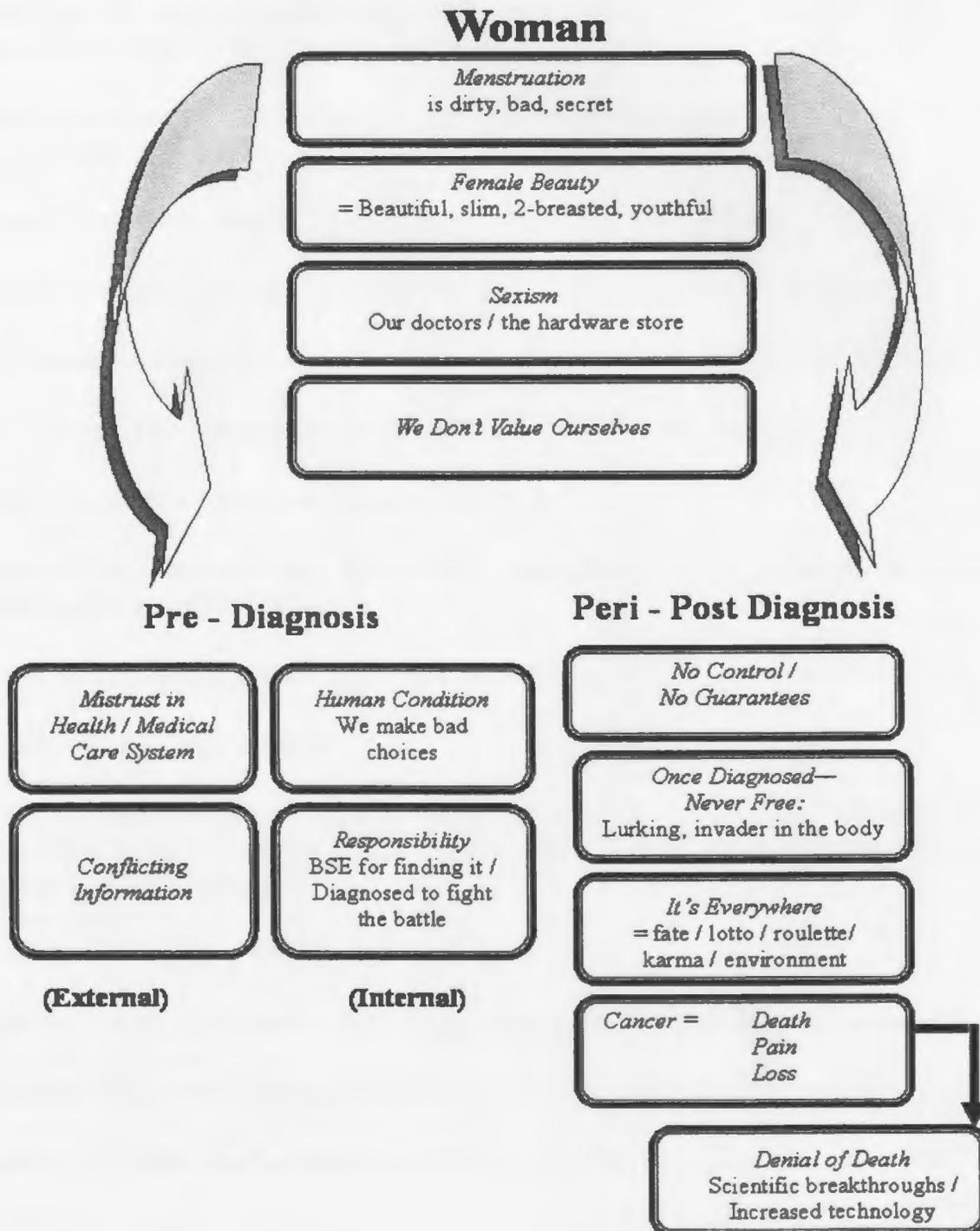
Joanne: Thin enough.

Lynn: Thin enough.

Diane: Yeah.

Joanne: We talked about that.

Figure 4: Concept Map of BSE created by Group B



*Menstruation  
is dirty, bad, secret*

*Female Beauty  
= Beautiful, slim, 2-breasted, youthful*

*Sexism  
Our doctors / the hardware store*

*We Don't Value Ourselves*

*Mistrust in  
Health / Medical  
Care System*

*Human Condition  
We make bad  
choices*

*Conflicting  
Information*

*Responsibility  
BSE for finding it /  
Diagnosed to fight  
the battle*

*No Control /  
No Guarantees*

*Once Diagnosed—  
Never Free:  
Lurking, invader in the body*

*It's Everywhere  
= fate / lotto / roulette/  
karma / environment*

*Cancer =  
Death  
Pain  
Loss*

*Denial of Death  
Scientific breakthroughs /  
Increased technology*

The following excerpt illustrates how the women brought meaning to the clusters. In this case, Diane suggested that of the four remaining temporal map components, two were under individual control and two were not. The women accepted this interpretation.

Diane: I think the 'conflicting information' and the 'mistrust' maybe go together. [ ] Because those are things that are external to us, but the 'human (*condition*)'- and 'making bad choices', those are personal decisions, right, and 'responsibility'. [ ] That's what an individual could put into the mix, but the other two come from outside, right - can you see what I mean?

Anne: Yeah, so 'human condition' and 'responsibility' a person brings. 'Mistrust' and 'conflicting' are outside.

Diane: They see ... they're coming from different directions (*agreement from women*).

In the following exchange, the women are labeling the three clusters they have created.

The women agreed on the following three labels: 'woman', 'pre-diagnosis' and 'peri-post diagnosis'. 'Woman' was chosen as the overarching theme of the concept map.

Lynn: - or what women are thought to be. [ ]

Joanne: Portrayed as being. Yeah, I'm ... pushed into being. [ ] These are the negatives (*referring to another cluster*).

Anne: These are the negatives? ... Out of control.

? This is like a roller coaster.

Diane: It's sort of like after you ... that's sort of what ... these other things maybe are before you have it or it's sort of around the situation but that column - those four - that's after you've got it, isn't it.

Joanne: Yeah. That's exactly it.

This final excerpt illustrates that while the women were creating their concept map, they were using it to reflect upon Joanne's sister who was refusing to have a suspicious breast change investigated even though she had previously been diagnosed with breast cancer. They indicated that her reluctance might be related to any one of four of their temporal map components.

Joanne: And my sister - I spoke with her today yet again about going and having a mammogram done. 'Why don't you just have a mammogram done and then, you know, even let somebody else worry about it' and she said, 'Why? I'm going to die anyway'. [ ] And I said, you know 'but this is a curable cancer if they find it early'. 'But' she said 'there's no guarantee a mammogram is going to find it anyway'.

Diane: Where's that coming from?

Joanne: I don't know where she's coming from but it's total -

Diane: 'Bad choices'.

Lynn: 'Bad choices'.

Marion: 'Bad choices'.

Joanne: But I don't know how to convince her.

Lynn: Well, actually, it could be under the 'no control, no guarantee'.

Diane: Yes, the fate things.

Lynn: Or the 'it's everywhere - fate' - that kind of thing.

Diane: It's also misinformation (*'conflicting information'*), isn't it?

Lynn: Yeah.

Joanne: 'But,' she said, 'we're all going to die! Have to die sometime'.

## Summary

This chapter has illustrated the consciousness-raising process the women were actively engaged in over a four-month period as they collectively reflected on, and discussed, the issues relevant to their practice of BSE. Through the identification of the temporal map components, they were able to identify personal and social factors influencing their practice of BSE. These factors were broadly grouped in relation to three major issues: cancer, being a woman, and the health care system. In relation to cancer, the women identified as relevant the arbitrary and unpredictable nature of cancer, its association with loss, the lack of clear information to guide

decision-making, and the burden of personal responsibility associated with finding it and surviving it. In relation to 'woman', the group members felt that the way women are portrayed and treated in society influenced their perceptions of self-worth and their personal decision-making. In relation to the health care system, the women identified increased technology, inconsistent medical policy, and dissatisfaction with medical care as issues undermining their trust. Through organizing the 13 temporal map components into a concept map, the women were able to reflect on and discover interrelationships between the components that increased their understanding of the complex range of factors influencing their practice of BSE and illuminated with greater clarity the meaning of BSE for them.

## Chapter VIII

### **Women's Views at the End of the Study- The Women's Raised Consciousness**

#### Introduction

The purpose of this chapter is to demonstrate that the women developed a critical awareness of issues pertinent to breast self examination, in particular those related to cancer and being a woman, through their participation in this research process. Change in the women, as discerned through their group discussion during their final joint meeting, will be highlighted.

Following the first five meetings with each group of women, a four-month break preceded a final joint meeting. The time lapse provided all research participants the opportunity to reflect on what had been discussed during the first five months of meetings. Eight women attended this final meeting, with equal representation from both groups. The final joint meeting allowed the women in the two groups to meet for the first time to discuss issues related to BSE. It provided an opportunity to ascertain if they were satisfied they had discussed all relevant aspects of BSE, and to determine if any change in the women, in the form of consciousness-raising, could be identified.

The following discussion highlights evidence of the women's increased awareness of issues related to BSE, including challenges to BSE practice and recommendations for BSE promotion, as identified by the women during this meeting.

#### The women's raised consciousness

Increased sensitivity to social messages related to BSE, breast cancer and women

The women became more aware of media advertisements related to BSE, breast cancer and women, including an increasing consciousness of how women are represented.

In this first excerpt, Adele and Beth talk about how much more aware they had become of messages related to breasts and breast cancer. Adele even remarked that she became aware of her increased sensitivity despite the fact that she was not comfortable with journaling. Beth uses the example of a segment on *Good Morning America* where they were introducing a piece on breast cancer. Contrary to her previous behaviour, Beth did not turn the channel but stayed to hear the report.

Adele: I must say I'm not a journal person so ... but we were having a talk - Beth and I talking about ... now that we go to these meetings, it seems like breasts everywhere, breast cancer. You hear this. You read that. You see that on TV. It's like ... I don't know if there's more or we're just paying more attention to it.

Beth: Suddenly aware of it, you know, suddenly conscious of it; but yeah, I just find everywhere I go there's breasts! It's just everywhere! (*laughter*) [ ] It's like when you learn a new word - all of a sudden, that word is everywhere because you're conscious of it (*agreement from others*). So I think now that we're kind of meeting and it's a topic that's in your head, when you hear it you don't tune it out anymore [ ] like Tuesday, I was telling Adele I was just flicking the channels in the morning and *Good Morning America* was on and it was the end of the segment and they said, 'stay tuned - there's something coming up about breast cancer' [ ] And ordinarily I just would've turned that off. I have to confess. I wouldn't have been interested.

In the following example, Adele remarked how this research process allowed her the opportunity to explore issues she had not discussed previously, to learn from other participants, and again, to become more aware of the media.

Adele: It's been a nice experience though going over all those issues and just talking about things that I think I never really talked about before. Like, I had all these ideas but like I've been hearing other people, their point of views and then paying more attention to commercials and magazines.

Adele also indicated that she had become more critical of media representations and found some of them offensive. She stated that one result of being more analytical was a strengthening of her own position in relation to the issue at hand.

Adele: There are some commercials that shock me and I think they're totally outrageous so it shouldn't be allowed to be on TV, like I just kind of ... (*makes remote control*

*clicking sound - i.e., turn it off*). That's like looking at magazines - you know. it's like a test - like being more of a critic or something, you know, like ... or ... or it may be emphasizing or strengthening your own values. That's the way I see it.

In the next excerpt, Beth described her excitement at discovering that a television ad for sanitary napkins had used the color red to denote blood. Reflecting on their earlier discussions of how menstrual blood was always the color blue on TV, she felt this was a breakthrough. Perhaps, to her, this was an indication that menstruation was beginning to be portrayed as less 'dirty, bad, and secret'. Note that several women in the group simultaneously said "blue" indicating their shared consciousness about this phenomenon.

Beth: I have to make a comment on that though. You know how we talked about how we watch the commercials for pads and *Tampax* and all this - everything is -

Diane and several others: Blue! (*laughter*)

Beth: - is blue. I saw a commercial yesterday and it was red.

Diane: Really? [ ]

Beth: It's a *red dot* and it follows the line of this pad and all this kind of stuff. And I was going - it's red! It's red! And (*my partner*) was like, what is your problem? (*laughter*) [ ] I was like, it's red! Finally! I just thought that was so great!

In the following exchange, the group members demonstrate a sophisticated degree of political awareness of how women are represented in the print media. Using the example of *Chatelaine*, Brenda remarked that even though some magazines seem to make an attempt to show a broader range of 'woman' than traditionally depicted, the representations are still largely within a narrow definition of beauty. When deviations from the norm were noted, such as a handicapped woman, Brenda perceived it as a mere token attempt to be more representative of 'woman'.

Brenda: I must admit I'm not a big fan of *Chatelaine*. They've cleaned up their act a lot over the years but they've been just as much offenders as any other.

Diane: That's right... they are complicit in that. (*agreement from women*) [ ]

Brenda: I mean they're much better now. you know, the spokes-models that they have in their magazines tend to be more toward normal weight than *not*, but you know, even so ... but, you know, let's face it - well now not all - but they've got flawless skin, really nice hair and once in awhile there's this really attractive woman but she's in a wheelchair - like that's sort of their -

Lynn: Token -

Adele: Token handicapped person.

### Recognition of the oppression of women

The group members articulated many examples of women's oppression in society. Most notably in the media, through mixed messages, stereotypical representations, and their internalization by women and through acceptable or quasi-acceptable social practices.

Adele expressed frustration with what she perceived to be contradictory messages in our society related to being a woman. We had been discussing how menstruation is still promoted in the media as something shameful and secret. At the same time, common modern advice to women is to take care of themselves; to be proud and independent.

Anne: Just listen though to all the things we used to do to hide our periods and hide our breasts and hide whatever, you know (*agreement*) ... These women talk about ... hiding their bodies and ... and then all of sudden we're supposed to grow up and take responsibility, you know, and get in touch with our bodies. (*agreement*)

Adele: What are we supposed to do, man? I find it very frustrating - like all this ... I thought - bullshit.

Beth: Yeah, there you go.

Adele: All these mixed messages and all this stuff and I guess I see a lot of it at school through my students, you know, and these ideas they have that come from TV commercials, society, the parents.

As well, Brenda talked about the mixed messages women receive from the media and how hypocritical these messages can be. She referred to magazines that tell women to break out

beyond the boundaries of traditional female beauty in one article, while at the same time reinforcing the stereotype in another article.

Brenda: I think they make an effort. I mean there's no doubt and you always, I guess, have to balance your revenue with doing what your conscience dictates. I must admit sometimes I read those articles, like "don't be a slave to fashion". You know, right in the same magazine as they've got the latest make-up tips for the season. [ ] Yeah, it must be a difficult balancing act so maybe publishing that kind of thing is one way of redressing it but we find it sometimes a bit hypocritical.

In the following excerpt, Brenda suggested that the narrow representation of 'woman' in society impacts on how women feel about themselves. She reflected on the two concept maps that had been taped to the wall and commented that it was easy to understand, given all the temporal map components, why women do not value themselves. She remarked that although women have achieved some recognition for their work outside the home, the fundamental measure of the value of a woman has not changed substantially since the 1960's, and is still based on a narrow definition of beauty. She commented on the recent resizing of women to size zero as one reflection of women's continued oppression in the world.

Brenda: Well, I think it is tied into some of the other things that are up there (*on the wall*) as well and that if you think about women who are valued or why women are valued in terms of what they look like, then it really makes sense that, you know, once you start growing hairs on your face and have to dye your hair, that that no longer fits the standard definition of what beauty is. [ ] It's like you have a career. You have a profession. You're well respected in the community. People still value you for that; but in terms of being valued as *a woman*, you know, I think that hasn't changed as rapidly because I think that's still caught up with beauty and with, you know, how womanly we are so [ ] the physical [ ] there was no - what's a size zero? To me, size zero is when the person is not there.

Lynn: A skeleton.

Brenda: No. I mean zero is nothing, right, so how can you be a size zero?

The following quotation is from a collection of writings by young women asked by *Chatelaine* magazine to write about their bodies (Torres, 1999). It was submitted by a young

woman within the 16 to 19 age group. I read it aloud to the women as part of a discussion of women's place in society. Note in particular the emphasis Adele placed on her words 'they know', perhaps referring to the pervasive oppressive effect of the media on women, even young women, and how it results in low self-esteem. Diane's remark further validates the young woman's feelings. Later in the meeting, Diane reintroduces the concept of the 'bored middle-aged men' who create the media representations of women.

Anne: "My hips are too wide. My chest too flat. My arms are too chubby. My thighs are too flabby. I'm too short, too small, too fat, too ugly, too flawed. Messages about our body - not being good enough for the social standards set by bored middle-aged men and the women who stand by and don't correct them is heard and seen on radio, TV, billboards, news, articles, movies, fashion runways and magazines everywhere. The result so far of the bombardment of 'if you don't look like this, you don't belong' is nothing but low self-confidence and self-worth and in some, death." (Fuller, 1999). That's how she starts hers... 16 to 19 years old.

Adele: Yeah. *They know*.

Diane: She's put a lot of thought into that.

The group members cited several examples of acceptable or quasi-acceptable social practices that oppressed women. While a discussion of culture is outside the scope of this study, these examples do cross cultural boundaries.

Diane: And xxxxx ... her daughter was a nurse - taught and worked in xxxxx (*country name edited out*); and when they went out they used to wear the [ ] chador - but they were spoken to in a market by males and they were arrested - she and one or more other nurses and they were tried and their sentence was so many lashes with this whatever they beat them with. [ ]

Adele: But sure in some of those countries if a woman is raped, she's the criminal. [ ]

Anne: Well, sure, even in Canada. Up until like they passed legislation, it was her sexual history on trial.

Lynn: But in these places she'd be put in jail, or killed. [ ]

Adele: Cause she was raped, and the guys are... they just -

Anne: Remember in xxxxx (*country name edited out*) one woman was stoned to death in public because she had committed adultery or it was suspected. [ ]

Beth: Oh my God! [ ]

Brenda: But yeah, there are a lot of murders of, you know ... by families ... like by the males, the brothers, or cousins or fathers or something and that's justifiable homicide.

Adele: Yeah, like in India they set you on fire and ... there was a show - an Oprah show -

Anne: Kitchen fire.

The crone is lost

The women demonstrated an increased awareness of the diminished value of aging women in our society and the losses associated with this reduced status, such as not being acknowledged or having a legitimate function. Lynn summed it up by stating that the role of the crone has been lost in modern society, thereby leaving only two dominant social roles for women – that of sexual object and mother.

Brenda discussed how she feels more invisible as she ages. While grateful that she has moved beyond the 'sexual object' phase of being a woman, she does feel a loss: a lack of a clearly defined place in the world, of being a non-person or a "mother". She felt this was exemplified in the usage of the term "ma'am" with older women. They remarked that the same losses were not true for men.

Brenda: I'm so glad I'm not young anymore. I really am! It's a big relief because I don't have to ... you know, I mean I still have vestiges of all that stuff about I'm not tall enough, thin enough, pretty enough, you know, whatever; but there's some of it ... it's like hey, I don't have to worry about this bullshit anymore because, I mean, in a way it's an upside and a downside because as you get older you become invisible anyway.

Diane: You become what? Sorry.

Lynn: Invisible. [ ]

Brenda: People don't really pay that much attention so it doesn't matter. [ ]

Lynn: Younger people look through you.

Brenda: Well, and men ... and men!

Lynn: You mean there are men out there?

Brenda: I mean, you become a ma'am, you know.

Several: Yes, I'm a ma'am. (*jumble of voices*)

Brenda: Young guys do nice things for you because, well, you could be their mother. [ ]

Lynn: But it is true. Men look abso ... straight through you. You are a *non-person*. [ ]

Mary: You're asexual. [ ]

Diane: Men become elder statesmen.

Beth: Oh yeah. Dignified.

Mary: Yes. And if men have gray hair, it's distinguished. If women have gray hair, they're old.

Brenda talked about the freedom she has experienced since becoming "invisible" or perceived as a "mother". She does not receive unwanted sexual remarks and feels less threat of physical or sexual harassment and believes this is because she is no longer considered to be within the social boundaries of sexual attractiveness.

Brenda: But, you know, the upside of what you're saying is that - I live by xxxxxx and I walk through there at lunchtime and one of the things I find that I *like* about sort of being quote-unquote invisible is that I can walk through a whole crowd of teenage boys and I don't even have to be *worried*.

Beth: They're not interested. (*laughter*)

Brenda: No! That's right! They're not interested. They're not going to make lascivious remarks, right. They're not going to whistle. They're not going to do any of that stuff. I can just ... and in fact, they stand aside and let me walk through. (*laughter*) Yeah - parts the sea - And I just find that such - so *freeing*, you know, not to have that kind of feeling of tension. I actually quite like it. [ ]

Lynn: You're old enough to be their mother, you know.

Various: Sure! Sure!

Lynn: It's that again.

Finally, Lynn proposed the theory that the role of the crone, or the wise matriarch, was lost in present society. She stated that at one time, women enjoyed more privilege and power as they aged, but no more. Now, older women are not valued at all. Too far beyond the role of sexual object, and even of mother, they do not have a replacement function in our society.

Lynn: I think we've lost that theory of the ...

Various: Matriarch.

Diane: The wise woman.

Lynn: ... the mother and then the crone, the crone not being the old hag which is what we always put on it as the connotation - but being the wise woman in the group - I mean, the woman that you refer to when you have a question or a problem; and in some cultures, that was certainly the woman in power and in fact, once a woman had hit menopause, she was given more power and more freedom. And in some areas she could do magic or she could do whatever, you know, whatever made her heart happy. But in our society, you hit menopause and you are a non-person. After all, you're no longer a woman, for goodness sakes. *(laughter)* [ ] And if you have gray hair, you're not either. No, I don't think we value our women ... our older women - at all.

Evidence of action: Rejecting dominant discourses of women

The following discussion will illustrate, using four examples, how the group members considered, critiqued, and then rejected ways in which women are oppressed in our society. The examples utilized are a research study pertaining to women's health, ads related to feminine sanitary products, cultural practices that include the chador, and a TV ad that promotes BSE. In each of these examples, the women demonstrated they have become more aware of, and critical about, how messages related to women are generated, perpetuated and disseminated in our society.

### Rejecting research

In this discussion, Adele brought up a research study that had been published in a popular women's magazine. The researchers suggested a direct relationship between the number of menstrual cycles experienced by a woman and her risk of breast cancer. They associated the increasing incidence of breast cancer with women having fewer pregnancies and spending less time breastfeeding than previous generations. The women challenged the legitimacy of the research, including a query about gender bias, and the inherent recommendations to women to spend a large segment of their life pregnant or breastfeeding to reduce their risk.

Adele: There was an article in *The Homemaker* about that, about having your periods and how years ago women would be pregnant most of their lives and would have so many periods in their lifetime and die early and what influence that has on your body because now they say that women now have an average of four hundred periods or whatever [ ] and these other women years ago would have maybe a hundred or two hundred because they'd be breastfeeding and that so. [ ]

Brenda: That's right and there's some suggestion that it's bad for your health to have that many... [ ]

Anne: I read that and I thought - could it get worse?

Brenda: Yeah, yeah really! (*chuckling*) Something we have no control over and now it's bad.

Lynn: Obviously ... men.

Adele: There was a big thing about it... [ ] These two men had done this research, I think. They didn't take into consideration other things.

Brenda: Yeah, but initially when the results came out, because they were looking at women having more periods ... partly because of that women having more periods and stuff and how that in fact has had a negative impact on women's health, it's like - give me a break. [ ]

Lynn: I mean the answer to that is simply be pregnant most of the time and breastfeeding and die young. [ ]

Beth: What a wonderful life.

### Rejecting feminine sanitary products ads

During this discussion, the women expressed anger and disbelief at the way sanitary products for women were being promoted in both print and TV advertising. They brought up five different ads for either sanitary pads or 'feminine wipes'. Some of these ads showed men taking a shower, or wearing a kilt or white form-fitting t-shirts and pants. They stated they found the ads disgusting and offensive and could not accept the messages they felt were portrayed: 'use our products and feel like a clean man' or, alternatively as Diane pointed out, 'use our products and be ready for your man'. The ads also implied that women's place in the world has improved – 'being a girl just got better' (i.e., more like a man) - but Brenda challenged this with a tongue in cheek question about wage parity. They were critical of ads that reinforced menstruation as something secret and shameful; attitudes they had learned and internalized as children, and now were being passed down to the next generation.

Brenda: There's a series of ads for like sanitary napkins and they have like men ...

Anne: Showers - in showers.

Diane: Oooh... (*sounding dismayed; jumble of voices*)

Brenda: No. It's on TV and it's guys like with different builds or something like that. [ ]

Adele: But the other one - dancing with the kilt on and ...

Brenda: Yeah that's right. [ ] And I'm looking at it thinking, what in God's name? [ ]

Marion: Every time I see it I get disgusted. I don't think it should be done.

Anne: Like what do they think they're trying to ... they got men building a pyramid. They've got white tee shirts on and shorts, I guess, or pants and they tumble. They do this and then they tumble.

Beth: That's a commercial for sanitary napkins? [ ] I know the ad you're talking about. I thought it was for like Tide or something - the men in the white shirts, right (*laughter*) [ ]

Lynn: These ads *don't* reflect... [ ]

Marion: But why do they have men doing ads for female products?

Anne: That's a good question.

Lynn: Listen, why do they even have ads for those things anyway? [ ]

Anne: This one is ... I don't get this [ ] here's a man - handsome - underneath a shower. There's nothing in the background and it says, fresh - instant refreshment anytime, any place. It's for *Always* feminine wipes. [ ]

Adele: So what - and you feel refreshed like a man in a shower.

Anne: Like a man.

Beth: You feel like a man, excellent!

Lynn: You feel like a real man.

Anne: *Oh!* You use these and you no longer feel like a woman; *you feel like a clean man!* *Good God.*

Diane: Or you feel ready for your man! You see, there are all kinds of layers.

Brenda: Anyway, it's all got to do with men. [ ]

Lynn: Most of them are offensive. [ ]

Diane: But again, what kind of demographic. It's fascinating to me! (*agreement from women*)

Anne: Oh actually, this is young girls because you know what it says? It says 'being a girl just got better'. That's underneath it. 'Being a girl ...

Diane: Because of these wipes that makes you feel like a man.

Brenda: Why do we have complete employment parity now?

Beth: I really don't like the commercials for *Tampax* and it's a school classroom and all you see is a desk and a woman's purse.

Adele: Never take your purse to the washroom. [ ] Taking your purse in the washroom means that you're on your period.

Brenda: Well, the thing is, we *never* would take our purse to the washroom anyway because then people *would know*. [ ] If you had to, you'd stick it up your sleeve.

Diane: Isn't that awful? [ ]

### Negotiating the chador

The women discussed whether the chador was a form of protection or oppression for women. This discussion began after I read out a quotation from a young woman who responded to *Chatelaine's* request for writings about female body image. The woman quoted was originally from a Middle Eastern country and stated that the representation of female beauty in Canada was different than in her country, in that beautiful women here looked starved and unhappy. Note the increasing levels of awareness as the discussion unfolds: First, the chador is a symbol of women's oppression; second, the chador may provide some protection to women; third, the women use the chador to obtain some freedom but they are still oppressed; and fourth, the women use the chador as an active form of resistance as they reduce their risk by becoming invisible.

Beth: That's interesting because xxxxx (*country name edited out*) is one of those countries where if you go out as a woman, you still need a shroud over your head and your face and ... [ ] My friend [ ] worked there [ ] And his wife wanted to come over and he wouldn't let her. He was like I'm terrified for you to come here – [ ] because when there would be American women and things, he said you could see the men leering at them - literally - (*agreement*) [ ] just the way that these men were looking at the women - he was like that's just scary. (*agreement*) [ ] he said you could almost see the thoughts - if we were in a dark alley right now –

Lynn: Pretty sexy to see that lower face. [ ]

Beth: - So it was interesting for this woman to make comments like that because it doesn't sound like they totally value their women as much over there as they do their men, you know what I mean? (*agreement*) And you don't see very much of the women.

From just pictures and everything, every woman I saw in pictures were literally covered from head to toe. You saw their eyes and that was it.

Brenda: But I think that's part of the point and one of the justifications they use for even some of the women for staying dressed like that is because that erases that whole thing.

Beth: Oh, that's true.

Brenda: You can't tell under that thing, you know, how big, how small, big breasts, little breasts, you know, different size breasts, whatever, and so it's like ... and so the whole markers of beauty are different (*agreement from women*) because there's not that same obsession with [ ] the physical.

Beth: That's a good point actually. [ ]

Brenda: Some of the younger women when they come here, either stay with the traditional dress or ones that have been born in Canada go back to traditional dress (*agreement*) and that's one of the things that they talk about. It's like it just ... it levels it all out. [ ]

Diane: Interesting though about your comments about leveling off but it's leveling off at the lowest common denominator because women have very few rights in those [ ] countries. [ ] I mean they have no rights at all. (*agreement*) [ ] They're property still, so whether there's some kind of connection there between – [ ] It's a much bigger issue than ...

Brenda: Because they do ... Well, the sense I got was because they do feel very vulnerable, because they have no power and in some way this gives them some protection...

Diane: You become invisible.

Brenda: Yeah. You become invisible and when you're invisible, basically people can't hurt you, right.

### Rejecting a BSE ad

Several of the women described feeling surprise and shock after watching a promotional TV ad in which an adolescent boy offers to do BSE for women. In the ad, he is ostensibly saying to women, "you don't examine your breasts. Let me do that for you", while his two hands are open and outstretched and his friends cheer him on. Although Beth originally thought the ad

humorous, she, like other women, was confused by the purpose of the ad. They felt the target demographic was not women, but young boys: further entrenching the stereotype of breasts as sexual objects and BSE as a sexual act. They feared this would undo years of public education that attempted to normalize touching one's body as a necessary part of BSE. As well, the group members thought the ad could increase the sexual harassment of women if young boys responded to its message encouraging them to touch women's breasts. Diane stated this was an example of a "bored middle-aged man" creating questionable media messages about women.

Diane: Anne, have you heard or seen about those ads [ ] - the young boy? Did they pull that or what's the ... [ ]

Anne: It's a young guy like a teenager going, okay, women, you don't examine your breasts, I'll do it for you. I'll take on the job.

Adele: Then he's like that! (*gesturing with her hands outstretched; laughter*)

Beth: When she told me that, I cracked up in the car. But I was like, oh my God!

Lynn: I remember seeing it once. [ ] As I recall, it's ends off with 'why don't you do it', right? [ ]

Beth: Oh yeah, I see the point but it's ...

Lynn: I mean what bright spark, it's like, I know, let's get a *young guy* ... you know - (*laughter*)

Beth: Who'd do anything to cop a feel -

Lynn: - and have him do an ad for breast cancer -

Adele: - and his two buddies are on the couch going 'Yeah! Yeah! Yeah!'

Brenda: What do they have - like a woman going 'okay guys, you don't want to check for prostate cancer but...'  
(*jumble of voice; laughter and tones of incredulity*) [ ]

Diane: - the girl (*Denise Fuller*) talking about the bored gray-haired man sitting at a desk making decisions! (*laughter*) [ ]

Lynn: That was one of the ads that [ ] right at the end it was like, *oh my goodness. Wait a minute! I've missed something here!* (*laughter and jumble of voices*) [ ]

Adele: It was a bit of a shock first watching that commercial but ... I didn't know what to think. It was like, *okay ... (laughter)*.

Beth: It kind of puts a funny slant on it because I mean when you think, you know, breast exam, it's a non-sexual act as far as I'm concerned (*agreement*) but when you see like a seventeen-year-old doing this on the screen, it's all of a sudden - they've made ... [ ] But, you know what I mean - this medical procedure, whatever you want to call it, into a sexual act. (*agreement*) What's it got to do with a breast self exam. I mean, I think it's funny. When she told me I laughed, you know, but I was like, okay ... [ ] It's like two completely opposite ends of what you're trying to do, you know.

Diane: I've never seen the ad but I wonder - listening to you - you folk have seen it - who would be the target demographic? Obviously, not me. [ ]

Beth: It's a younger person.

Lynn: 'These guys will examine any breasts'. (*laughter*) No, no, no. that's what they say... the way it starts - 'wait a minute - you don't have time to do your BSE' - that's the way they say it - offering the service. And I think that's rude.

Diane: But the people making the ads always state the demographics, *So... who did this middle-aged gray haired man...? Was he...?* [ ]

Beth: Much younger. Like 15-24. [ ]

Lynn: I think it was on during a sports -

Adele: Oh! Watching the sports. [ ]

Lynn: It wasn't the right place (*sounding puzzled*). [ ] That's the wrong demographic.

Anne: Like they were targeting boys with it.

Diane: That's right, the wrong demographic. I think that's sexist.

Lynn: Well no, they were going to be the ones *who would offer to do it!*

Diane: I know what you are talking about now.

Lynn: 'I saw this commercial and I thought I'd offer my services.' (*as if quoting a young man*). [ ] You know, just to help you out, my dear.

### An increased awareness of challenges to BSE practice

During the joint meeting, the women were asked to consider how they would promote BSE if they were charged with that responsibility. Their discussion demonstrated a good understanding of the challenges women encounter as they perform or consider performing this personal screening mechanism. This question had initially been posed to each group in their fifth meeting, and their comments in the joint meeting reflected their previous discussions. Consequently, quotations from both the fifth meeting with each group and from the joint meeting will be used to illustrate their increased awareness of the challenges to BSE practice.

The women identified five challenges to the practice of BSE: (a) the perception that BSE is sexual, (b) BSE is embarrassing, (c) there is a lack of understanding about its relevance and how to do it, (d) fear of finding something, and (e) there is work involved in its performance.

#### BSE is sexual

The group members felt that BSE has been associated with sexuality, even for young teenage girls, and women would therefore be reluctant to perform it. As one of Susan's grade seven female students told her, "well Miss, you know, it's because every time you talk about breasts, you're talking about having sex", and "sure, that's just like feeling yourself up", from a grade nine female student.

#### BSE is embarrassing

The women also felt that from a very young age, girls receive messages about their bodies that instill a sense of shame and embarrassment. Brenda pointed out that we need to look at the "kinds of things that culture teaches us about touching your own bodies and about what breasts mean". They drew upon two examples to illustrate this: (a) the disgust that some women

and physicians shared with them about breastfeeding at the time when they were having their children, and (2) the socially prohibitive act of women scratching an itch, even though men felt no similar constraint (even on international television). The result was a perception among young women that their bodies are dirty or shameful. As Susan stated in reference to BSE, “the kids don’t buy into it. They’ll listen to it but as far as they’re concerned it’s all icky. It all has to do with their bodies. It’s way too embarrassing.” This feeling does not go away as young girls mature into adults and it influences their openness to doing BSE, or even hearing about it. In the following quote, Adele talked about the attitude of some women.

Adele: I mean we’ve been talking about it and pretty open about it - but a lot of women are very shy, very. You know, they’re not open about this and they could be very uncomfortable being talked to or being showed how to do breast self examination, so that would be like the tricky part - to reach out to these women.

#### Lack of knowledge

The group members also discussed the fact that some women have never been taught how to do BSE or do not understand its relevance to them. When Diane realized in an earlier meeting that she had never talked to her daughter about BSE, she then asked her what she knew about it. In reference to her daughter, Diane stated, “*nowhere* in her education - in her school or health courses - *nowhere* was it discussed. [ ] But she said she and her friends never ever discussed it and she says they’re not concerned”. The teachers in the group also remarked that BSE is not taught consistently in the school curriculum. It is usually offered as part of the Family Living or Health courses, but most students do not take Family Living and it can be dropped from Health class if the teacher runs out of time. Some women stated that they did not know how or when to do BSE. For example, Adele remarked that BSE was a set of “complicated steps” that she could not seem to remember. Lynn stated that for post-menopausal women, who could no longer rely

on their periods to cue them into when to perform BSE, “just the mathematics of it all - it just becomes too overwhelming and that’s never discussed”. Other women agreed with her.

### BSE causes fear

The women also discussed fear as a barrier to doing BSE. This may be the most profound reason. Although they could provide a variety of reasons why they did not examine their breasts regularly (including that it is not a habit, it is not a priority, life is too busy, and they do not remember to do it), they realized their reluctance to do BSE may reflect a profound subconscious fear of detecting something if it is there. Note that Adele shifted her perspective from ‘not knowing’ why she does not do BSE, to acknowledging that it was related to this deep fear.

Adele: ... and now I’m at these meetings and that’s really got to get me started so I thought that would be the thing that would convince me to get started on BSE, and I still don’t do it so I don’t know. [ ] For me, it’s just going to be – well maybe if I write on the calendar now tonight.

Brenda: Yeah, no that’s it.

Mary: It’s still fear [ ] It’s still fear... Maybe in the background. Right deep somewhere is maybe it’s still the fear of finding something when you do it.

Adele: I don’t want to find it if it’s there. [ ]

Brenda: I think there could be some aspect of that too.

Mary: I think somewhere in the deep subconscious we’re afraid to do it because we’re afraid we’ll find something.

Adele: I think it’s true for me, yeah. (*agreement from women*)

This fear may be related to the association of BSE to cancer in general, and not just to breast cancer. The women felt that the negative connotations of cancer would take a long time to go away.

Susan: When you hear the word cancer, it's automatically negative and, you know, it's true. Like you would like to introduce it in such a way that they wouldn't be anxious; but honestly, I think that would take a very long time for it to come to that place.

### BSE is work

Partially tongue-in-cheek, the women talked about the number of personal grooming chores they performed on a regular basis such as flossing, shaving legs, plucking eyebrows, and painting their nails. BSE was just one more activity they had to perform in an already busy life. While the women laughed during this exchange, they brought this issue up several times.

Brenda: I find by the time I wash my hair, shave my legs, you know, wash my body - stuff like that it's like - gee, is it that time already? I'll do it tomorrow!

Beth: It's true. You can't do all the maintenance in one shower!

Brenda: - and evenings are for flossing and plucking my eyebrows so -

Beth: It's high maintenance, I tell you! *(laughter throughout)*

### The women's recommendations for BSE promotion

Within the context of the challenges to BSE practice identified by the women, they were asked to consider how they would promote BSE; specifically, what would be the overall messages they would give women and how to promote these, rather than the specific steps or techniques to teach woman about how to perform BSE. In their discussion, the women made three recommendations related to the promotion of BSE: (a) BSE education should start early, (b) BSE should be promoted as normal and healthy, and (c) moral attitudes related to BSE need to change.

BSE education should start early

The group members recommended that BSE be introduced to young women at an early age. They felt the more information young girls have, and the more open the discussion, the less fear and reluctance they will experience related to touching their breasts to perform BSE.

Diane: I think any information is good information [ ]

Joanne: Education is power.

Diane: I wonder if it takes away some of the fear. [ ] I'm wondering if the more [ ] young girls are - not taught to do it maybe as a young girl - but the more the topic is broached, the more this just becomes part of being a woman, part of aging - if the fear will diminish somewhat [ ] Familiarity does have a way of sort of leveling your responses to things. The more you see and hear something, the less you tend to react to it.

The women in Group A recommended introducing BSE as early as 10 years of age in the grade-five school curriculum, reinforcing the message that BSE is just "part of being a woman", and not something to be frightened or embarrassed about.

Janet: They start in grade five, I think - teaching, you know, teaching about menstruation - well, it would ... probably a good starting point - right then and there.

Beth: Almost like one is part of the other, almost - (*agreement from others*)

Madonna: This is part of being a woman and being healthy and whatever. Here's the things you should do. [ ]

Madonna: Get to know your body at such an early age. Where we started - and it was like you're frightened to death.

BSE should be promoted as normal and healthy

The women felt that BSE should be presented within the context of routine care that women do to take of their bodies and their health. If young girls are provided with normalizing messages about BSE at a young age, they may grow up with the attitude that it is just something else that women do to stay well: part of regular body maintenance and a healthy lifestyle.

Madonna: I think it should be taught as a normal thing (*strong agreement from women*) and not as an abnormal thing 'Oh my God, I have to have to check my breasts because this is a real negative thing!' (*agreement from women*) ... 'I might have cancer!'

Adele: Like, you know, you got a tooth that hurts - you go see the dentist [ ] You think you got a cold, you check it out. It's just [ ] your body needs to be maintained [ ]

Madonna: You fall down; you cut your knee; we're going to clean it up and put a band-aid on.

Janet: Yes, you know. It would be just normal. [ ]

Adele: You feed it; you clean it. [ ] You've got to do a lot of work! [ ]

Beth: Just maintain your health, right.

Madonna: Or know your body.

Rose: It's part of a healthy lifestyle.

The women also recommended that BSE education in school should include both girls and boys, so that everyone becomes educated about that aspect of adulthood, along with menstruation and sexuality. At the end of this excerpt, Adele is referring to a male cousin, who was taught about menstruation by his mother, and who she felt had a respect for women not shared by some other males.

Diane: When they talk about birth control, I mean the whole class is there, when they bring in the box of condoms and the plastic penis, you know. Everybody's there! [ ]

Adele: And I find then they have more respect for the other gender. (*agreement*) I remember one of my cousins - a male cousin - who didn't have sisters but knew all about periods and all this stuff [ ] and he seemed to have a kind of like a respect, like knowing how the female body was and just the way it is, and other boys were like this is disgusting.

In addition to normalizing BSE, the women felt that educating boys as well as girls in school would make them more aware of issues related to breast cancer and more supportive of women in their lives who might become diagnosed with the disease.

Rose: That's the way it is done in our high school too. It's done specifically for girls but I really think that idea about making it a general thing *is marvelous*.

Beth: But another issue in making it a general thing is that, okay, yes, as a male you probably won't get breast cancer. I mean the chances are slim; but your chances of being married to a woman with it, you know [ ]

Rose: Supportive thing, you know. That's right.

Beth: Right! You should be informed and if they're informed at a young age, they can be more supportive and more understanding if ... [ ] if they end up with a woman with breast cancer.

### Moral attitudes related to BSE need to change

As previously discussed, BSE is associated with sexuality, and touching one's body is considered shameful. Acknowledging that attitudes young women have about their breasts and touching their body are partially learned at home, they recommended parents receive education about BSE. This would decrease any contradictory and confusing messages young girls are receiving and internalizing about their body and BSE, from school and at home.

Brenda: So we also talked about - I think, in our group - about educating their parents and older women so that they can also provide a different context in which girls can feel okay about doing that because it's no good if they're getting it in school but at home are being taught, you know, like you shouldn't touch yourself or those kinds of things.

However, the women also realized this type of attitude change would take a long time, possibly even a generation. For real attitude change to occur, young girls would have to be taught BSE (in school) so that as they grew older and had children of their own, they could pass these attitudes and practices on to their children.

Beth: Yeah. I think if you start with the kids [ ] when they're 10 [ ] by the time they get to [ ] say 30 or 35 [ ] and they have a 10-year-old, well, the 35-year-old is doing the breast self exam and that's going good; so then when the 10-year-old learns it, 'oh yeah, I think my mom does that. Yeah, that's what you're supposed to do. Okay, well, I'll do it too'. I think it could take that long but ...

Adele: Yeah ... a generation.

### Reflection on the concept maps

The women were asked to reflect on the concept maps and suggest any changes they felt were necessary. The women remarked on how similar the two concept maps were but did not want to make any changes to either map. They stated that the headings of the two concept maps (woman and responsibility) are the two central concepts relevant to BSE. Their agreement with the concept maps, and assertion that any similar discussion of BSE by women would result in the same concepts being generated, validated the research process and its results.

In this first exchange, the women remarked it was very difficult to tell which group (A or B) created which concept map because they were so similar.

Anne: You look up at the posters on the wall, and this is what you came up with when we did our concept mapping in June. Does it look familiar? (*agreement from women*)

Diane: It's interesting the similarities.

Marion: Yeah, I was looking at it earlier.

Lynn: And maybe that's what made it difficult to actually divide ... look at that and decide which group you were in. [ ]

Mary: You certainly wouldn't pick it out. [ ]

While initially surprised, on further reflection they stated it was not that remarkable because the issues related to BSE were universal to women. They felt that any group of women who discussed BSE would generate the same issues.

Beth: Yeah, it's amazing that - two completely separate groups of people ... That's 90% the same - it's amazing.

Adele: Well I guess... It's just the way it is. It's supposed to be like that. [ ]

Mary: That's what I wondered - if you got several other different groups whether - I'd bet in the end they'd all come up with the same idea. [ ]

Beth: Yeah. Because the issues are the issues so.

Mary: I think so... If you talk about it enough ...

When the women were asked if they would change any component of either concept map, and how they would put them together, they stated that both maps were acceptable and equivalent. They did recommend that if they were put together, the two maps would stay the same with 'breast self examination' as a major heading, over the two sub-headings of 'woman' and 'responsibility'.

Anne: So would you think about how ... do you have any ideas how you might put them together?

Adele: Well, to me, they're the same. They're just organized differently and they're both just as good. *(agreement)* [ ] It's just taking the same information and organizing it in a different way. [ ] Just the jigsaw puzzle put together differently [ ] You know, maybe one way I would put it together would be responsibilities of being a woman but ... *(agreement from women)*

Beth: Pretty much. Put the two together.

Anne: So you wouldn't change anything, given the option?

Adele: Because like, it's not there but all of that was our discussion about breast cancer. It's not actually there but we know that's what we're talking about. That might be something we want to put on the top of it. [ ]

Lynn: Yeah. Yeah. Breast self-examination. Responsibility - woman [ ] two separate charts under one.

### Women's awareness of their raised consciousness

The women were aware they had changed as a result of participating in this research study. During the last meeting with Group A, Adele described the research process as a positive experience for her. She stated, "[it] made me feel somehow a little more empowered or you know, you know where you're going". Joanne described the series of group discussions as a process that all of the women went through. With respect to the effect it had on her, she stated,

“for me this whole course of events has made a major impact on my life ... now I feel I’ve taken control. I really do”. During the last meeting with Group B, an exchange occurred between Diane and Joanne that demonstrated their unwillingness to be subjugated by Medicine and other social institutions.

Diane: We don’t accept everything the medical profession says as law.

Joanne: We don’t accept anything anybody says anymore.

### Summary

The women’s raised consciousness was evident in many different ways at the end of this research process. They demonstrated an increased sensitivity to, and critical awareness of, the myriad of messages related to BSE, cancer, and being a woman. They identified two dominant social roles for women, as sexual object and mother, and mourned the loss of the wise female elder. They were particularly critical of evidence of women’s oppression in society, and discussed exemplars in television ads, cultural mores, and medical advice. As well, the women reflected on their preceding discussions and identified five major challenges to BSE practice and five recommendations for the promotion of BSE to women. Finally, they reflected on their individual concept maps and validated them both.

The engagement of women in a series of group discussions over a period of time has allowed them the opportunity to identify and reflect upon personal and social factors relevant to their practice of BSE. The next chapter will provide a consolidation and interpretation of these personal and social factors to increase understanding of the meaning of BSE to women.

## Chapter IX

### Discussion

#### Introduction

The purpose of this study was to actively engage women in a cycle of collective self-reflective inquiry to explore personal and social factors influencing the meaning of BSE to them. This was accomplished by meeting with two groups of women over a period of time, using focus group methodology, to provide them with the opportunity to reflect on their everyday experiences related to their practice of BSE. As co-researchers, the women were actively involved in the framing and analysis of the research problem. Consistent with a feminist experiential approach, the events of the women's daily lives were considered a valuable source of knowledge. As a result of their participation in this study, the women demonstrated an increased awareness of the complexity of issues related to their practice of BSE.

This study has shown that BSE is an intensely personal issue for women that brings to the fore a complex web of interrelated meanings and experiences such as those related to cancer (breast cancer in particular), being a woman (and having breasts), and the health care system (including their treatment by physicians). Most women, when asked, are unable to clearly articulate why they do not perform BSE. By situating BSE at the juncture between these phenomena, a greater understanding of its meaning for women can be achieved.

#### BSE: Challenging the power relations of knowledge production

##### The standpoint of women

This study challenges the perceived objective scientific model that has been applied to the evaluation of BSE as an effective screening technique. Using the everyday experiences of

women, it has illuminated other forms of knowledge minimized or dismissed by Medicine and science. Women have a different understanding of what BSE means to them than can be derived from a positivist approach. These understandings are shaped by complex social and political forces related to their subject position, such as the representations of women in society, the imagery associated with breast cancer, and the hegemony of Medicine in the present health care system.

Foucault (1980) advocated for a critical appraisal of the production of knowledge. Because no knowledge is value-neutral, it is important to ask questions related to what knowledge is being produced, who is producing it, and whose interests are being served. This perspective is taken up by Dorothy Smith (1990) whose feminist approach to the sociology of knowledge illuminates the central role gender plays in the production of, and resistance to, what is considered legitimate knowledge. Because women both live within and are oppressed by social institutions, they can offer a unique and valuable viewpoint to the experience of BSE that cannot be produced by those in positions of power, in this case the masculine bio-medical scientific sphere. Within this critical standpoint, women can provide a useful critique of the dominant system of knowledge production through sharing and exploring their everyday experiences. In so doing, they can highlight where gaps and contradictions exist between the knowledge created within the biomedical model and that known to women through their life experiences. Through this examination, what has been accepted as ‘the truth’ is challenged and the systems of power relations that subjugate the voices of the oppressed and marginalized (in this case women) are illuminated.

## The evolving discourses of breast cancer

### Breast cancer is a private affair

Prior to the 1970's breast cancer was firmly relegated to the sphere of the private (Sherwin, 2002). Cloaked in secrecy, it was associated with shame and embarrassment. Women did not publicly speak of their breast cancer and were not encouraged to do so. Whether a result of the second wave of feminism, or the declaration of a 'war on cancer' by U.S. President Richard Nixon in 1971, women began to talk amongst themselves and become organized, and advocate for a concerted government and medical response to reduce the incidence, morbidity and mortality associated with breast cancer.

### The war on cancer

The coining of the phrase 'war on cancer' opened up a plethora of military metaphors that have remained associated with cancer, most particularly cancer treatment. This metaphor transmits many messages, not the least of which is the need for an all-out effort to control the risk, which is contained wholly within the woman's body. Several authors have written about the war metaphor in relation to cancer including Sontag (1978), Lupton (1994a, 2000), and Sherwin (2002). Words such as enemy, attack, fight, destroy and bombard are plentiful in the lay and academic literature in relation to cancer. Once through treatment, affected individuals are called survivors and often portrayed as brave heroes.

Similar to any other type of war, critical questioning of the means and outcomes is not encouraged. That could be construed as an act of treason. A military metaphor encourages compliance to those in command and a tolerance of 'collateral' damage in order to defeat the enemy. It also justifies the expenditure of large amounts of money and a reliance on technology

to develop and utilize maximal intervention to respond to this threat (Lupton, 1994a; Sherwin, 2002).

The battleground of the war against breast cancer is of course the woman's body, and the justifiable 'collateral damage' is the morbidity and disfigurement associated with recommended treatment. As eloquently stated by Sherwin (2002):

It makes it a moral duty of women to join the fight by delivering their bodies to medical authorities empowered to wield the high-tech interventions they have devised and to permit that fight to be pursued until either the woman or the cancer is destroyed (p. 20).

As described by Kaufert (1998), the woman undergoing treatment is an extreme example of Foucault's 'docile body', under the control of external regulation. Women have to submit to the medical assault in order to destroy the cancer and within this approach, physicians have ultimate authority by virtue of their scientific education.

One caveat of this approach by biomedicine is that there can only be one true victor. In the case of breast cancer in particular, Medicine had not been able to substantially reduce its incidence, morbidity, or mortality in the first twenty years of the declared 'war on cancer'. The technological and scientific approach that dominated cancer treatment was not successful and questions of prevention had not even been adequately approached within this paradigm.

### The turn to early detection

The Western world has always valued individual autonomy and the responsibility of the individual to take control of their destiny. In the last fifteen years of the twentieth century, this extended into the realm of personal health management with respect to cancer. Early detection became the new key to cancer control and individuals were encouraged to be alert for any sign or symptom of emerging cancer. Critics of the turn to early detection stated that it had been utilized

to keep the public from recognizing that accepted treatment regimens were not working (Leopold, 1999).

Health promotion campaigns sprang up everywhere in the developed world and emphasized the risk of cancer, and the pivotal role of the individual to reduce this risk. Twenty years ago, there were three early detection methods widely accepted for breast cancer including mammography, clinical breast examination, and BSE. To this day, early detection has been presented to women as the best way to reduce their risk of breast cancer.

The widespread adoption of screening as a critical component of breast cancer control had a number of consequences. Firstly, women began to overestimate their risk of getting this disease, which leads to greater fear of the disease (Kaufert, 1999). Secondly, women were encouraged to monitor their own bodies for potential signs of breast cancer. This is not surprising given the directive from the U.S. National Institute of Health, “once the fear of getting a disease has been created, people are encouraged to accept responsibility for their health, assess their risk, and take appropriate action to prevent the disease” (as cited in O’Brien Cousins & Edwards, 2002, p. 327). To some critics, including Lupton (1994a, 2000) and Potts (2000), this self-surveillance caused women to question the integrity of their bodies, which in turn increased their anxiety and feelings of vulnerability. Within this context of increased responsibility for health care, the individual who did not perform the recommended self-surveillance or did not detect cancer early enough had somehow failed (Lupton, 1994a, 2000; Potts, 2000). While illness has historically been associated with ‘moral failure’ related to perceived insufficient self-discipline to lead a healthier life (Lupton, 2000), now this judgment and responsibility was extended into the realm of disease detection. A woman who failed to do BSE well, or on a regular basis, was often described in ways that inferred she was irrational or irresponsible (Kline, 1999; Lupton,

2000; Sherwin, 2000). In the case of breast cancer, the responsibility (and failure) is two-fold: failure to prevent the disease in the first place, and a further failure to detect it early enough to save one's life. A third fallout from the turn to early detection is that mammography became a tool for the widespread technological surveillance of women's bodies. The emphasis on mammography has increased over the years, with a trend toward recommending that younger women begin routine screening, and at more frequent intervals, than previously recommended. It is perhaps not surprising that mammography has risen to central prominence in the fight against breast cancer. As stated previously, critics of early detection allege that it takes attention away from the failure of treatment protocols to control cancer. It has been seven years since Bailar and Gornick (1997) announced that the 'war on cancer' had been lost, despite the billions of dollars spent on medical care and research to treat or prevent cancer.

#### Disrupting dominant bio-medical knowledge

Women are positioned at an uneasy juncture in relation to breast cancer. On the one hand they have been taught to take responsibility to screen their breasts regularly. On the other hand, the care of any abnormal findings found through BSE, and in particular if breast cancer is diagnosed, is under the control of the physician. The management of self is therefore negotiated through the complex web of Medicine.

Women and Medicine have shared a peculiar and ambivalent relationship. While Medicine has appropriated many normal life experiences such as menstruation, pregnancy and menopause as requiring the care of a physician, they have, on the other hand, complained that women seek their care unnecessarily for minor complaints (Chrisler, 2001). Malterud (1999) asserts that the trivialization of women's health concerns by Medicine is unavoidable as medical

theory and practice have been constructed by men, within their clinical gaze, and within the context of their lives.

In addition to this uneasy alliance between women and Medicine, there are a number of contradictory messages that women are hearing in relation to BSE including:

1. Early detection is key to survival but BSE is not effective.
2. BSE is not effective but do practice 'breast awareness'.
3. BSE is not effective but report any breast changes to your physician without delay.
4. BSE is not effective but most women find their own breast cancer.

Besides being confusing and disempowering to women, these contradictory messages point to a conflict between positivist 'objective' knowledge disseminated by science and dominant in biomedicine, and experiential knowledge held by women. Women know that most breast cancers are found by women themselves, and most women, when asked, would most likely feel they are the best person to find any change in their breast. In the case of BSE, the knowledge held by women about their bodies and the value of BSE practice is subjugated by the empirical evidence provided by epidemiological studies that failed to detect a mortality reduction.

The term 'breast awareness', coined by the U.K. Department of Health in 1991, is a confusing concept (English, 2003). Their Advisory Committee for Breast Cancer concluded that the ritualistic nature of breast self examination creates anxiety in women who worry about not doing it properly (referencing only one study conducted over 20 years ago). In its place, they recommend that women practice breast awareness, which instructs women to 'look and feel' for any changes from their normal breast tissue and report any suspected abnormalities to their

physician 'without delay'. It is difficult to understand how women would know how to detect changes in their breast with such vague instructions. Combined with the admonishment to contact their physician without delay, women may become more, not less, dependent on medical care.

Not all forms of knowledge are considered equal and what is accepted as credible reflects social relations of power. As stated by Fosket (2000), "a crucial aspect of the multiplicity of knowledges about breast cancer is the unequal distribution of credibility and legitimacy afforded to knowledge derived from different sources". In this case, the power wielded by biomedicine and the scientific community dominates health care ideology and takes precedence over the knowledge created and shared by women. Medicine has enjoyed the privilege of being perceived as an unbiased, objective science. But the practice of Medicine is still much of an art form. Daily decisions have to be made for which there are no clear answers; assumptions and biases consciously and subconsciously affect these decisions.

The experiential knowledge shared by women disrupts the dominant biomedical knowledge that is largely accepted as 'truth'. It challenges Medicine to consider an alternative approach to the examination of BSE effectiveness. When Baxter's review of BSE for the Canadian Task Force on Preventive Health Care was released in 2001, there was a chorus of outrage from women who were described in newspapers around the country as feeling betrayed, indignant, patronized, incredulous, and angry. Women could not believe they were being advised to rely almost solely on mammography for the early detection of breast cancer (as clinical breast examination is not well taught or practiced). They challenged Baxter's assertion that it caused unnecessary medical work up and anxiety for women, asking if the same would be said about testicular cancer. Whether or not women practiced BSE, they recognized it as a legitimate

component of a holistic approach to breast cancer detection. BSE, long promoted to women, was now being dismissed as useless because of the review of a small number of trials that attempted to measure its effectiveness.

In order to understand what BSE means to women, it is necessary to first examine personal and social factors influencing their practice of BSE.

BSE and women: Addressing the aim of this study

Through a cycle of collective self-reflective inquiry on their everyday experiences, the women were able to identify and examine personal and social factors related to their practice of BSE. Through this active engagement, they explored the meaning of BSE for them and recommendations for its promotion to women.

Personal factors influencing BSE practice

The women were very enthusiastic in their endorsement of the need for self-care, stressing in particular the importance of a positive attitude. However, they also were keenly aware that despite their desire to take control of their health status, there were a lot of challenges to them doing that. The women identified four personal factors influencing their practice of BSE: (a) not having clear answers, (b) not having control, (c) not trusting health care, and (d) ambivalence about seeking medical care.

Not having clear answers

The women were aware they had a lack of clarity about breast cancer. They spoke about a copious amount of conflicting information they are hearing from family, friends, the media, and health care providers. Without prompting, they discussed not knowing how to do BSE, what

a normal breast feels like, when to seek a medical opinion, the risk factors for breast cancer, and the usefulness of mammography.

#### Not having control

The women knew that despite their desire to take control of their health, there were many risk factors for breast cancer beyond their control, such as their gender, family history, cell biology, and the physical and social environment in which they live. Interestingly, the women also identified fate or destiny as an important factor in determining their health status.

#### Not trusting health care

Despite the wide variety of health care professionals that play an important role in the delivery of health services, the women singled out the role of the physician as pivotal in the quality of care they received. In particular, they were concerned about cursory examinations, errors in care, and poor or insensitive communication by their physicians. They also recognized the inequities in the health care system in that the care received could be dependent on ‘who you know’.

#### Ambivalence about seeking medical care

The women experienced contradictory feelings about seeking medical care. They discussed their need for medical reassurance, to be told that ‘everything was alright’ by their physician, despite their doubts about the quality of care received and their feeling of being patronized when medical care was sought for legitimate health concerns. In addition, they stated they ‘panicked’ when they sought a medical opinion for a lump or other change in their breast, while at the same time describing cancer as a lethal disease requiring prompt medical attention to increase the chance of survival. The women repeated this ambivalence over the course of the

group meetings: feeling dependent on medical reassurance, even though the care was sometimes perceived as poor, and feeling somewhat ridiculous about seeking care ('I panicked') even though cancer was equated with death.

### Social factors influencing BSE practice

The women explored social factors influencing their practice of BSE. Through the course of their discussions, they came to realize that 'BSE is a complex issue touching on something inner and unidentified', perhaps related to the way women are valued in society. They commented many times on the way women are defined by their physical bodies, and how this serves to oppress them by being related to both sexuality and shame. The sexualization of women is the overriding social issue affecting their health in relation to BSE. The women identified four social factors influencing their practice of BSE: (a) the ideal female body, (b) hiding the messy body, (c) not valued in society, and (d) not valuing ourselves.

### The ideal female body

In our society, the ideal female body conforms to the physical standards of sexual attractiveness. Paradoxically, the standard for female beauty is currently the woman who is thin to the point of being androgynous, but has well-defined breasts. Women strive to achieve this largely unattainable goal by chronically dieting or engaging in exercise regimes because they are 'terrified to gain weight'. The relatively new 'size zero' and its common depiction in the media is an excellent example of the current social obsession with female weight. While the whole female body has been objectified as a symbol of sexuality, no part of the anatomy has been as targeted as the breast, which has been glorified as *the* representation of female sexuality. As long as breasts are seen as sexual objects, they are welcomed and glorified in the media and society in

general. With very little censure, breasts are freely displayed and accentuated in the media. However, the breast that has been disfigured by disease or trauma is not considered appropriate for public display. As remarked by the women, the billboard displaying a mastectomy scar was too stark a contrast to the sexual female body commonly promoted as it 'remove[d] women from that fantasy world that objectifies women'. It is too much reality to portray. This connects with the growing literature on body image, which describes the social imperative of women to display a narrowly defined (slender) body shape, and its relation to subjectivity and health (Bordo, 1993, 1997; Gimlin, 2002; Grosz, 1994). Lastly, BSE is related to autoeroticism, still a taboo subject in our society. It is ironic that despite the almost totalising sexual representation of women, sexual self-stimulation is still wholly prohibited. It is such a closed concept that very few academic articles on BSE have even mentioned the association.

### Hiding the messy body

While the female body is glorified and valued for its sexuality, the purpose of that sexuality, reproduction, is not. So while breasts can be displayed quite freely for sexual enjoyment in the Western world, the breastfeeding breast cannot. Until very recently when health care professionals started promoting breastfeeding again, women were discouraged from breastfeeding at all and it was almost prohibited in public. Even today, it is rare to see a woman freely breastfeed, even within her own home. Somehow the breastfeeding breast is shameful, perhaps because it is removed from the sexual sphere.

Menstruation is considered shameful as well. As the women aptly described, menstruation is considered 'secret, bad, dirty, abnormal'. It is to be kept hidden at all costs and sanitary products are to be carried about and disposed of in secret. When sanitary products are promoted in media ads, blood is not portrayed (in stark contrast to violent blood readily seen on

television); it is replaced by a sterile blue liquid that is supposedly less offensive. In addition, recent ads have men in white spotless clothes or in the shower promoting the product, with the obvious association that using these products will make you feel like a (clean) man.

Breastfeeding and menstruation, both undeniable physical reminders of the reproductive female body, are not welcomed as public currency. As with the representation of breast cancer by the mastectomy scar, the reproductive female body contradicts the dominant discourse of women as sexual objects.

#### Not valued in society

Perhaps because women are primarily valued for their physical sexual characteristics, they are not treated as full members of society. In the public sphere, they feel patronized, ignored or constrained within narrow social roles such as that of sexual object or mother. They hold far less social power in roles traditionally occupied by men. Women still do not have wage parity, or an equitable distribution of leadership positions in the private or public sector. The women described being overlooked or trivialized within their workplace, within commercial businesses, and as previously stated, within their relationships with their physicians. The message to women has been clear – they are not expected to, and not welcome to, enjoy full social power as is accorded automatically to men on the basis of their gender.

#### Not valuing ourselves

The women discussed their reticence to take care of themselves. While a common excuse put forward by women is that they 'don't have time', through the course of these discussions they began to question if this was in fact used as a convenient and benign excuse for what is a more complex and profound issue. They wondered if the real issue, perhaps hitherto

subconscious, was that they did not feel worthy of self-care. They described their reaction to the ubiquitous representation of the female body as young, slender, and attractive (two-breasted is taken for granted); not able to attain this 'ideal' or maintain it with advancing age, they feel less than worthy, inferior, and not meriting self-care. The women dismissed the usual pat reasons put forward for not examining their breasts, such as denial, using other forms of screening, fear, and lack of time. They rejected these as too simplistic and felt the 'essential' question was whether women felt they were good enough if they did not conform to the narrow standards of the ideal female body.

#### The meaning of BSE to women

BSE is situated at the juncture of three interrelated phenomena: being a woman, having cancer, and interacting with the health care system. In order to adequately explore the meaning of BSE for women, it is necessary to examine these phenomena in greater depth. A seminal article by Lupton (1994a) provides a useful framework for this examination. Ten years ago, she undertook a review of the dominant discourses of breast cancer present in the Australian press from 1987-1990. While there were conflicting messages about breast cancer in the press coverage, three dominant discourses were evident: femininity; medical and technological dominance; and lifestyle and responsibility for breast cancer. These discourses are still relevant today in relation to BSE and can increase our understanding of the meaning of BSE to women. For the women in this study, they are intertwined with their perception of cancer as a lethal disease.

## Dominant discourses related to BSE

### Femininity

In Lupton's review of the media (1994a), she found repeated references to the reproductive role of women as protective against breast cancer. Women who chose to have children late, because of their career or other reasons, were described as 'failing' to have children early enough. This reinforced the traditional social role of women as childbearers by describing breast cancer as "retribution for the rejection of motherhood and the traditional feminine role" (p. 86).

In this study, women are oppressed by the messages they receive in relation to breast cancer, but in a different way. In addition to the obvious threat of death posed by breast cancer, women are threatened as well by the loss of their femininity if diagnosed with this disease. Because the concept of being a woman is tightly intertwined with her physical sexual characteristics, any workup or treatment for breast cancer is an immediate threat to her being able to sustain (or even attain in the future) the ideal female body. If, as the women in this study queried, the self-esteem of women is largely dependent on having this ideal, or the potential for it, then breast cancer takes on a complex meaning for women that would not be easy for them to articulate. BSE, as a self-surveillance screening tool and completely under the control of every woman, also takes on a larger meaning – as a potential direct threat to her self-concept and self-worth. The decision-making process related to BSE then becomes more profound and would not be fully described or measured in any quantitative study of knowledge, attitudes or beliefs associated with BSE. The link between BSE and the potential loss of femininity may provide some insight into the gap that currently exists between women's cognition and practice related to

BSE. Women who are making the decision about BSE have to negotiate their understandings about their femininity and self-worth in the context of cancer as a lethal disease.

### Medical and technological dominance

Lupton (1994a) found that messages related to breast cancer often emphasized the importance of medical and technological approaches. Strengthened by military metaphors, aggressive and sometimes harmful treatments and diagnostic approaches were favoured. She found breast cancer was portrayed as a “killer disease” (p. 79), an enemy that needed to be stopped. Medical technologies were put forward as the weapons needed to control the risk. In addition to medical treatment, screening mammography was publicized “at the expense of other, less invasive ways of dealing with breast cancer” (p. 79), such as BSE. She found little discussion of the limitations or controversies surrounding screening mammography. Within this discourse as well, women were brave fighters who combined their personal courage with medical expertise and technology to triumph over this disease.

Medical and technological dominance is also evident in this study. Most particularly in the inconsistent utilization of evidence related to screening. As discussed in the literature review, poorly executed studies of BSE (U.K and WHO/Russia trials) are often quoted to provide evidence against it, usually without any consideration of the quality of the evidence. In addition, well-done observational studies, such as the nested case-control study in the U.K. trial, are not included (Baxter, 2001). In contrast, well-executed studies that have raised important questions about the usefulness of mammography (the Canadian National Breast Screening Study, 1 and 2) have been excluded from some analysis, while poorly executed studies that support mammography (such as the HIP study) have been included.

A recent meta-analysis of mammography screening trials carried out by Olsen and Grotzsche (2001), seriously questioned the effectiveness of screening mammography. However, recommendations for breast cancer screening do not appear to be affected by these findings. Younger and younger women are being encouraged to begin breast screening, at more frequent intervals than previously recommended. Annual mammography screening for women in their forties is now recommended by many leading health organizations, most notably American. As previously stated, there have been no screening trials testing the effectiveness of clinical breast examination. This leaves mammography as the screening tool of choice.

Medical and technological dominance is evident in criticisms of BSE. Baxter (2001) reported that BSE results in a string of ‘unnecessary’ outcomes such as visits to the physician, biopsies, anxiety, and the cost associated with teaching it. In contrast, the false positive rate associated with screening mammography is not commonly mentioned in the academic or lay literature. False positive mammography screens would certainly result in diagnostic workup such as physician consultation, biopsies and surgery, costs to the health care system, and anxiety for women. Perhaps the harshest criticism of screening mammography is that it results in the over diagnosis of DCIS, which may or may not develop into true cancer, but is often treated as such with various treatment regimens such as surgery (including lumpectomy and mastectomy) and radiotherapy (Humphrey et al., 2002). As well, the costs associated with mammography far outweigh those related to BSE, but are also not commonly commented upon. These costs are related to training experts for years to provide and interpret the x-rays, as well as the capital costs associated with equipment purchase and maintenance. And while there have been no adequate studies on anxiety in relation to BSE (Humphrey et al., 2002), the anxiety associated with mammography screening has been well documented (Humphrey et al, 2002; Lampic, Thurffjell,

& Sjoden, 2003; National Cancer Institute, 2003). Based on her review of the evidence related to BSE, Baxter recommended that health professionals caution women who choose to do BSE that it may cause harm. In contrast, a similar warning has not been recommended in relation to screening mammography, even though it carries the additional risk of radiation exposure. In fact, the radiation risks of screening mammography are usually not emphasized or are justified in the context of the lethal threat of breast cancer.

The women in this study developed an awareness of the preference for technological surveillance over self-care for the early detection of breast cancer. They were critical of the conflicting recommendations of various provinces and organizations related to screening mammography and questioned whether the remuneration models of physicians were responsible for the discrepancies noted. They also described the preference for screening mammography over BSE as a symptom of a 'boys with toys' phenomenon, essentially that of a masculine approach to medical care. The women were aware of increasing reliance on science and technology for health care, most notably in their discussions about the modern tendency to expect to live disease-free longer with its assistance. Even so, Diane described her realization that technology was favoured at the expense of self-care as 'chilling'.

The women were also aware of the war metaphors associated with breast cancer, describing it as a 'lurking invader'. In addition, by equating cancer with death, the perception of breast cancer as an enemy to be fought at all costs was validated.

The medical and technological dominance described by Lupton (1994a) is still relevant today, perhaps more so. By the continued use of the war metaphor for cancer, increasing technological and scientific approaches are validated, leading to a growing dependence of women on medical care to control their risk for breast cancer. Within this paradigm, high-tech

expert-driven approaches are favoured over self-care. BSE rests firmly within a divide between women and Medicine for the control of personal health care. Women considering whether or not to examine their breasts must acknowledge and negotiate their relationships with their physician, the health care system and their perception of cancer as lethal.

### Lifestyle and responsibility for breast cancer

The third discourse identified by Lupton (1994a) in relation to breast cancer was individual responsibility for health. She noted that women were often told they could prevent breast cancer if they made the necessary lifestyle choices such as those related to diet, exercise and even sexual activity. This approach placed the blame for getting breast cancer “squarely upon women in an often disparaging and patronizing way” (p. 83). In emphasizing the role women play in preventing the occurrence of disease, controversial issues such as the success of treatment and screening, and conflicting information about the disease, were obscured. As well, there was little exploration of the valid reasons women gave for not participating in screening activities, implying that women who did not were “irresponsible and neglectful” (p. 85).

In this study, individual responsibility for health is the third and final piece of a complex puzzle that attempts to explain the meaning of BSE for women. The women recognised the importance of individual responsibility for finding breast cancer early and for fighting breast cancer well, once diagnosed. They were aware of the myriad of choices that had to be made to reduce their risk, including those related to lifestyle and screening manoeuvres. And despite their collective belief in the value of self-care, they were reluctant to accept this responsibility. This is perhaps related to the copious amount of contradictory information in the popular media about breast cancer. While it is difficult for health care professionals to know and integrate the latest information related to breast cancer, this becomes almost impossible for the average woman, no

matter how motivated. The reluctance expressed by the women in the group could also have been related to the popular valorisation of women with breast cancer as 'brave fighters' and 'warriors' who 'won their battle', despite the tremendous toll of the disease and its treatment. The women expressed doubt that they would have the vast physical and emotional resources seemingly essential for survival. They clearly felt the individual responsibility associated with breast cancer but also knew that despite all the exhortations to 'find breast cancer early' and 'fight the battle', there were many factors beyond their control that could more profoundly influence their mortality, such as risks in the physical environment and their own genetic makeup.

In this context, BSE carries a risk of personal culpability in relation to surviving breast cancer. Given the persistent discourse of individual responsibility, the woman who does not survive breast cancer either did not find it early enough ('failed to find it') or did not have the necessary personal resources to beat the enemy. Either way, the woman somehow failed herself, her loved ones, and perhaps even her physician and treatment regimen. The women in this group avoided doing BSE because they could not then be held responsible for not finding it early enough, and they would not have to feel any guilt if they were not to survive it. Women who are making the decision whether or not to do BSE are negotiating through a web of meanings associated with individual responsibility for a disease that they know is both not well understood and lethal.

#### Integrating dominant discourses related to BSE

BSE is a complex phenomenon situated within the juncture of cancer, the health care system, and being a woman. The three dominant discourses related to breast cancer introduced by Lupton (1994a) ten years ago are still relevant today in relation to BSE. BSE is intimately related to a woman's sense of self: her expression of femininity and self-worth. To the extent that

breast cancer is seen as a threat to her self-worth, she will be reluctant to do it. BSE also illuminates the relationship of women to the health care system. BSE can be seen by women as a gateway to escalating dependency on their physician and the health care system within the context of ever-increasing technological and medical approaches to care. To the extent that a woman is ambivalent about her relationship with her physician and medical technology, BSE may be seen as a threat to her ability to care for herself. Finally, BSE also emphasizes the role of the individual to accept responsibility for the risks associated with breast cancer. Within this climate of personal culpability, a woman who does not survive breast cancer has failed. To the extent that the diagnosis and treatment of breast cancer is not well understood, BSE brings to the foreground the uncertainties of the disease, and the reluctance of women to be held accountable for its disease trajectory.

The concept maps created by the women reflect these social influences on their health and the practice of BSE. The overriding context of Group A's concept map was 'responsibility: BSE for finding it / diagnosed to fight the battle', reflecting their recognition of individual responsibility for surviving breast cancer. The overriding context of Group B's concept map was 'woman' reflecting the central role of gender in the performance of BSE. Issues related to the health care system are threaded throughout both concept maps and reflected in such temporal map components as 'mistrust in the health / medical care system', 'denial of death: scientific breakthroughs / increased technology', among others. All of this was playing out over the backdrop of cancer as a lethal disease as reflected in such temporal map components as 'cancer = death, pain, loss' and 'once diagnosed – never free: Lurking, invader in the body'.

A reflection on the women's recommendations for the promotion of BSE

While all the women who participated in this study admitted they did not do BSE on a

regular basis, they believed that it was an important self-care technique and felt that all women should do it regularly. The challenges they identified were consistent with the framework utilized in this interpretation. They recognised that reluctance to perform BSE was related to the sexual and shameful body. They also knew that there were a lot of gaps in their understanding of how to do BSE, perhaps related to conflicting messages in the media and the recent promotion of 'breast awareness' as an alternative to BSE. The women also expressed fear as a challenge to doing BSE, highlighting their perception of breast cancer as a lethal disease. Finally, the women stated that BSE was work, perhaps reflecting the individual responsibility they feel related to its performance. Their three recommendations for BSE promotion were related to social changes that would need to occur before the practice of BSE by women would increase. The first was recognizing the importance of educating young women early about their bodies so that BSE is incorporated into the health curriculum, perhaps combined with classes on menstruation. Related to the first, the women recommended that BSE be presented as a normal part of self-care and 'normal breast maintenance'. In this way, BSE would be less associated with disease, the health care system, and death. Finally, the women recommended that moral attitudes which equate the female body with sexuality would have to change so that BSE is not considered shameful. This would require time and broad attitudinal change across generations. It is evident in the women's recommendations for BSE promotion that they had a sophisticated understanding of the complexity of personal and social factors related to its practice and the meaning of BSE to them.

#### Final reflections on the research process

##### The women's validation of the research

The women validated the research in two main ways. The first was by reflecting on and

providing feedback on the procedure and analysis as it unfolded, including the creation of the temporal map components and two concept maps. The second was through their feedback on the research findings following the extended thematic analysis by the external researcher. Three and a half years after data collection ended, the women were invited to a presentation of research findings (one woman had since moved out of province). Eight women attended. Before, during and after the presentation, the women talked about the same issues they had discussed years previously. At times, some of the expressions and examples they used were the same or similar to those previously verbalized. This validated the data collected as the issues previously recognized by the women as important remained so, even after the passage of time. The women also expressed agreement with the interpretation of findings as presented, both verbally and through their non-verbal cues. Please see Appendix 11 for a written summary of this meeting, and the women's reactions, as noted by an outside recorder.

### Change in the women

It is evident the women changed as a result of being actively engaged in this research process. Their raised consciousness was demonstrated in many ways, as described in Chapter 8. The women expressed an increased sensitivity to social messages related to BSE, breast cancer, and women. In addition, they expressed a greater awareness of the oppression of women by the media and social institutions, and less tolerance to accept these social practices. This was demonstrated by their rejection of dominant discourses of women in our society. Their recommendations related to BSE promotion, in particular their dismissal of superficial reasons for women's non-practice of BSE, demonstrated an understanding of its inherent complexity. Finally, the women were aware of and verbalized a change in themselves as a result of participating in this research study.

## The research method

### A reflection on the research method

Looking back over the research process, it was a far greater undertaking than I had ever anticipated. The complexity of the research design and analysis only became fully known when I attempted to formally describe and document them. But having now finished, I would not change any aspect of the approach taken. I feel that the participatory research design, and working in partnership with the women over time, was the most appropriate approach to address the broad issues associated with BSE practice. The concept mapping exercise led to a deeper understanding of the phenomenon than may have been achieved through a researcher-driven analysis of data obtained from a one-time-only contact with individuals. It was gratifying to see the women attend the meetings, so enthusiastic about discussing this topic, and having a meaningful voice in the examination of issues.

The theoretical framework was one of the most challenging pieces to consolidate within this study. The choice of an experiential feminist approach, within a standpoint framework, was difficult to fully integrate at first but proved to be the unifying factor for all other aspects of the research design. Analysis as well proved to be difficult. There were many false starts, with initial attempts at constant comparative technique and then narrative analysis, before thematic analysis was successfully utilized. Once these methodological pieces were sorted out, it was clear how a feminist experiential approach could inform participatory action research with two groups of women who were engaged in group discussions in a consciousness-raising process around issues pertinent to BSE.

Most importantly, completing the interpretation of the research results has been the most exciting and affirming part of the research study. The bewilderment and frustration I felt at the breast screening program has now been replaced by a beginning understanding of the complexity of social issues that are influencing the promotion and practise of BSE. And while the literature was consulted to assist in the extended thematic analysis (after the concept maps were completed), it did not drive the organization and presentation of research results. That the research results fit so well with Lupton's three dominant discourses was a very late stage discovery (less than one week prior to completing the first draft of this chapter). Perhaps because of this, it was even more exciting to see the pieces of the puzzle come together in a meaningful and coherent way. As a result of this research process, I have more knowledge of the vast literature pertaining to breast screening, and the many theoretical and methodological approaches that can be utilized to address this and many other health issues. It has been an empowering experience for me as well as the other research participants.

No one study can adequately explore all dimensions of a phenomenon and areas for future research have been highlighted as a result of the findings of this research study. One is the need to more fully explore and understand the relationship between women's practice of breast self examination and their body image. It was apparent in these focus groups that the 'ideal' female body, imposed through social discursive practices, was an issue of concern to these women but this could not be adequately explored in this study. The current literature supports the relationship between the construction of women's subjectivities through social discourse (including that of biology and Medicine), and the desire of women to display largely unattainable standards of beauty (Bordo, 1993, 1997; Gimlin, 2002; Grosz, 1994). Similarly, there is a need to more fully explore the relationship between dominant social discourses, such as those of

Medicine, their relationship with individual responsibility for health status, and the maintenance of existing power relations in society. This issue has been taken up by Turner (1996), Beausoleil and Rail (2003), among others, and deserves further attention.

### Challenges encountered during the research process

#### Challenges in data collection

Learning how to do participatory research with a group of co-researchers required reflection and intuition. One of the first challenges was becoming comfortable with my role in the group so that I could appropriately facilitate discussion with these women, especially with regard to knowing how much to say and share with the women. Emergent questions included: Was my role more of 'leader' or group member? Should I actively participate and share my opinions and experiences as any other team member? Should I try to direct the discussions according to the proposed questions?

While I felt a member of each group with valid experiences to share, I was concerned that my knowledge of the academic literature related to BSE might bias the discussion. It was important that the women did not perceive me as an expert and defer to my opinion. This in fact did not happen, as these women were not easily influenced. I sometimes found my commentary disruptive to the group dynamics, as if they were happy to discuss the issues without the input of 'the researcher'. I tried to strike a balance between group facilitator (main role) and group participant (secondary role). I shared information from time to time, and specifically when asked. This was done mostly to clarify a factual point, rather than an attempt to change a woman's attitude. To this end, I perhaps did not participate as much as other women, in order for them to have a lead role in the research process and the issues discussed.

With regard to directing the discussion, few questions or other means of facilitating the discussion were necessary as the women needed little or no prompting to openly discuss issues related to BSE. As my comfort level with the research process grew over time, I learned to allow the women to introduce any topic they felt relevant and to interject with a probing or clarifying question only sporadically. As for re-directing the women when they went 'off-topic', it soon became obvious that some of the most interesting discussion occurred when the women were left to follow a course of conversation that at first seemed only marginally related to the research question. This was especially the case when larger issues related to their social context were explored. This approach allowed for a very relaxed environment with much lively, spontaneous, and fun discussion.

Another major challenge in the data collection phase was technology. My original transcriptionist suggested I use a four-track legal audio recorder. This included several individual microphones and would provide great clarity of the recorded discussion, particularly important as group members often talked at the same time. In addition with feeling nervous because of my unfamiliarity with this technology, a problem occurred during the first meeting of Group B. The tapes recorded the conversation at the wrong speed, which then had to be taken to a technical specialist to slow down. This resulted in the voices becoming slightly slurred and at a deeper tone than normal. At the same time, my transcriptionist felt she could not continue. This meant the recordings had to be transferred to another tape, as only a legal recorder (to which there was no longer access) could replay the original recordings. Once the recordings were transferred (a micro cassette was recommended), some of the clarity was lost. However, hours of listening to the tapes and poring over the transcripts have resulted in a good representation of the first two

group discussions. The lesson in this frustrating experience was that all technical equipment should be pre-tested and wholly familiar to any researcher, before data collection begins.

### Challenges in data transcription

Creating an accurate transcription of a group discussion is a time-consuming and difficult task. In addition to the poorer sound quality of the first audiotapes, it was sometimes difficult to hear what the women were saying, and to know who was speaking, as they often spoke simultaneously. The transcription process was a far more time and labor-intensive experience than I had anticipated.

### Challenges in data analysis

The first attempt to identify change in the women over time was achieved through using the constant comparative technique. In doing so, discrete categories, ‘super-categories’ and later, codes and themes, were created by using the *Ethnograph* software program for qualitative data analysis. After three and a half months of committed coding, all analysis to date was lost when my hard drive collapsed. Not having a complete backup of all data analysis (although this was attempted a few times), I was left without any coding to consider my next steps. Interestingly, this was the same time that I was investigating narrative analysis as an alternative approach to analysis. This incident was instructive in that it taught me the importance of having everything backed up all the time, and that perhaps it really was time for a change in approach.

### Potential biases

There is a potential bias associated with self-selection. The women who volunteered for this research were generally university or college educated and employed in a professional capacity. It is not known if the women’s educational and professional status greatly influenced

the data produced and if the same personal and social factors would be relevant to women with lower socio-economic status.

Another characteristic of this participant group that may have impacted on the results is that, while most of the women had a family member or close friend with breast cancer, none of the women themselves had been diagnosed with the disease. The experiences of women with breast cancer could be expected to be different to those without, but how this would change the meanings held by them concerning BSE remains unknown.

The geographic location of the Crafters' Guild meant that all of the women lived in and around the capital area of the province. It is not known whether women living in rural areas would differ from this participant group in ways that are significant to the research problem.

As previously mentioned, three women who initially volunteered to participate in this research had dropped out by the time of the first meeting with each group. The small amount of demographic information collected at the time of recruitment did not indicate any appreciable difference in the women who did not continue versus those who did, although significant differences might have existed that influenced this decision and may have impacted on the research outcome.

Finally, my assumptions, beliefs and life experiences could have introduced bias into the research process. This was minimized during data collection by my informal approach and the group dynamic. While I had general activities planned for each meeting, the group members themselves greatly directed the course of the meeting. They often discussed areas of interest to them without being prompted by me, sometimes in areas that had not been anticipated, indicating their collective leadership in the research process. I tended to participate less than other women during the discussions to allow them the opportunity to discover and explore issues in ways that

were most meaningful to them. As previously discussed, I also used memoing, journaling, and reflection throughout the process to increase researcher reflexivity. This ongoing reflection allowed me to explore my reactions to the group process, the issues discussed, and my own commentary during the discussions. Where I felt my personal biases emerging in the discussion, an effort was made to limit any leading commentary. A small preface at the beginning of this report provides some transparency about who I am and the experiences that have brought me to this research problem.

### Concluding comments

BSE is a complex issue that is not well understood. This study actively engaged women over time in a process of collective self-reflective inquiry. The women were considered co-researchers and helped in the framing and analysis of the research problem. An experiential feminist research approach that valued women's everyday experiences grounded the interpretation of data in the realities and complexities of their lives. Reflection on the personal factors influencing their practice of BSE led the women to examine larger social factors influencing that practice. This resulted in a greater understanding of the meaning of BSE to women.

Experiential knowledge held by women in relation to the factors influencing their health is a valid source of information that can be utilized with other, more empirical forms of knowledge to increase our understanding of BSE and other health issues. The current preoccupation with positivist data as the only true measure of BSE effectiveness has done a disservice to women's health in that it has taken power away from women to decide for themselves. While most women do not practice BSE on a regular basis, the women in this study clearly wanted the right to make their own choice in this respect and felt patronized by being told

to not bother doing it anymore. It is important to listen to the voice of women. Future research into BSE and other health issues should be done collaboratively with women so that they are really heard as they discover and explore the important factors influencing their health. We should not let this important experiential knowledge be subjugated by increasing medical and technological dominance.

Based on the current evidence, health professionals should encourage women to examine their breasts as a prudent approach to self care. However, any promotion of BSE to women must ultimately empower them to make their own decision in this regard. In order to do this, women must be given access to all relevant information so they can be informed in doing so. This may be accompanied by an objective interpretation by a health professional so that the morass of conflicting information is not overwhelming to them. In addition, it is important to be alert to disempowering discourses promoted through the ideology of self-responsibility and technological and scientific superiority so that women are not made to feel responsible for their prognosis or guilty about their choices, particularly if they did not choose to screen regularly.

Women have the right to care for their bodies in the way they determine to be appropriate. It is condescending to tell women not to bother doing BSE because the scientific evidence does not support it. Women know better.

## References

- Albert, U.S., & Schultz, K.D. (2003). Clinical breast examination: What can be recommended for its use to detect breast cancer in countries with limited resources? *The Breast Journal*, 9 (Suppl. 2), S90-93.
- Alcoe, S.Y., & McDermott, R.S.R. (1979). Is there a case for teaching breast self examination? *Canadian Journal of Public Health*, 70, 418-422.
- Alcoe, S.Y., Wallace, D.G., & Beck, B.M. (1990). Ten years later: An update of the case for teaching breast self-examination. *Canadian Journal of Public Health*, 81, 447-449.
- Alexander, F.E., Anderson, T.J., Brown, H.K., Forrest, A.P., Hepburn, W., Kirkpatrick, A.E., et al. (1999). 14 years of follow-up from the Edinburgh randomised trial of breast-cancer screening. *Lancet*, 353(9168), 1903-1908.
- Anderson, B.O., Braun, S., Carlson, R.W., Gralow, J.R., Lagios, M.D., Lehman, C. et al. (2003). Consensus statements: Overview of breast health care guidelines for countries with limited resources. *The Breast Journal*, 9(Suppl 2), S42-50.
- Andersson, I., & Janzon, L. (1997). Reduced breast cancer mortality in women under age 50: Updated results from the Malmo Mammographic Screening Program. *Journal of Cancer Institute Monographs*, 22, 63-67.
- Aronson, K. (2003). Alcohol: A recently identified risk factor for breast cancer. *Canadian Medical Association Journal*, 168(9), 1147-1148.
- Ashton, L., Karnilowicz, W., & Fooks, D. (2001). The incidence of beliefs structures associated with breast self-examination. *Social Behaviour and Personality*, 29(3), 223-229.
- Austoker, J. (2003). Breast self examination. *British Medical Journal*, 326(7379), 1-2.
- Auvinen, A., Elovainio, L., Hakama, M. (1996). Breast self examination and survival from breast cancer: A prospective follow-up study. *Breast Cancer Research and Treatment*, 38, 161-168.
- Bailar, J.C., & Gornick, H.L. (1997). Cancer Undefeated. *New England Journal of Medicine*, 336, 1569-1574.
- Baker, L.H. (1982). Breast cancer detection demonstration project: 5-year summary report. *Cancer-A Cancer Journal for Clinicians*, 32(4), 194-225.
- Band, P.R., Le, N.D., Fang, R., Deschamps, M. (2002). Carcinogenic and endocrine disrupting effects of cigarette smoke and risk of breast cancer. *Lancet*, 360(9339), 1044-1049.

- Bandura, A. (1977). *Social Learning Theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Barbour, R.S., & Kitzinger, J. (1999). *Developing focus group research: Politics, theory and practice*. London: Thousand Oaks.
- Basche, C.E. (1987). Focus group interview: An underutilized research technique for improving theory and practice in health education. *Health Quarterly*, 14, 411-418.
- Batt, S. (1994). *Patient no more: The politics of breast cancer*. Charlottetownm PEI: gynergy books.
- Baxter, N. (2001). Preventive health care, 2001: Should women be routinely taught breast self-examination to screen for breast cancer? (with the Canadian Task Force on Preventive Health Care). *Canadian Medical Association Journal*, 164(3), 1837-1846.
- Beck, L., Trombetta, W., & Share, S. (1986). Using focus group sessions before decisions are made. *North Carolina Medical Journal*, 47(2), 73-74.
- Begg, C.B. (2002). On the Use of Familial Aggregation in Population-Based Case Probands for Calculating Penetrance. *Journal of the National Cancer Institute*, 94(16), 1221-1226.
- Bener, A., Honein, G., Carter, A.O., Da'ar, Z., Miller, C., & Dunn, E.V. (2002). The determinants of breast cancer screening behaviour: A focus group study of women in the United Arab Emirates. *Oncology Nursing Forum*, 29(9), E91-98.
- Bennett, B.B., Steinbach, B.G., Hardt, N.S., Haigh, L.S. (2001). *Breast disease for clinicians*. New York, NY: McGraw-Hill Medical Publishing Division.
- Beral, V. and the Million Women Study Collaborators. (2003). Breast cancer and hormone-replacement therapy in the Million Women Study. *The Lancet*, 362(9382), 419-427.
- Berg, B.L. (2001). *Qualitative research methods for the social sciences*. Boston, MA: Allyn and Bacon.
- Bjurstam, N., Bjorneld, L., Duffy, S.W., Smith, T.C., Cahlin, E., Erikson, O., et al. (1997). The Gothenburg breast Screening trial: first results on mortality, incidence and mofe of detection form women ages 39-49 years at randomization. *Cancer*, 80(11), 2091-2099.
- Blais, J. (2002). Breast self-examination: Is it really so dangerous? *Canadian Family Physician*, 48, 1038-1039.
- Blamey, R.W., Locker, A.P., Mitchell, A.K., & Caseldine, J. (1988). The Nottingham breast self-examination project. *Acta Oncologica*, 28, 1-3.
- Bordo, S. (1997). *Twilight zones*. Berkeley, CA: University of California Press.

- Bordo, S. (1993). *Unbearable weight*. Berkeley, CA: University of California Press.
- Brody, H. (1992). Philosophic approaches. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research*, pp. 174-180. Research Methods for Primary Care, Volume 3. Newbury Park: Sage.
- Bush, J. (2000). It's just part of being a woman: Cervical screening, the body and femininity. *Social Science and Medicine*, 50, 429-444.
- Butcher, H.K., Holkup, P.A., Park, M., & Maas, M. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Research in Nursing and Health*, 24(6), 470-480.
- Campbell, R., & Wasco, S.M. (2000). Feminist approaches to social science: Epistemological and methodological tenets. *American Journal of Community Psychology*, 28(6), 773-791.
- Canadian Cancer Society. (1996). *Breast health edu-kit*. Ontario Division Breast Health Program. Toronto: Author.
- Canadian Cancer Society. (2003). *Seven steps to health*. Retrieved June 3, 2003 from [http://www.cancer.ca/ccs/internet/standard/0,3182,3172\\_12959\\_\\_langId-en,00.html](http://www.cancer.ca/ccs/internet/standard/0,3182,3172_12959__langId-en,00.html)
- Canadian strategy for cancer control*. (January, 2002). Ottawa, ON: Secretariat Office for the Canadian Strategy for Cancer Control.
- Canales, M., & Wilkinson, L. (2002). Taking charge of self: Breast health practices of older rural women. *Journal of Women and Aging*, 14(3-4), 165-188.
- Champion, V.L. (1993). Instrument refinement for breast cancer screening behaviours. *Nursing Research*, 42(3), 138-143.
- Charlier, C., Albert, A., Herman, P., Hamoir, E., Gaspard, U., Meurisse, M. et al. (2003). Breast cancer and serum organochlorine residues. *Occupational and Environmental Medicine*, 60(5), 348-51.
- Chart, P.L., & Franssen, E. (1997). Management of women at increased risk for breast cancer: Preliminary results from a new program. *Canadian Medical Association Journal*, 157 (6), 1235-1242.
- Cheek, J., Lacy, J., Toth-Fejel, S., Morris, K., Calhoun, K., & Pommier, R.F. (2002). The impact of hormone replacement therapy on the detection and stage of breast cancer. *Archives of Surgery*, 137(9), 1015-1021.
- Chenitz, W.C., & Swanson, J.M. (1986). *From practice to grounded theory: Qualitative research in nursing*. Menlo Park, CA: Addison-Wesley.

- Chiarelli, A., & Whittingham, E. (1998). *Contribution of clinical breast examination to the Ontario Breast Screening Program, 1990-1996*. Unpublished manuscript.
- Chlebowski, R.T., Hendrix, S.L., Langer, R.D., Stefanick, M.L., Gass, M., Lane, D., et al. (2003). Influence of estrogen plus progestin on breast cancer and mammography in health postmenopausal women. *JAMA*, *289*(24), 3243-3253.
- Cho, E., Spiegelman, D., Hunter, D.J., Chen, W.Y., Stampfer, M.J., Colditz, G.A., & Willett, W.C. (2003). Premenopausal fat intake and risk of breast cancer. *Journal of the National Cancer Institute*, *95*(14), 1079-1085.
- Chong, P.N., Krishnan, M., Hong, C.Y., & Swah, T.S. (2002). Knowledge and practice of breast cancer screening amongst public health nurses in Singapore. *Singapore Medical Journal*, *43*(10), 509-516.
- Chrisler, J.C. (2001). Gendered bodies and physical health. In R.K. Unger (Ed.), *Handbook of the psychology of women and gender* (pp. 289-302). New York, NY: John Wiley & Sons, Inc.
- Chu, K.C., Lamar, C.A., & Freeman, H.P. (2003). Racial disparities in breast carcinoma survival rates. *Cancer*, *97*(11), 2853-2860.
- Cohen, M. (2002). First-degree relatives of breast-cancer patients: Cognitive perceptions, coping and adherence to breast self-examination. *Behavioural Medicine*, *28*(1), 15-22.
- Collaborative Group on Hormonal Factors in Breast Cancer. (2002). Breast cancer and breastfeeding: Collaborative reanalysis of individual data from 47 epidemiological studies in 30 countries, including 50,302 women with breast cancer and 96,973 women without the disease. *Lancet*, *360*(9328), 187-195.
- Crabtree, B.F., & Miller, W.L. (1992). A template approach to text analysis: Developing and using codebooks. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research* (p. 93-109). Newbury Park, CA: Sage Publications.
- Crawford, M., & Unger, R. (2004). *Women and gender: A feminist psychology* (4th ed.). Boston, MA: McGraw Hill.
- Curtis, S., Bryce, H., & Treloar, C. (1999). Changing the paradigm for health psychology researchers. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 202-217). London: Sage Publications.
- Dixon, J.M. (Ed.). (1995). *ABC of Breast Diseases*. London: BMJ Publishing Group.
- Dowle, C.S., Mitchell, A., Elston, C.W., Roebuck, E.J., Hinton, C.P., Holliday, H., & Blamey, R.W. (1987). Preliminary results of the Nottingham breast self-examination education programme. *British Journal of Surgery*, *74*, 217-219.

- Dunne, E.A., & Quayle, E. (2001). The impact of iatrogenically acquired Hepatitis C infection of the well-being and relationships of a group of Irish women. *Journal of Health Psychology, 6*(6), 679-692.
- Eastman, P. (1996). Task force issues new screening guidelines. *Journal of the National Cancer Institute, 88*, 74-76.
- Egbert, N., & Parrott, R. (2001). Self-efficacy and rural women's performance of breast and cervical cancer detection practices. *Journal of Health Communication, 6*(3), 219-233.
- Ehrenreich, B. & English, D. (1978). *For her own good: 150 years of the experts' advice to women* Garden City, NY: Anchor Books.
- Ellman, R., Moss, S.M., Coleman, D., & Chamberlain, J. (1993). Breast self examination programmes in the trial of early detection of breast cancer: Ten year findings. *British Journal of Cancer, 68*, 208-212.
- Elmore, J.G., Barton, M.B., Mocerri, V.M., Polk, S., Arena, P.J., & Fletcher, S.W. (1998). Ten-year risk of false positive screening mammograms and clinical breast examination. *New England Journal of Medicine, 338*(16), 1089-96.
- Engel, J. (1996). *The Complete Breast Book*. Toronto, ON: Canadian Medical Association.
- English, J. (2003). Importance of breast awareness in identification of breast cancer. *Nursing Times, 99*(40).
- Epstein, R.J. (2003). Breast self examination provides entry strategy. *British Medical Journal, 326*(7391), 710.
- Facione, N.C. (1999). Breast cancer screening in relation to access to health services. *Oncology Nursing Forum, 26*(4), 689-696.
- Fern, E.F. (1982). The use of focus groups for idea generation: The effects of group size acquaintanceship, and moderator on response quantity and quality. *Journal of Marketing Research, 19*, 13.
- Findlay, D. (1993). The good, the normal and the healthy: The social construction of medical knowledge about women. *Canadian Journal of Sociology, 18* (2), 115-135.
- Fine, M. (Ed.). (1992). *Disruptive voices: The possibilities of feminist research*. Ann Arbor: University of Michigan Press.
- Fish, J., & Wilkinson, S. (2003). Understanding lesbians' healthcare behaviour: The case of breast self-examination. *Social Science and Medicine, 56*(2), 235-245.

- Fisher, S., & Davis, K. (Eds.). (1993). *Negotiating at the margins: The gendered discourses of power and resistance*. New Brunswick, NJ: Rutgers University Press.
- Flick, U. (1992). *An introduction to qualitative research (2<sup>nd</sup> ed.)*. London: Sage.
- Fosket, J. (2000). Problematizing biomedicine: Women's construction of breast cancer knowledge. In L.K. Potts (Ed.), *Ideologies of breast cancer: Feminist perspectives* (pp. 15-36). New York, NY: St. Martin's Press, Inc.
- Foster, R.S. Jr., & Costanza, M.C. (1984). Breast self examination practices and breast cancer survival. *Cancer*, 53, 999-1005.
- Foucault, M. (1973). *The birth of the clinic: An archeology of medical perception*. New York: Pantheon Books.
- Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings*. New York, NY: Pantheon Books.
- Frank, J.W., & Mai, V. (1985). BSE in young women: More harm than good? *Lancet*, 2, 654-657.
- Frank, E., Rimer, B.K., Brogan, D., & Elon, L. (2000). U.S. women physicians' personal and clinical breast cancer screening practices. *Journal of Women's Health and Gender-based Medicine*, 9(7), 791-801.
- Freire, P. (1970/1993). *Pedagogy of the oppressed*. New York, NY: Continuum.
- Frissel, J., Lidbrink, E., Hellstrom, L., & Rutqvist, L.E. (1997). Followup after 11 years – update of mortality results in the Stockholm mammographic screening trial. *Breast Cancer Research and Treatment*, 45(3), 263-270.
- Fuller, D. (1999). Figuratively speaking. In S. Torres (Ed.), *That body image thing: Young women speak out* (pp. 31-33). Ottawa: CRIAW/ICREF.
- Gasalberti, D. (2002). Early detection of breast cancer by self-examination: The influence of perceived barriers and health conception. *Oncology Nursing Forum*, 29(9), 1341-1347.
- Gastrin, G. (1987). Self examination in the early detection of breast cancer: Is it effective? *Recent Results in Cancer Research*, 105, 106-110.
- Geertz, C. (1983). Thick description: Toward an interpretive theory of culture. In R.M. Emerson (Ed.), *Contemporary field research: A collection of readings* (pp. 37-59). Toronto, ON: Little, Brown.
- Gimlin, D.L. (2002). *Body work: Beauty and self-image in American culture*. Berkeley, CA: University of California Press.

- Goodman, S.N. (2002). The mammography dilemma: A crisis for evidence-based medicine. *Annals of Internal Medicine*, 137(5, part 1), 363-365.
- Gottlieb, S., (2002). Tamoxifen may increase risk of uterine sarcoma. *British Medical Journal*, 325(7354), 7.
- Graham, M.E. (2002). Health beliefs and self breast examination in black women. *Journal of Cultural Diversity*, 9(2), 49-54.
- Greenberger, N.J., & Hinthorn, D.R. (1993). *History taking and physical examination*. St. Louis, MO: Mosby Yearbook.
- Greenwood, D.J., & Levin, M. (1998). *Introduction to action research: Social research for social change*. Thousand Oaks, CA: Sage Publications.
- Grosz, E. (1994). *Volatile bodies: Toward a corporeal feminism*. Bloomington: Indiana University Press.
- Grunfeld, E.A., Ramirez, A.J., Hunter, M.S., & Richards, M.A. (2002). Women's knowledge and beliefs regarding breast cancer. *British Journal of Cancer*, 86(9), 1373-1378.
- Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage Publications.
- Haagensen, C.D. (1956). *Diseases of the breast*. Philadelphia, PA: W.B. Saunders.
- Haji-Mahmoodi, M., Montazeri, A., Jarvandi, S., Ebrahim, M., & Haghghat, S. (2002). *The Breast Journal*, 8(4), 222-225.
- Hankshaw, A.K., & Paul, E.A. (2003). Breast self-examination and death from breast cancer: A meta-analysis. *British Journal of Cancer*, 88(7), 1047-1053.
- Harding, S. (1983). Why has the sex-gender system become visible only now? In S. Harding and M. Hintikka (Eds.), *Discovering reality: Feminist perspectives on epistemology, metaphysics, methodology, and the philosophy of science* (p. 311-324). Dordrecht: Reidel.
- Harding, S. (1991). *Whose science? Whose knowledge? Thinking from women's lives*. Ithaca, NY: Cornell University Press.
- Harding, S. (1997). Comment on Hekman's "Truth and Method: Feminist Standpoint theory revisited": Whose standpoint needs the regimes of truth and reality. *Signs*, 22(2), 387-391.

- Hardy, C., Palmer, I., & Phillips, N. (2000). Discourse as a strategic resource. *Human Resource*, 53(9), 1227-1248.
- Harris, R., & Kinsinger, L.S. (2002). Routinely teaching breast self-examination is dead. What does this mean? *Journal of the National Cancer Institute*, 94 (19), 1420-1421.
- Hartsock, N. (1983). The feminist standpoint: Developing the ground for a specifically feminist historical materialism. In S. Harding and M. Hintikka (Eds.), *Discovering reality: Feminist perspectives on epistemology, metaphysics, methodology, and the philosophy of science* (p. 283-310). Dordrecht: Reidel.
- Hartsock, N.C.M. (1997). Comment on Hekman's "Truth and Method: Feminist Standpoint theory revisited": Truth or Justice. *Signs*, 22(2), 367-374.
- Harvey, B.J., Miller, A.B., Baines, C.J., & Corey, P.N. (1997). Effect of breast self-examination techniques on the risk of death from breast cancer. *Canadian Medical Association Journal*, 157 (9), 1205-1212.
- Hekman, S. (1997). Truth and method: Feminist standpoint theory revisited. *Signs*, 22(2), 341-365.
- Helewa, M., Levesque, P., & Provencher, D. (2002). SOGC Clinical Practice Guidelines: Breast cancer, pregnancy and breastfeeding. *Journal of Obstetrics and Gynaecology Canada*, 111, 1-8.
- Henderson, D.J. (1997). Consciousness-raising as a feminist nursing action: Promise and practice, present and future. In S.E. Thorne & V.E. Hayes (Eds.), *Nursing praxis: Knowledge and action* (pp. 157-179). Thousand Oaks, CA: Sage Publications.
- Hiatt, R.A., Pasick, R.J., Stewart, S., Bloom, J., Davis, P., Gardiner, P., et al. (2001). Community-based cancer screening for underserved women: Design and baseline findings from the Breast and Cervical Cancer Interventions Study. *Preventive Medicine: An International Journal devoted to Practice and Theory*, 33(3), 190-203.
- Hill Collins, P. (1997). Comment on Hekman's "Truth and method: Feminist standpoint theory revisited". *Signs*, 22(2), 175-381.
- Hill, D., White, V., Jolley, D., & Mapperson, K. (1988). Self-examination of the breast: Is it beneficial? Meta-analysis of studies investigating breast self examination and extent of disease in patients with breast cancer. *British Medical Journal*, 297, 271-275.
- Hislop, T.G., Worth, A.J., Kan, L., & Rousseau, E. (1997). Post screen-detected breast cancer within the Screening Mammography Program of British Columbia. *Breast Cancer Research and Treatment*, 42, 235-242.

- Holmberg, L., Ekblom, A., Calle, E., Mokdad, A., & Byers, T. (1997). Breast cancer mortality in relation to self-reported use of breast self-examination: A cohort study of 450,000 women. *Breast Cancer Research and Treatment*, 43, 137-140.
- Holmes, M.D., Colditz, G.A., Hunter, D.J., Hankinson, S.E., Rosner, B., Speizer, F.E., et al. (2003). Meat, fish and egg intake and risk of breast cancer. *International Journal of Cancer*, 104(2), 221-227.
- Huguley, C.M., Brown, R.L., Greenberg, R.S., & Clark, W.S. (1988). Breast self-examination and survival from breast cancer. *Cancer*, 62, 1389-1396.
- Humphrey, L.L., Helfand, M., Chan, B.K.S., & Woolf, S.H. (2002). Breast cancer screening: A summary of the evidence for the U.S. Preventive Services Task Force. *Annals of Internal Medicine*, 137 (5, Part 1), 347-360.
- IBIS Investigators and Cuzick, J. (2002). First results from the international breast cancer intervention study (IBIS-1): A randomized prevention trial. *Lancet*, 360(9336), 817-824.
- Janda, M., Obermair, A., Haidinger, G., Waldhoer, T., & Vutuc, C. (2000). Austrian women's attitudes toward and knowledge of breast self-examination. *Journal of Cancer Education*, 15(2), 91-94.
- Janda, M., Stanek, C., Newman, B., Obermair, A., & Trimmel, M. (2002). Impact of videotaped information on frequency and confidence of breast self-examination. *Breast Cancer Research and Treatment*, 73(1), 37-43.
- Jarvandi, S., Montazeri, A., Harirchi, I., & Kazemnejad, A. (2002). Beliefs and behaviours of Iranian teachers toward early detection of breast cancer and breast self-examination. *Public Health* 116(4), 245-249.
- Jatoi, I. (2003). Screening clinical breast examination. *Surgical Clinics of North America*, 83(4), 789-801.
- Jirojwong, S. & Manderson, L. (2001). Beliefs and behaviours about Pap and breast self-examination among Thai women in Brisbane, Australia. *Women and Health*, 33(3-4), 47-66.
- Johnson, A. (1996). 'It's good to talk': The focus group and the sociological imagination. *Sociological Review*, 44(3), 517-538.
- Judge, R.D., Zurdema, G.D., & Fitzgerald, F.T. (1989). *Clinical diagnosis* (5<sup>th</sup> ed.). Boston, MA: Little-Brown.
- Katapodi, M.C., Facione, N.C., Miaskowski, C., Dodd, M.J., & Waters, C. (2002). The influence of social support on breast cancer screening in a multicultural community sample. *Oncology Nursing Forum* 29(5), 845-52.

- Kaufert, P. A. (1998). Women, resistance and the breast cancer movement. In P.A. Kaufert (Ed.), *Pragmatic women and body politics* (pp. 287-309). Cambridge, UK: Cambridge University Press.
- Kegeles, S.S. (1985). Education for breast self-examination: Why, who, what and how? *Preventative Medicine, 14*, 702-720.
- Keller, E.F. (1985). *Reflections on gender and science*. London: Yale University Press.
- Kemmis, S., & McTaggart, R. (1988). *The action research planner (3<sup>rd</sup> ed.)*. Victoria, Australia: Deakin University Press.
- Kline, K.N. (1999). Reading and reforming breast self-examination discourse: Claiming missed opportunities for empowerment. *Journal of Health Communication, 4*, 119-141.
- Koibuchi, Y., Iino, Y., Takei, H., Maemura, M., Horiguchi, J., Yokoe, T., et al. (1998). The effect of mass screening by physical examination combined with regular breast self-examination results in the earlier detection and better clinical course of Japanese women with breast cancer. *Oncol Rep, 5*, 151-155.
- Kosters, J.P., & Gotzsche, P.C. (2003). Regular self-examination or clinical examination for early detection of breast cancer. *The Cochrane Library* (CD003373).
- Kurebayashi, J., Shimosuma, K., Sonoo, H. (1994). The practice of breast self-examination results in the earlier detection and better clinical course of Japanese women with breast cancer. *Japanese Journal of Surgery, 24*, 337-341.
- Kuroishi, T., Tominaga, S., Ota, J., Horino, T., Taguchi, T., Ishida, T., et al. (1992). The effect of breast self-examination on early detection and survival. *Japan Journal of Cancer Research, 83*, 344-350.
- Lampic, C., Thurfjell, E., & Sjoden, P.O. (2003). The influence of a false-positive mammogram on a women's subsequent behaviour for detecting breast cancer. *European Journal of Cancer, 39*(12), 1730-1737.
- Larsson, L.G., Andersson, I., Bjurstam, N., Fagerberg, G., Frissell, J., Tabar, L., et al. (1997). Updated overview of the Swedish Randomized Trials on Breast Cancer Screening with Mammography: Age group 40-49 at randomization. *Journal of the National Cancer Institute Monographs, 22*, 57-61.
- Lather, P. (1988). Feminist perspectives on empowering research methodologies. *Women's Studies International Forum (11)*, 569-581.
- Lauver, D.R., Kane, J., Bodden J., McNeel, J., & Smith, L. (1999). Engagement in breast cancer screening behaviours. *Oncology Nursing Forum, 26*(3), 545-554.

- Lee, I. (2003). Physical activity in women: How much is enough? *Journal of the American Medical Association*, 290(10), 1377-1379.
- LeGeyte, M., Mant, D., Vessey, M.P., Jones, L., Yudkin, P. (1992). Breast self-examination and survival from breast cancer. *British Journal of Cancer*, 66, 917-918.
- Leight, S.B., Deiriggi, P., Hursh, D., Miller, D., & Leight, V. (2000). The effect of structured training on breast self-examination search behaviours as measured using bio-medical instrumentation. *Nursing Research*, 49(5), 283-289.
- Leopold, E. (1999). *A darker ribbon: Breast cancer, women, and their doctors in the twentieth century*. Boston, MA: Beacon Press.
- Lerner, B.H. (2002). When statistics provide unsatisfying answers: Revisiting the breast self-examination controversy. *Canadian Medical Association Journal*, 166(2), 199-201.
- Lewin, K. (1948). *Resolving social conflicts: Selected papers on group dynamics*. New York, NY: Harper.
- Li, C.I., Malone, K.E., Porter, P.L., Weiss, N.S., Tang, M.C., Cushing-Haugen, K.L., et al. (2003). Relationship between long duration and different regimens of hormone replacement therapy and risk of breast cancer. *JAMA*, 298(24), 3254-3263.
- Lillberg, K., Verkasalo, P.K., Kaprio, J., Teppo, L., Heleniou, H., & Koskenvuo, M. (2003). Stressful life events and the risk of breast cancer in 10,808 women: A cohort study. *American Journal of Epidemiology*, 157, 415-423.
- Locker, A.P., Caseldine, J., Mitchell, A.K., Blamey, R.W., Roebuck, E.J., & Elston, C.W. (1989). Results from a seven-year programme of breast self-examination in 89,010 women. *British Journal of Cancer*, 60, 401-405.
- Love, S. (2000). *Dr. Susan Love's breast book*. New York, NY: Perseus Publishing.
- Lu, Z.J. (2001). Effectiveness of breast self-examination nursing interventions for Taiwanese community target groups. *Journal of Advanced Nursing*, 34(2), 163-170.
- Ludwick, R., & Gaczkowski, T. (2001). Breast self-exams by teenagers: Outcome of a teaching program. *Cancer Nursing*, 24(4), 315-319.
- Lupton, D. (1994a). Femininity, responsibility, and the technological imperative: Discourses on breast cancer in the Australian press. *International Journal of Health Services*, 2(1), 73-89.
- Lupton, D. (1994b). *Medicine as culture: Illness, disease and the body in Western societies*. London: Sage Publications.

- Lupton, D. (2000). The social construction of medicine and the body, In G.L. Albrecht, R. Fitzpatrick, and S.C. Scrimshaw (Eds.), *Handbook of social studies in health and medicine* (pp. 50-63). London, UK: Sage Publications.
- Lybstug, A. (1997, December). Clinical breast examination in breast screening. In *OBSP Nurses' Continuing Education Days*. Symposium conducted during a meeting of the Ontario Breast Screening Program, Toronto, Canada.
- Lykes, M.B. (1997). Activist participatory research among the Maya of Guatemala: Constructing meanings from situated knowledge. *Journal of Social Issues*, 53(4), 725-746.
- Madriz, E. (2000). Focus groups in feminist research. In N.K. Denzin and Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 835-850). Thousand Oaks, CA: Sage Publications Inc.
- Maguire, P. (2001). Uneven ground: Feminisms and action research. In P. Reason & H. Bradbury, (Eds.), *Handbook of action research: Participative inquiry and practice* (pp. 59-69). London: Sage Publications.
- Maguire, P. (1996). Proposing a more feminist participatory research: Knowing and being embrace openly. In K. de Koning & N. Martin, (Eds.), *Participatory research in health* (pp. 27-39). London: Zed Books.
- Malterud, K. (1999). The (gendered) construction of diagnosis interpretation of medical signs in women patients. *Theoretical Medicine and Bioethics* 20(3), 275-286.
- Mant, D., Vessey, M.P., Neil, A. McPherson, K., & Jones, L. (1987). Breast self-examination and breast cancer stage at diagnosis. *British Journal of Cancer*, 55, 207-211.
- Marchbanks, P.A., McDonald, J.A., Wilson, H.G., Folger, S.G., Mandel, M.G., Daling, J.R., et al. (2002). Oral contraceptives and the risk of breast cancer. *New England Journal of Medicine*, 346(26), 2025-2032.
- Marks, D.F., Murray, M., Evans, B., & Willig, C. (2000). *Health psychology: Theory, research and practice*. London, UK: Sage Publications.
- Martin, E. (1987). *The woman in the body: A cultural analysis of reproduction*. Boston: Beacon Press.
- McCormack, V.A. dos Santos Silva, I. De Stavola, B.L. Mohsen, R., Leon, D.A., & Lithell, H.O. (2003). Fetal growth and subsequent risk of breast cancer: results from long term follow up of Swedish cohort. *British Medical Journal*, 326(7383), 248-250.

- McMichael, C., Kirk, M., Manderson, L., Hoban, E., & Potts, H. (2000). Indigenous women's practice of breast cancer diagnosis and treatment in Queensland. *Australian and New Zealand Journal of Public Health, 24*(5), 515-519.
- McPherson, C.P., Swenson, K.K., Jolitz, G., & Murray, C.L. (1997). Survival of women ages 40-49 with breast carcinoma according to method of detection. *Cancer, 79*, 1923-1932.
- McTeirman, A., Kooperberg, C., White, E., Wilcox, S., Coates, R., Adams-Campbell, L., et al. (2003). Recreational physical activity and the risk of breast cancer in postmenopausal women: The Women's Health Initiative Cohort Study. *Journal of the American Medical Association, 290*(10), 1331-1336.
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Miller, A.B., Baines, C.J., To, T., & Wall, C. (1992). Canadian National Breast Screening Study: Breast cancer detection and death rates among women aged 40-49 years. *Canadian Medical Association Journal, 147*(10), 1459-1476.
- Miller, A.B., Chamberlain, J., Day, N.E., Hakama, M., & Prorok, P.C. (1990). Report on a workshop of the UICC Project on Evaluation of Screening for Cancer. *International Journal of Cancer, 46*, 761-769.
- Miller, A.B., Chamberlain, J., & Tsechkovski, M. (1985). Self-examination in the early detection of breast cancer: A review of the evidence with recommendations for further research. *Journal of Chronic Disease, 38*, 527-540.
- Miller, A.B., To, T., Baines, C.J., & Wall, C. (2000). Canadian National Breast Screening Study-2: 13-year results of a randomized trial in women aged 50-59 years. *Journal of the National Cancer Institute, 92*, 1490-1499.
- Miller, A.B., To, T., Baines, C.J., & Wall, C. (2002). Canadian National Breast Screening Study-1: Breast cancer mortality after 11-16 years of follow-up. A randomized screening trial of mammography in women 40-49 years. *Annals of Internal Medicine, 137*, 305-312.
- Miller, S. (1997). Multiple paradigms for nursing: Postmodern feminisms. In S.E. Thorne & V.E. Hayes (Eds.), *Nursing praxis: Knowledge and action* (pp. 140-156). Thousand Oaks, CA: Sage Publications.
- Mitra, I. (1994). Breast Screening: The case for physical examination without mammography. *The Lancet, 343* (8893), 342-343.
- Morrison, B.J. (1995). Screening for breast cancer. In *The Canadian Guide to Clinical Preventive Health Care* (pp. 789-795). The Canadian Task Force on the Periodic Health Examination. Ottawa, ON: Canada Communication Group.

- Morrison, R.S. (1999). Using focus group methodology in nursing. *The Journal of Continuing Education in Nursing*, 30(2), 62-65.
- Morrison, S. (2002, June 26). Breast cancer assault: MD's tackle the riddle of why. *The Hamilton Spectator*, p. A1, A14.
- Murray, M., & Chamberlain, K. (1999). Health psychology and qualitative research. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: theory and methods* (pp. 3-15). London, UK: Sage Publications.
- Murray, M., & Chamberlain, K. (2000). Qualitative methods and women's health research. In J. Ussher (Ed.), *Women's health: An international reader* (pp. 40-50). Leicester, UK: British Psychological Society.
- Muscat, J.E., & Huncharek, M.S. (1991). Breast self-examination and extent of disease: A population-based study. *Cancer Detection and Prevention*, 15, 155-9.
- National Cancer Institute. (2003, December 23). *Screening for breast cancer*. Retrieved January 12, 2004, from: [www.cancer.gov/cancerinfo/pdq/screening/breast/health\\_professional/](http://www.cancer.gov/cancerinfo/pdq/screening/breast/health_professional/)
- National Cancer Institute of Canada. (2003). *Canadian Cancer Statistics*. Toronto, ON: Author.
- National Cancer Institute of Canada. (2004). *Canadian Cancer Statistics*. Toronto, ON: Author.
- National Institutes of Health. (1997). Consensus Development Statement: Breast Cancer Screening for Women Ages 40-49. January 21-23.
- Newcomb, P.A., Weiss, N.S., Storer, B.E., Scholes, D., Young, B.E., & Voigt, L.F. (1991). Breast self examination in relation to the occurrence of advanced breast cancer. *Journal of the National Cancer Institute*, 83, 260-265.
- Nystrom, L. Andersson, I., Bjurstam, N., Frissel, J., Nordenskjold, B., & Rutqvist, L.E., (2002). Long-term effects of mammography screening: Updated overview of the Swedish randomised trials, *Lancet*, 359, 909-919.
- O'Brien Cousins, S., & Edwards, K. (2002). Alice in menopauseland: The jabberwocky of a medicalized middle age. *Health Care for Women International*, 23, 325-343.
- Odusanya, O.O. (2001). Breast cancer: Knowledge, attitudes, and practices of female schoolteachers in Lagos, Nigeria. *The Breast Journal*, 7(3): 171-175.
- Ogawa, H., Tominaga, S., Yoshida, M., Kubo, K., & Takeuchi, S. (1987). Breast self-examination practice and clinical stage of breast cancer. *Japanese Journal of Cancer Research*, 78, 447-452.

- Olsen, O., & Grotzsche, P.C. (2001). Screening for breast cancer with mammography. *Cochrane Breast Cancer Group: The Cochrane Database of Systematic Reviews* (AN: CD001877).
- Peltzer, K. (2001). Breast self-examination and cervical (Pap) smear test: Attitudes and self-reported practices among South African women. *Psychological Reports*, 89(1), 27-32.
- Petro-Nustus W., & Mikhail, B.I. (2002). Factors associated with breast self-examination among Jordanian women. *Public Health Nursing*, 19(4), 263-271.
- Phillips, J.M., Cohen, M.Z., & Moses, G. (1999). Breast cancer screening and African American women: Fear, fatalism, and silence. *Oncology Nursing Forum*, 26(3), 561-571.
- Picard, A. (2001, June 26). Breast self-examination of no use, doctors declare. *The Globe and Mail*, p. A1, A6.
- Polit, D.F. & Hungler, B.P. (1991), *Nursing research: Principles and methods* (4<sup>th</sup> ed.). Philadelphia, PA: J.B. Lippincott Company.
- Potts, L.K. (2000). Introduction: Why ideologies of breast cancer? Why feminist perspectives? In L.K. Potts (Ed.), *Ideologies of breast cancer: Feminist Perspectives*. New York, NY: St. Martin's Press, Inc.
- Priest, L. (2001, June 27). Breast-exam advice stirs confusion and anger. *The Globe and Mail*, A1, A6.
- Rail, G. & Beausoleil, N. (2003). Introduction to 'Health Panic and Women's Health'. *Atlantis*, 27(2), 1-5.
- Rauscher, M. (2003a). Primary hypothyroidism linked to reduced incidence of breast cancer. Reuters Health Information. Retrieved from Medscape April 24, 2003: <http://www.medscape.com/px/urlinfo>
- Rauscher, M. (2003b). Strong inverse link between breast cancer and NSAID use. Reuters Health Information. Retrieved from Medscape April 24, 2003: <http://www.medscape.com/px/urlinfo>
- Reinharz, S. (1992). *Feminist methods in social research*. New York, NY: Oxform University Press.
- Remennick, L.I. (1999). Breast screening practices among Russian immigrant women in Israel. *Women and Health*, 28(4), 29-51.
- Ritchie, J. E., Herscovitch, F., & Norfor, J.B. (1994). Beliefs of blue collar workers regarding coronary risk behaviors. *Health Education Research*, 9, 95-103.

- Rosenstock, I.M., Strecher, V.J., & Becker, M.H. (1988). Social learning theory and the health belief model, *Health Education Quarterly*, 15, 175-183.
- Rosvold, E.O., Hjartaker, A., Bjertness, E., & Lund, E. (2001). Breast self-examination and cervical cancer testing among Norwegian family physicians: A nation-wide comparative study. *Social Science and Medicine*, 5(2), 249-258.
- Russo, I.H. (2002). Cigarette smoking and the risk of breast cancer in women. *The Lancet*, 360(9339), 1034-1044.
- Sadler, G.R., Dhanjal, S.K., Shah, R.B., Ko, C., Anghel, M., Harshburger, R., et al. (2001). Asian Indian women: Knowledge, attitudes, and behaviours toward breast cancer early detection. *Public Health Nursing*, 18(5), 357-363.
- Saunders, J.C. & Byrne, M.M. (2002). A thematic analysis of families living with schizophrenia. *Archives of Psychiatric Nursing*, 16(5), 217-223.
- Screening Program for Breast Cancer. (August, 1996). *Breast Health*. SK: Saskatchewan Cancer Agency.
- Scully, D. & Bart, P. (1981). A funny thing happened on the way to the orifice: Women in gynecology textbooks (p. 350-355). In P. Conrad and R. Kern (Eds.), *The Sociology of Health and Illness: Critical perspectives*. NY: St. Martin's Press.
- Seidel, H.M., Ball, J.W., Dains, J.E., & Benedict, G.W. (1991). *Mosby's guide to physical examination* (2<sup>nd</sup> ed.). St. Louis, MO: Mosby Yearbook.
- Semiglazov V.F., Moiseenko, V.M., Manikhas, A.G., Protsenko, S.A., Kharikova, R.S., Popova, R.T., et al. (1999). Interim results of a prospective randomized study of self-examination for early detection of breast cancer (Russia/St. Petersburg/WHO). *Voprosy-onkologii*, 45(3), 265-271.
- Semiglazov, V., Moiseyenko, V., Protsenko, C., & Kharikova, R. (1996). Russia (St. Petersburg)/WHO study of the role of BSE in reduction breast cancer mortality (meaning of age). *Voprosy-onkologii*, 42(4), 49-55.
- Semiglazov, V.F., Sagaidak, V.N., Moiseyenko, V.M., & Mikhailov, E.A. (1993). Study of the role of breast self-examination in the reduction of mortality from breast cancer. *European Journal of Cancer*, 29A (14), 2039-2046.
- Senie, R.T., Rosen, P.P., Lesser, M.L., & Kinne, D.W. (1981). Breast self-examination and medical examination related to breast cancer stage. *American Journal of Public Health*, 71, 583-590.
- Shapiro, S. (1997). Periodic screening for breast cancer: The HIP Randomized Controlled Trial. Health Insurance Plan. *Journal of the National Cancer Institutes Monographs*, 27-30.

- Sherwin, S. (2002, May). *Personalizing the political: Negotiating feminist, medical, scientific, and commercial discourses surrounding breast cancer*. Paper presented at the Community Health Speaker Series, Memorial University of Newfoundland, St. John's, Newfoundland and Labrador.
- Shin, M.H., Holmes, M.D., Hankinson, S.E., Wu, K., Colditz, G.A., & Willett, W.C. (2003). Intake of dairy products, calcium, and vitamin D and risk of breast cancer. *Journal of the National Cancer Institute, 94*(17), 1301-1310.
- Siahpush, M., & Singh, G.K. (2002). Sociodemographic variations in breast cancer screening behaviour among Australian women: Results from the 1995 National Health Survey. *Preventive Medicine: An International Journal devoted to Practice and Theory, 35*(2), 174-180.
- Sim, J. (1998). Collecting and analysing qualitative data: Issues raised by the focus group. *Journal of Advanced Nursing, 28* (2), 345-352.
- Smith, D. (1987). *The everyday world as problematic: A feminist sociology*. Boston: Northeastern University Press.
- Smith, D. (1990). *The conceptual practices of power: A feminist sociology of knowledge*. Boston, MA: Northeastern University Press.
- Smith D.E. (1997). Comment on Hekman's "Truth and method: Feminist standpoint theory revisited". *Signs, 22*(2), 392-397.
- Smith, E.M., & Burns, T.L. (1985). The effects of BSE in a population-based cancer registry: A report of differences in extent of disease. *Cancer, 55*, 432-437.
- Smith, E.M., Francis, A.M., & Polissar, L. (1980). The effect of breast self-examination practices and physician examination on extent of disease at diagnosis. *Preventive Medicine, 9*, 409-417.
- Sontag, S. (2002). *Illness as metaphor*. New York, NY: Farrar, Strauss, and Giroux.
- Stephens, T., & Fowler, C.D. (Eds.). (1993). *Canada's Health Promotion Survey 1990: Technical Report*. Ottawa, On: Health and Welfare Canada.
- Stewart, B.W., & Kleihues, P. (Eds.). (2003). *World Cancer Report*. World Health Organization: International Agency for Research on Cancer.
- Strickland, C.J., Feigl, P., Upchurch, C., King, D.K., Pierce, H.I., Grevstad, P.K., et al. (1997). Improving breast self exam compliance: A Southwest Oncology Group randomized trial of three interventions. *Preventive Medicine, 26*(3), 320-332.

- Stringer, E.T. (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA: Sage Publications.
- Tabar, L., Vitak, B., Chen, H.H., Duffy, S.W., Yen, M.F., Chiang, C.F., et al., (2000). The Swedish Two-County Trial twenty years later. Updated mortality results and new insights from long-term follow-up. *Radiologic Clinics of North America*, 38, 625-651.
- Tabar, L., Yen, M.F., Vitak, B., Chen, H.H.T., Smith, R.S., Duffy, S.W. (2003). Mammography service screening and mortality in breast cancer patients: 20-year follow-up before and after introduction of screening. *The Lancet*, 361(9367), 1405-1410.
- Taylor, G., & Jones, A. (2002). Effects of a culturally sensitive breast self-examination intervention. *Outcomes Management for Nursing Practice*, 6(2), 73-78.
- Thomas, D.B., Gao, D.L., Ray, R.M., Wang, W.W, Allison, C.J., Chen, F.L., et al. (2002). Randomized trial of breast self-examination in Shanghai: Final results. *Journal of the National Cancer Institute*, 94(19), 1445-1457.
- Thomas, D.B., Gao, D.L., Self, S.G., Allison, C.J., Tao, Y., Mahloch, J., et al., (1997). Randomized trial of breast self-examination in Shanghai: Methodology and preliminary results. *Journal of the National Cancer Institute*, 89 (5), 355-365.
- Thomas, B., Stamler, L.L., Lafreniere, K.D., & Delahunt, T.D. (2002). Breast health educational interventions: Changes in beliefs and practices of working women. *AAOHN*, 50(10), 460-467.
- Torres, S. (Ed.). (1999). *That body image thing: Young women speak out*. Ottawa: CRIAW/ICREF.
- Tri-Council Policy Statement. (2000, November 21). *Ethical conduct for research involving humans*. Retrieved July 25, 2003 from <http://www.nserc.ca/programs/ethics/english/policy.htm>
- Trotto, P.A. (2002). The effect of message framing and imagination on breast self-examination compliance. *Dissertation Abstracts International*, 62(9-B), 4250.
- Turner, B.S. (1988). *Medical power and social knowledge*. London: Sage.
- Turner, B.S. (1996). *The body and society* (2<sup>nd</sup> ed.). London: Sage.
- UK Trial of Early Detection of Breast Cancer Group. (1993). Breast cancer mortality after 10 years in the UK trial of the early detection of breast cancer. *The Breast*, 2, 13-20.
- UK Trial of Early Detection of Breast Cancer Group. (1999). 16- year mortality from breast cancer in the UK trial of early detection of breast cancer. *Lancet*, 353, 1909-1914.

- Umeh, K., & Rogan-Gibson, J. (2001). Perceptions of threat, benefits, and barriers in breast self-examination amongst young asymptomatic women. *British Journal of Health Psychology*, 6(4), 361-372.
- United States Preventive Services Task Force. (2002). Screening for breast cancer: Recommendations and rationale. *Annals of Internal Medicine*, 137(5 Part 1), 344-346.
- Ussher, J. (1999). Feminist approaches to qualitative health research. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theory and methods* (pp. 98-114). London, UK: Sage Publications.
- Velicer, C.M., Heckbert, S.R., Lampe, J.W., Potter, J.D., Robertson, C.A., & Taplin, S. H. (2004). Antibiotic use in relation to the risk of breast cancer. *JAMA*, 291(7), 827-835.
- Walter, S.D., & Jadad, A.R. (1999). Meta-analysis of screening data: A survey of the literature. *Statistical Medicine*, 18(24), 3409-3424.
- Warner, E. (2002). Breast self- examination [Letter to the editor]. *Canadian Medical Association Journal*, 166(2), 163.
- Weiss, N. S. (2003). Breast cancer mortality in relation to clinical breast examination and breast self-examination. *The Breast Journal*, 9(Suppl 2), S86-89.
- Wilkinson, S. (1998). Focus groups in health research. *Journal of Health Psychology*, 3(3), 329-348.
- Wilkinson, S. (1999). How useful are focus groups in feminist research? In R.S. Barbour and J. Kitzinger, (Eds.), *Developing focus group research: Politics, theory and practice* (pp. 64-78). London, UK: Sage Publications Ltd.
- Wilkinson, S. (2001). Theoretical perspectives on women and gender. In R.K. Unger (Ed.), *Handbook of the psychology of women and gender* (pp. 17-28). New York, NY: John Wiley & Sons, Inc.
- Wilkinson, S. (2003). "Feminist contributions to a critical health psychology" in M. Murray (Ed.), *Critical Health Psychology* (pp. xxxx - in publication). London, UK: Palgrave.
- Williams, T.L., Clarke, V., & Borland, R. (2001). Effects of message framing on breast-cancer-related beliefs and behaviours: The role of mediating factors. *Journal of Applied Social Psychology*, 31(5), 925-950.
- Wood, R.Y., Duffy, M.E., Morris, S.J., & Carnes, J.E. (2002). The effect of an educational intervention on promoting breast self-examination in older African American and Caucasian women. *Oncology Nursing Forum*, 29(7), 1081-1090.

Working Group for the Women's Health Initiative Investigators. (2002). Risks and benefits of estrogen plus progestin in healthy postmenopausal women. *JAMA*, 288(3), 321-333.

World Health Organization. (2003). *Global cancer rates could increase by 50% to 15 million by 2020*. Retrieved June 3, 2003 from <http://www.who.int/mediacentre/releases/2003/pr27/en/>

Yanovski, J.A., Greenhut, S.F., Chandler, D.W., Franklin, F.A., Barton, B.A., Buckman, D.W. et al. (2003). Diet and sex hormones in girls: Findings from a randomized controlled clinical trial. *Journal of the National Cancer Institute*, 95(2), 132-141.

Zyzanski, S.J., McWhinney, I.R., Blake Jr., R., Crabtree, B.F., & Miller, W.L. (1992). Qualitative research: Perspectives on the future. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research*, pp. 231-247. Research Methods for Primary Care, Volume 3. Newbury Park: Sage.

**Appendix 1: Letter to Crafters' Guild**

August 9, 1999

Ms. XXXXXXXXXXXXX  
President  
XXXXXXXXXXXXXXXXXXXX Guild  
XXXXXXXXXXXXXXXXXXXX  
XXXXXXXXXXXX, Newfoundland  
XXXXXXX

Dear Ms. XXXXX:

This is a follow up letter to our telephone conversation on July 9, 1999. I am a Ph.D. student in the Faculty of Medicine at Memorial University of Newfoundland. An important part of this program is the completion of a research project. I am keenly interested in the practice of breast self examination by women and the factors which influence that practice. I would like to seek volunteers for this study from the XXXXXXXXXXXXXXXXXXXX Guild.

I plan to study this health behavior by meeting with four groups of six to eight women over the course of six months to discuss with them what they feel to be important factors influencing the practice of breast self examination by women. In the event that four focus groups are not obtainable from the XXXXXXXXXXXXXXXXXXXX Guild, the researcher will seek volunteers from other sources (i.e., the XXXXX Centre, the XXXXXXXXXXXXXXXXXXXXXXXX Program, undergraduate students at XXXXXXXXXXXX).

Women in these small groups will be asked to reflect upon various issues related to breast self examination including health, cancer and what it means to be a woman. Women will be co-researchers in this project and will be active members of all phases of the process, from framing the problem to analyzing and reporting the results.

As discussed with you by phone, given the consent of your executive, I would like to let your guild members know about this study through a small article in your next newsletter, which I understand will be sent out to your membership within the next month. In addition, I would like to provide a full explanation of this research study at your next general meeting, September 21, and ask for volunteers to come forward or contact me at a later date. All members of your guild will have the choice to participate or decline. For women who choose to be a part of this study, all questions and concerns will be addressed before their full and informed signed consent is obtained.

Data will be collected through focused group discussion. This may take the form of four crafting groups that each meet once a month for six months to craft and explore issues related to breast self examination. The focus groups will be audiotaped. All members of the group will generate questions and issues for discussion and will be an integral part of data analysis and the writing of results. All information collected from women will be held confidential by the researcher and the identity of the participants will not be disclosed at any time. A final report will be forwarded

to all participants at the completion of the study. The research process and results may be presented at professional conferences and meetings, and in the academic literature.

I look forward to working with your guild. I am enclosing a copy of the research proposal. If you would like more information about this study, please do not hesitate to contact me at home (754-6336), at work (737-7194) or by fax (737-3836). Thank you very much for your consideration.

Sincerely,

Anne Kearney BN RN MHSc.

**Appendix 2: Copy of Newsletter Article to Generate Interest from Crafters' Guild**

To all members of the XXXXXXXX Guild:

I would like to take this opportunity to introduce myself. I am a registered nurse who is also a Ph.D. student in Medicine (Community Health) at Memorial University of Newfoundland. A major part of this degree is the completion of a research project. I am keenly interested in issues related to breast cancer and have decided to do my research on the factors influencing women's practice of breast self examination. I have spoken to your President, XXXXXXXXXXXX, and your executive and committee chairs. They have given me permission to speak to the general membership of your guild about this research project at your next meeting in September.

At this meeting, I will explain my research in detail, answer all your questions and concerns, and ask for volunteers to participate in the study. You will have complete control over whether or not you will be involved in this research.

I plan to hold discussion groups with four small groups of women (6-8 women per group). Each group will be asked to meet six times. All women who volunteer will be considered co-researchers and will help determine what will be discussed. All information will be held confidential.

I look forward to sharing more information about this project with you in September.

Sincerely,

Anne Kearney BN RN MHSc.

**Appendix 3: Questionnaire regarding Demographic Data**

**Data Collection Tool for Demographic Data**

Questions related to demographic data are taken from Canada's Health Promotion Survey 1990 (Health and Welfare Canada) and the First Visit Questionnaire given to clients of the XXXXXXXXXXXXXXXXXXXX Program for Newfoundland and Labrador.

1. **What is the month and year of your birth?**  
 Month \_\_\_\_\_ Year \_\_\_\_\_
  
2. **What would you say is the main ethnic group of your ancestors: Check one only.**  
 English \_\_\_ French \_\_\_  
 Irish \_\_\_ Scottish \_\_\_  
 Aboriginal \_\_\_ I don't know \_\_\_  
 Other \_\_\_\_\_
  
3. **What is your last level of education completed. Check one only.**  
 Grade 9 or less \_\_\_  
 Some high school \_\_\_  
 High school diploma \_\_\_  
 Some college/university \_\_\_  
 University degree \_\_\_
  
4. **What is your current work situation?**  
 Homemaker \_\_\_ Retired \_\_\_  
 Employed outside the home \_\_\_ Unemployed \_\_\_  
 Employed in the home \_\_\_ Other \_\_\_\_\_
  
5. **What is or was your main occupation? Check one only.**  
 Farming or fishing or processing \_\_\_ Sales or service \_\_\_  
 Clerical \_\_\_ Skilled labourer or trades person \_\_\_  
 Factory work or manual labour \_\_\_ Management or administration \_\_\_  
 Professional \_\_\_ I have not worked outside the home \_\_\_  
 Other \_\_\_\_\_
  
6. **What is your current marital status?**  
 Single (never married) \_\_\_  
 Married (and not separated) or living common law \_\_\_  
 Separated \_\_\_  
 Divorced \_\_\_  
 Widowed \_\_\_

**Appendix 4: Thank You Note in Crafters' Newsletter after Recruitment**

*A note of thanks!*

*I would like to thank the executive and membership of the  
XXXXXXXXXXXXXXXXX Guild for allowing me some time to speak  
at your meeting on September 21, 1999. I received a lot of  
interest for participation in my research study on breast self  
examination. I am really looking forward to starting these group  
discussions in January. All members are welcome to call me at  
any time if you have any questions, comments or concerns  
regarding my research. I may be reached at work at XXX-XXXX,  
at home at XXX-XXXX or by email at  
XXXXXXXXXXXXXXXXXXXXX.*

Anne Kearney

**Appendix 5: Application for Ethical Review**

**HUMAN INVESTIGATION COMMITTEE – APPLICATION FORM**

**FACULTY OF MEDICINE – MEMORIAL UNIVERSITY OF NEWFOUNDLAND  
AND  
HEALTH CARE CORPORATION OF ST. JOHN'S**

**Forward 20 copies of application and consent forms to:  
Office of Research (HIC), Room 1759, Health Science Centre. (Phone 737-6974)**

**12. Investigators.**

Principal Investigator: <b>Anne Kearney</b>	If a student, indicate program and name of supervisor <b>PhD, Medicine, Dr. Michael Murray</b>
Mailing Address. Telephone Number: <b>6 Charlottetown Place St. John's, Nf A1B 3V6 709-754-6336</b>	Co-Investigators:

**2. Title of study. Include protocol number, if any,  
and ending dates.**

**3. Starting**

<b>Promoting Breast Self Examination (BSE): An Action Research Project</b>	<i>Proposed start date: (at least 4 weeks from date of submission)</i>  January, 2000  <i>Anticipated completion date:</i> August 31, 2001
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**4. Please fill in the appropriate information, if any.**

**Check applicable boxes.**

Hospital or Community Setting <i>Involved</i>	Involves		
	Patients or Residents	Records	Facilities
Not applicable			

**12. In the space provided, list the main objectives of the investigation. No attachments please.**

**Purpose:** To use an action research approach to engage women to critically reflect on their experience of BSE in order to develop appropriate recommendations for practice.

**Objectives:**

1. To engage women in an exploration of the meaning of BSE for them within the context of being a woman, the female body, their health status and the broader cultural system within which they live.
2. To engage women in a cycle of action and collective self-inquiry to determine the broad cultural and personal factors relevant to their practice of BSE.
3. To identify appropriate approaches for the promotion of BSE to women.
4. To describe the impact of BSE practice or non-practice on women's health.

**6. Introduction to study.**

**12. What is the scientific background to the study?**

Action research methodology is appropriate for the purpose of this study because it recognises women as experts of their own lived experience and as valued members of the research inquiry. As a type of qualitative research, it has the potential to provide rich contextual description about women's performance (or non-performance of BSE). Action research involves a recurring cycle of planning, action, observation, and reflection on what has been learned. Members of the group are considered co-researchers and encouraged to seek insights into how their assumptions and practices came to be constructed. In this way, participants in the action research process can pose problems that have never been posed before, rather than focusing on the solution to problems, the framing of which may have been problematic in the first place (Brooks & Watkins, 1994). Through systematic critical examination of commonly held assumptions and practices, the researcher can facilitate change. This proposal employs focus group discussions to gather information because the spontaneous and dynamic discussion between group members increases the likelihood of "gaining deeper insights than might arise with individual structured interviews or questionnaires (Ritchie, Herscovitch, & Norfor, 1994, p.97). Data analysis will be informed by grounded theory, which will help identify important themes as they emerge in the action research process.

**(b) What is the rationale for the study?**

BSE has been the subject of academic debate for 20 years. The results of the three large trials on BSE have once again questioned the effectiveness of BSE. This may cause more health care providers and women to question the value of BSE. Despite the conflicting evidence in the research literature, 70-80% of all breast cancers are found by women themselves (Semiglazov, Sagaidak, Moiseyenko & Mikhailov et al., 1993). This qualitative study will explore with women the meaning of BSE for them, the personal and cultural factors influencing BSE practice, and the most appropriate way to promote this practice to women. It is hoped this in-depth exploration of BSE practice with women will help explain the theoretical gaps between BSE promotion, practice and research.

☞ Summarize any relevant human or animal studies already conducted.

Quantitative studies that support BSE have demonstrated the ability of BSE to find tumours at an early stage (Foster & Costanza, 1985), to reduce the mortality associated with breast cancer (Harvey, 1997), or to find breast tumours not seen on concurrent mammography (Chart & Franssen, 1997). Quantitative studies that have criticized BSE have claimed that BSE increases the anxiety of Women (Frank & Mai, 1985), or leads to the detection of advanced-stage disease (Newcomb et al., 1991). Three large trials carried out to date have not proven BSE can reduce breast cancer mortality (Ellman, Moss, Coleman & Chamberlain, 1993; Semiglazov et al., 1993; Thomas et al., 1997).

There have been four qualitative studies about BSE. These have described the decision making process related to BSE (Salazar & Carter, 1993), compliance with BSE practice (Olson & Morse, 1994), breast health practices among women with a family history of breast cancer (Chalmers & Luker, 1996), and the reasons why women with advanced breast cancer delayed seeking care (Facione & Giancarlo, 1998). A review of the literature did not identify any studies that employed action research as a way to involve women as co-researchers in an exploration of the personal and cultural influences of BSE practice.

## 7. Blood or other tissue sampling.

12. List samples to be taken from participants. State type of sample, frequency and amount

Not applicable

Will any samples be kept after the completion of the study? NA If yes, include section 9 on consent form

## 8. Research interventions.

List any procedures, tests or substances to be administered to participants: e.g. imaging, special diets, drugs (state dose and frequency), isotopic tracers, ECGs etc. List only those that are not part of normal patient management. Not applicable

(b) List questionnaires, interview scripts or chart audit forms to be used: Attach copies of each.

Proposed Questions for Focus Group Discussion (attached). Questions Pertaining to Demographic Data (attached).

## 9. For studies involving patients.

12. What treatment do *you* now use for patients who would meet the inclusion criteria for this study? (i.e. How would you manage these patients if they did not go into this study?) Is this considered "standard treatment"?

(b) Is this an application for a clinical trial? No

If yes, what phase is this trial? NA

What is the design of the trial (e.g. open, double blind, crossover etc.): NA

12. In the space provided, give a brief description of the design of the study, including participant selection, interventions and outcome measurement. (Attach one copy of a protocol if available).

The study will be conducted through action research, grounded theory and focus group methodology. It is hoped that four focus groups will be utilized, each as internally consistent as possible with regard to age and socio-economic status. Women from the XXXXXXXXXXXXXXXXXXXX Guild will be asked to volunteer for these focus groups. If four appropriate focus groups are not obtainable from this guild, the researcher will approach other community agencies such as the XXXXXX Centre and the XXXXXXXXXXXXXXXX Learners' Program. Private interviews (as requested) and participant observation will also provide data. Discussions will be facilitated by the researcher through the proposed discussion guide and through other sources of data such as guest speakers, media representations and personal anecdotes, as decided by the group. Focus group discussions and private interviews will be audiotaped and transcribed verbatim. Data collected through participant observation will be captured in field notes and transcribed. There will be no identifying information on any transcripts. All audiotapes and field notes will be kept in a locked cabinet. Data analysis will be concurrent with data collection and will actively involve the women as co-researchers in the discovery of knowledge. The data analysis will be achieved first by a line-by-line coding of the transcriptions and, following the constant comparative technique, into categories. Emerging categories are shared with the participants who are asked to reflect upon their current practices of BSE through a critical reflection of the cultural and personal influences on that practice. Issues and themes identified at one focus group may be shared with another to allow a comprehensive exploration of the research problem. The outcome of the action research process may be a change in the way BSE is promoted to women.

11. Participants.

Number of participants	Approximately 32	Will pregnant women be excluded?	N
Is this part of a multi-centre study?	N	If Yes, what is the total number of participants at all sites?	NA
How will participants be recruited?			
<p>The researcher has received consent from the executive of the XXXXXXXXXXXXXXXXXXXX Guild to explain the research study to the general membership of the guild during their next general meeting (September 21, 1999). Guild members will be given a full explanation of the study and all questions will be addressed before volunteers are requested. Women who are interested will be given a copy of the consent form and asked to contact the researcher if they wish to proceed. A short questionnaire will collect demographic information on all interested women and will help determine focus group composition. In the event that more women are interested in this study than can be included, the researcher will take their names and phone numbers and contact them if participant attrition occurs.</p>			

12. What is the basis for the choice of sample size? (Consider the total number of participants for multi-centre studies).

A group size of six to eight participants is recommended in the literature for focus group research (Curtis, Bryce, & Treloar, 1999; Wilkinson, 1998). This allows for optimal communication among focus group participants, increasing the likelihood that useful data will be generated. This study will employ four focus groups for a total number of 24-32 women.

13. What risks, discomforts or inconveniences are involved?

(a) risks: Psychological distress related to discussions of breast self examination and breast cancer.

(b) discomforts: Potential for embarrassment of women as they begin to discuss breast self examination .

(c) inconveniences: Potential for inconvenience of participants related to focus group discussion schedule.

14. Benefits.

Are there any immediate benefits for the participants (including controls)?  N Please specify.

Although there are no direct benefits to the women for participating in this study, the opportunity to share their feelings and experiences about BSE may prove to be satisfying for some women because their opinion has been sought and they have been heard.

15. Confidentiality.

(a) What steps will be taken to preserve confidentiality?

In the dissemination of project outcomes, a pseudonym will be used for the XXXXXXXX Guild. The identity of the participants will not be shared between the focus group discussions. All tapes and written material will be kept in a locked cabinet, separate from the consent forms. The data generated will not be used for any other study and any final reports will not identify the participants.

(b) List names of all personnel who can access information that could be linked to individual participants.

Thesis Committee: Dr. Michael Murray (Supervisor) and Dr. Roy West, Faculty of Medicine, MUN  
Dr. Shirley Solberg and Dr. Sandra Lefort , School of Nursing, MUN

16. Consent process.

(a) Who will make the initial contact with the participant? Anne Kearney

(b) Who will obtain the consent of the participant? Anne Kearney

(c) Explain procedure for obtaining consent.

All women will be given a full explanation of the purpose of the research and how data will be collected, stored, analysed and disseminated. All potential participants will be asked to read the *Consent to Participate in Health Research* (attached). Once all questions and concerns have been addressed, women will be asked to provide their free and informed consent by signing the attached consent form. Because all risks in qualitative research cannot be known, a process consent will be employed throughout the study in which women can refuse to answer any question, stop any interview, or withdraw from the study at any time.

17. Vulnerable populations.

Will participants include: Minors (less than 19yrs)?  N or Persons incompetent to give consent?  N

If no, please justify. Outline the measures that will be used to protect their rights (attach separate sheet if required)

\* Usually prohibited by Provincial legislation on Advanced Health Care Directives. (Situation as of November 1997)

18. Debriefing.

Explain the mechanism, if any, for feedback to participants.  
**Action research methodology involves a recurring cycle of planning, action, observation, and reflection on what has been learned. Women will be considered co-researchers and will be an important part of the data analysis and discovery of knowledge. A copy of the final report of the study will be sent to all participants. All women will be informed that the results may be published or presented at academic and professional conferences (without identifying information).**

19. Payments.

(a) Will participants receive: reimbursement for expenses incurred?      N payment for participation in the study?      N	Please specify on separate sheet according to "Guidelines for the Remuneration of Research Subjects."*
(b) Will there be any payment to a third party for referral of patients?      N	Please specify on separate sheet according to "Guidelines for Payment of Finders' Fees."*

\* Available in the HIC office and on HIC web page.

20. Budget

Please enclose a copy of the budget for this study, including source of funding.

Will the budget be administered through the University Finance Office?    Y    If no, where?

Will any investigator receive financial or other benefit by virtue of conducting this study? N. If yes, specify.

21. Ownership of data.

Will data become the exclusive property of a pharmaceutical company or other external agency?    N

If yes, what is the policy of the company regarding publication of the data?

22. Reminders.

We would like to remind you that it is your responsibility to ensure that permission is obtained from clinicians, departments, institutions or communities whose patients / residents will be involved in the study.

We would also like to remind you that you must read A Ethical Conduct for Research Involving Humans @ (available in the HIC Office and on HIC Web Page.)

Signature of principal investigator.	Signature of supervisor, in case of student application.
Date:	

**Appendix 6: Consent Form and Statement**

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF  
NEWFOUNDLAND  
AND  
HEALTH CARE CORPORATION OF ST. JOHN'S

Consent To Participate In Health Research

TITLE: Promoting Breast Self Examination: An Action Research Study

INVESTIGATOR: Anne Kearney

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time.

Information obtained from you or about you during this study, which could identify you, will be kept confidential by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

The purpose of this study is to gather information about the reasons why women do or do not examine their breasts and the potential influences on women within our society that may affect their decisions regarding this. At the present time, research on breast self examination has not provided clear evidence to health care workers that it can save lives. This has led to some confusion among health care workers and women about the value of breast self examination. The information gained from this study may lead to recommendations about how breast self examination should be promoted to women (if at all). It may also raise questions that will need further study.

If you choose to enter this study, you will be asked to take part in a series of discussions with approximately five to seven other women. These discussion groups are called focus groups. In these focus groups, you may be asked to consider questions such as: What is health? What does cancer mean to me? What does breast cancer mean to me? What does being a woman mean to me? What does breast self examination mean to me? What messages do I receive in society about being a woman...about having breasts...about doing breast self examination? Should women be encouraged to examine their breasts? How should breast self examination be promoted to women? You are considered a co-researcher in this study and you will help determine the issues that will be discussed. The focus group discussions may be stimulated by all group members through various means, including guest speakers, news articles, personal anecdotes or advertisements that include women.

You will meet in your focus group about once a month for six months. Each focus group will last about 90 minutes. You may refuse to discuss any issue or leave the focus group at any time. If there are particular issues that you would prefer to share privately, you can request to meet

with me for a separate interview. Some information may also be collected from general discussions that occur before or after the focus group, if it is relevant to the study. As a co-researcher, all information collected and the results of all analysis will be shared with you throughout the study to ensure that, together, we are capturing the information as accurately as possible.

Your name or any identifying information about you will not be made public. There are no risks to you in this study unless you find it difficult to discuss breast cancer or examining your breasts. There may be no direct benefit to you because you are in this study.

You will receive a copy of the final report. General findings from this study may be presented at meetings and conferences or published in health journals.

Your signature indicates your consent and that you have understood the information regarding the research study. In no way does this waive your legal rights nor release the investigator or involved agencies from their legal and professional responsibilities.

Signature Page

Title of Project: Promoting Breast Self Examination: An Action Research Project

Name of Principal Investigator: Anne Kearney, Ph.D. student, Faculty of Medicine, M.U.N.

To be signed by participant

I, \_\_\_\_\_, the undersigned, agree to my participation in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realise that participation is voluntary and that there is no guarantee that I will benefit from my involvement.

I acknowledge that a copy of this form has been given to me.

(Signature of Participant)

(Date)

( Signature of Witness)

(Date)

To be signed by investigator

To the best of my ability I have fully explained the nature of this research study. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

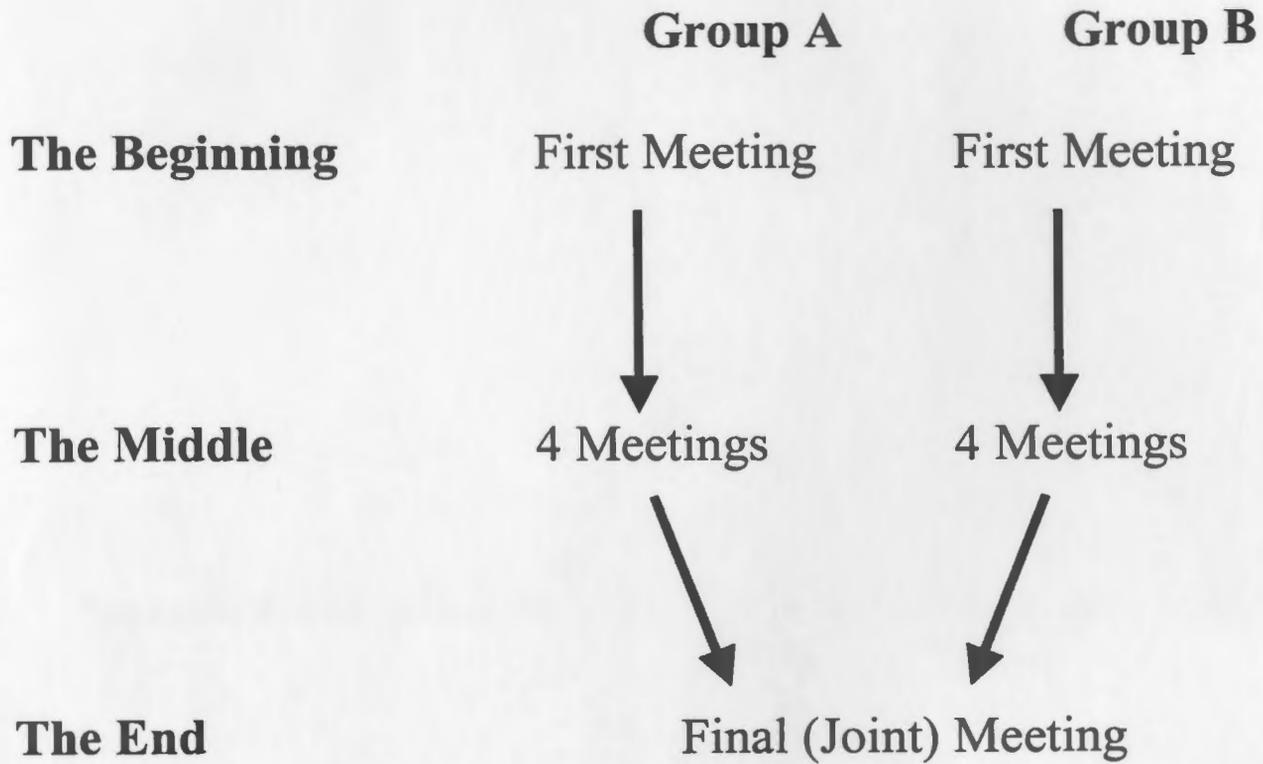
(Signature of Investigator)

(Date)

Phone Number

**Appendix 7: Schematic Representation of the Data Collection Process**

**Figure 1: Process of Data Collection and Analysis**



**Appendix 8: List of Questions Proposed at the Outset of Data Collection**

**List of Questions Proposed at the Outset of Data Collection**

- What do you know about breast self examination (BSE)?
- Where have you received information about BSE?
- Do you examine your breasts? Why? Why not?
- How do you usually feel when you are examining your breasts?
- What do you know about breast cancer?
- Most women do not examine their breasts. Why do you think this is so?
- What does it mean to be a woman?
- What does it mean to have breasts?
- What does it mean to have the potential to get breast cancer?
- What does health mean?

**Appendix 9: Questionnaire regarding Women's Knowledge, Attitudes and Behaviours related to Cancer, Breast Cancer, and BSE**

**Questionnaire regarding women's Knowledge, Attitudes and Behaviours related to Cancer, Breast Cancer, and BSE**

**1. Has a doctor or nurse ever examined your breasts?**

Yes

No

**2. Do you examine your breasts?**

Yes

No

**3. Do you feel you *know how* to examine your breasts correctly?**

Yes

No

**4. How often do you think a woman should examine her breasts?**

Once a month

Once every 2-3 months

Once every 4-6 months

Less often than every 4-6 months

Never

Don't know

**5. How often do you examine your breasts?**

More than once a month

Once a month

Once every 2-3 months

Once every 4-6 months

Less often than every 4-6 months

**6. Have you ever had a mammogram (x-ray of the breast)?**

Yes

No

**7. In general, compared to other people your age, how would you describe your health?**

- Excellent
- Very good
- Good
- Fair
- Poor

**8. How likely do you think it is that you will develop cancer at some point during your lifetime?**

- I will definitely not get cancer
- It is unlikely that I will get cancer
- My chances are 50/50 - I may or may not get cancer
- It is likely that I will get cancer
- I will definitely get cancer

Use the following scale when answering the next question. A response of 1 would indicate “not effective at all” through to 5 “very effective”.

**9. How effective do you think BSE is for the early detection of breast cancer?**

- |                         |                       |         |                       |                   |
|-------------------------|-----------------------|---------|-----------------------|-------------------|
| 1.....                  | 2.....                | 3.....  | 4.....                | 5.....            |
| Not effective<br>at all | Not very<br>effective | Neutral | Somewhat<br>effective | Very<br>effective |

**10. Do you feel that breast cancer is treatable?**

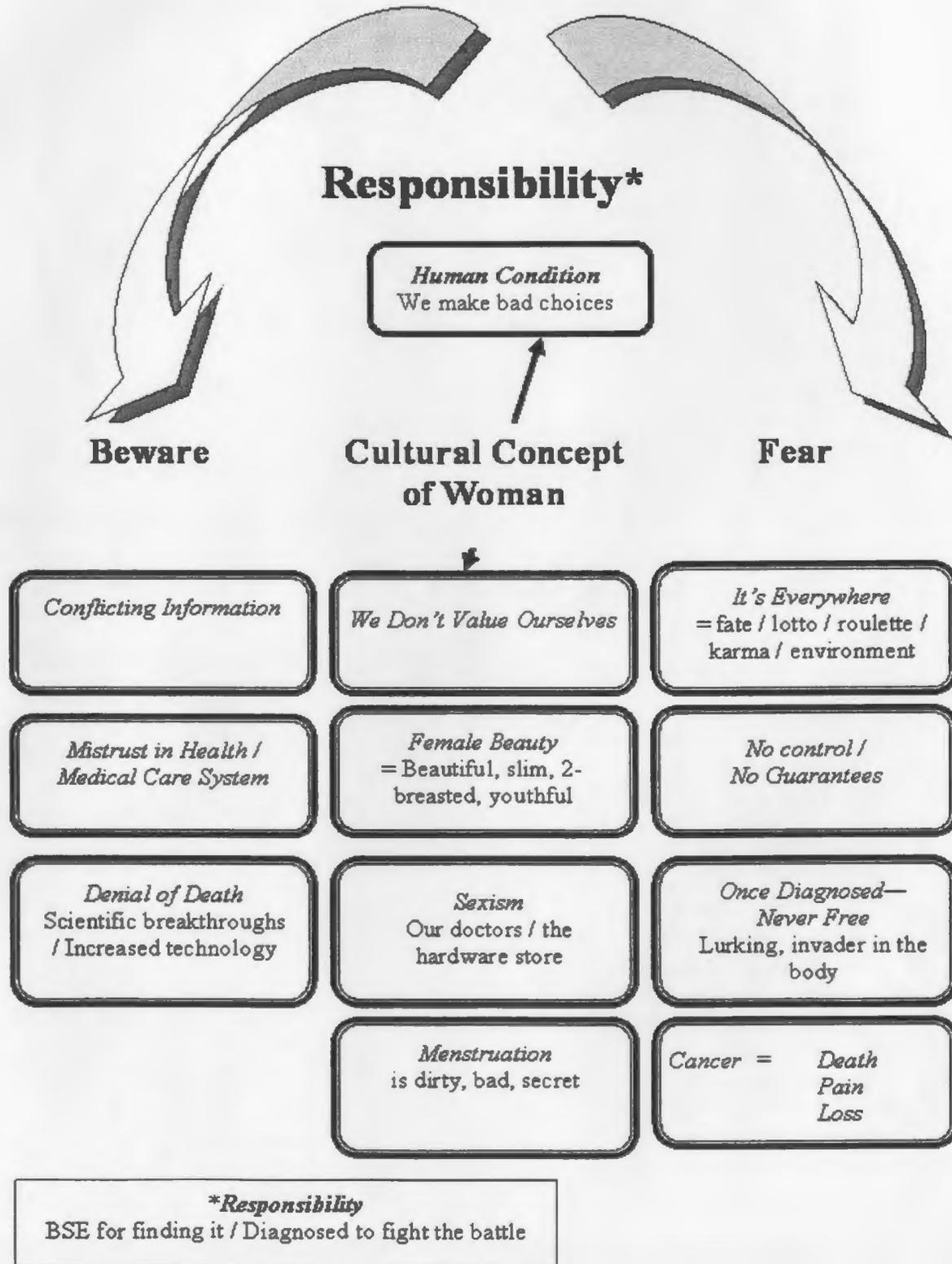
- |        |                   |           |         |        |
|--------|-------------------|-----------|---------|--------|
| 1..... | 2.....            | 3.....    | 4.....  | 5..... |
| Never  | Not very<br>Often | Sometimes | Usually | Always |

**11. In general, do you think cancer is treatable?**

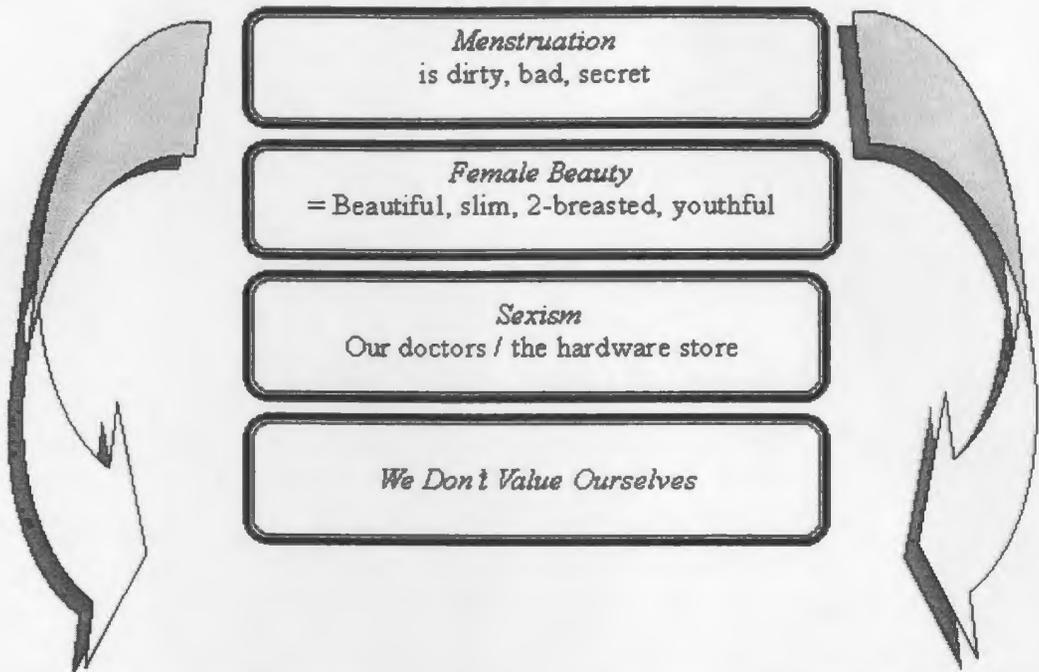
- |                |          |           |         |        |
|----------------|----------|-----------|---------|--------|
| 1.....         | 2.....   | 3.....    | 4.....  | 5..... |
| Never<br>Often | Not very | Sometimes | Usually | Always |

**Appendix 10: Concept maps of BSE created by Groups A and B**

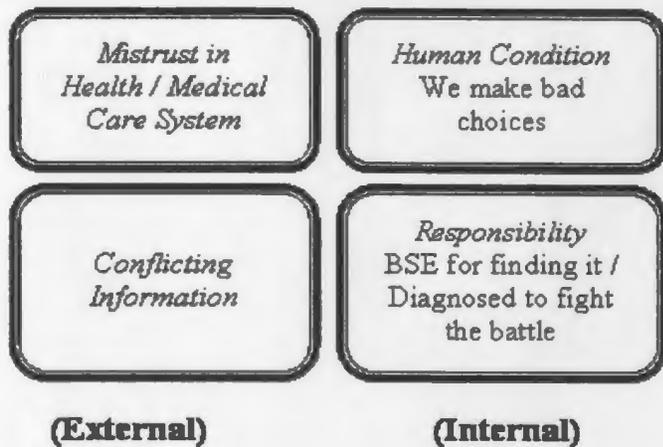
Concept Map created by Group A



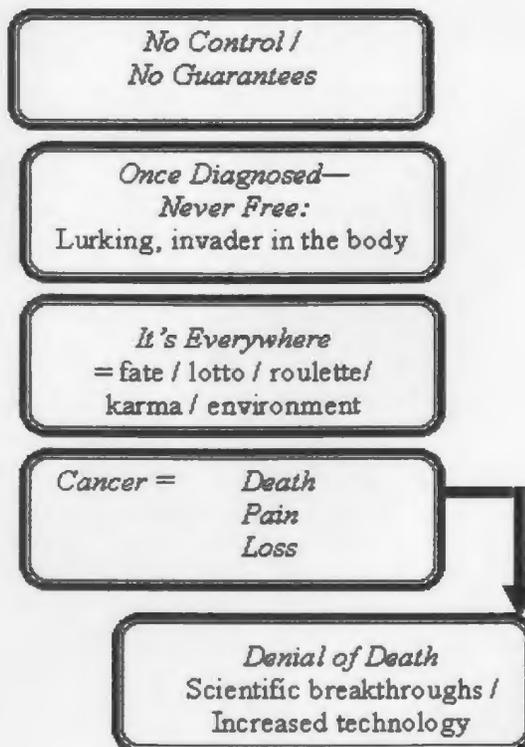
# Woman



## Pre - Diagnosis



## Peri - Post Diagnosis



**Appendix 11: Feedback from Co-researchers on the Research Findings**

### Feedback from Co-researchers on the Research Findings

Date of meeting: March 3, 2004

Attendance: Marion, Jean, Beth, Rose, Adele, Madonna, Joanne, and Lynn.

The notes of the meeting with the co-researchers were taken by Sheila Tucker, BA, MLS. Pseudonyms for the women are utilized here. Except in one instance, individual names are not presented in this discussion as the recorder acknowledged the comments of only two women by name.

Anne provided an overview of the purpose of the meeting with the co-researchers: to report research findings and elicit their feedback. She explained her personal and professional relationship with the issue of BSE, and gave a general overview of the research process utilized. The literature was reviewed including the epidemiology of cancer, and breast cancer in particular. Information was presented related to risk factors and the role of early detection in breast cancer, including a critique of the epidemiological studies related to BSE and mammography effectiveness. In relation to the findings of the systematic review of BSE by the Cochrane Collaboration (which did not recommend BSE as a screening tool for breast cancer), the women made the following comments: “stupid”, “foolish”, “you have to know your own body”, “what harm is it [BSE]?”, “well, they may think it causes unnecessary anxiety, but it doesn’t”, “do they have the same information as you did?”. Other questions were raised by the women in relation to the Shanghai randomized controlled trial of BSE: “who paid for the Shanghai study?”, “what was the political situation at the time of this study?”, “the authors obviously don’t raise children”. In relation to the information presented on the effectiveness of screening mammography, one woman said: “we hear people say *I went for my mammogram only six months ago and now I have cancer*”. Anne reviewed the literature related to women’s knowledge, attitudes, beliefs and practices related to BSE, as well as provided information related to the feminist action research approach utilized and the way the research was carried out with these women. Following a description of the collaborative data analysis utilized, the results were presented.

There was much discussion about the findings. The women stated that “size zero” was talked about many times during the meetings. One woman remarked of a friend: “she doesn’t do it [BSE] because she is terrified of finding something, and if she finds something, she would feel like she should have found it years ago”. One woman remarked that everyone should read the book *The Red Tent* about women who have to enter a tent for the entire time they are menstruating. She said the whole book summarizes the slides entitled ‘*The Middle*’. In relation to the discussion of female beauty, one of the women remarked that she had recently read that “one of the biggest-best presents a high school female graduate can get is a breast enlargement”, which caused considerable reaction and discussion among the women. In relation to female body image, Beth relayed a story about a five year old girl who refuses to eat a snack during school recess because she is concerned about her weight. This was followed by a discussion of how women are portrayed in the media. The women also talked about social beliefs related to women, in particular the notion that women who don’t have children have no value. One woman,

childless at 35, stated: "my father thinks I am a lost cause". With regard to media ads regarding menstruation (*Feel like a clean man*), one woman stressed that this discussion needed to be kept in the doctoral thesis. Consistent with their discussion three and a half years previously, the women continued to feel that the ad of the young boy offering to examine women's breasts sexualized BSE. The group reflected on the concept maps and commented that they were indeed a representation of the issues related to women's practice of BSE. With regard to responsibility for BSE, it was remarked that there is "a lot of work to being a woman". When evidence of the women's raised consciousness was presented, the recorder noted that the women were critical of media and social messages related to woman.

Anne presented her interpretation of research findings. One of the women asked: "what do they mean when they talk about the *risks of BSE*?" One woman remarked: "too much information is contradictory". Another stated that she has a sister who refuses to have a mammogram because of the radiation risk.

Comments made by the women at the end of the presentation: "Even though they've been fighting cancer for 30 years, people are still dying". "I have an acquaintance who has had cancer, and is now clean, but fears the reemergence". One woman spoke of her mother who has had two cancer episodes and won't travel anymore. The women verbalized that it was better to be cautious than not. Joanne stated that when she participated in these discussions, she felt that her weight and sedentary lifestyle were two factors she could control, among a variety of risk factors for breast cancer she could not control (i.e., her gender, age and family history). She decided to take control of these factors and lost 25 pounds. She stated that although she still feels in control of these factors, she believes the concept of personal responsibility is a "double-edged sword". She felt there were "two senses of responsibility: (a) my fault, and (b) my responsibility to find it and fight it. [It is] our responsibility even though we are not encouraged to do it!".

The recorder commented after the meeting that she watched the women's body language and facial expressions, in addition to noting their comments, and felt they had signified their agreement with the findings through their actions (e.g., nodding, murmuring). She stated she found no indication the women disagreed with or did not relate to the information presented. She felt their comments built on, and added to, what had been presented.





