

WOMEN'S EXPERIENCES WITH BREAST HEALTH

by

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in Partial Fulfillment of the Requirements
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Jo-Ann Marie Colette Trudeau

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
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ABSTRACT

Breast cancer is a compelling issue for women. With no primary prevention available, women are encouraged to accept and practice secondary prevention strategies such as breast health. This study investigated women's breast health experiences under the current model of public health, the New Public Health (NPH). The NPH seeks to instruct the individual and the collective on how to live their lives. This is achieved through health promotion that includes three interrelated concepts: risk, surveillance and the self.

By conducting 16 semi-structured interview, three main themes emerged from the interviews: Breast Cancer: Family Matters; Breast Cancer Prevention Strategies: Peace of Mind?; and the Rational Self: Under Construction. The women shared their experiences and it was determined that women engage in breast cancer screening behavior that best fits their psycho-social environmental contexts. These women illustrated that in order to become more effective, the NPH framework needs to become less punitive, accepting of differences and personal experiences, and cease to regulate social behavior. Only then is there an opportunity for the relationship between the health care system and women to improve.

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“You make a plan and stick to it.”

Anonymous

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INTRODUCTION

Breast cancer is a compelling issue for women. In Canada, a woman dies of breast cancer every ninety minutes (Hoy, 1995). For Canadian women, breast cancer is the most frequently occurring cancer with the majority of cases appearing in women aged sixty and older (Statistics Canada, 1996: 9). While over 18,000 Canadian women will be diagnosed with breast cancer every year, resulting in approximately 5,300 deaths, the cause of this disease remains controversial and unknown (Health Canada, 1999: 1; Statistics Canada, 1996: 14-15). As a result, women are encouraged to accept and practice secondary prevention strategies such as breast health.

The breast health perspective, a health promotion framework for supplying clinical and information services to asymptomatic women in the community, has gained popularity. The objective of this perspective is to educate women in self-care intervention. Breast health encompasses many prevention strategies (Nettles-Carlson, 1995: 675), however, none are primary prevention methods in preventing breast cancer. Moreover, the absence of primary risk factors, except for aging and being female, offers no explanation for the incidence of breast cancer. Lacking a primary prevention strategy and identifiable risk factor(s), breast health encompasses breast cancer screening practices (BCSPs) and encourages women to modify their lifestyles in areas such as diet and exercise (King & Schottenfeld, 1996; Nettles-Carlson, 1995).

Breast cancer screening practices have become the predominant forms of breast cancer intervention. Three breast cancer screening modalities, breast self-examination (BSE), clinical breast examination (CBE) and mammography (MAM), are used to detect breast cancer at its earliest stage. Mammography is purported to be

the most effective in detecting breast cancer pre-metastasis (Abraham & Seremetis, 1997; Kelsey & Bernstein, 1996; Nettles-Carlson, 1995) since it is able to reduce breast cancer mortality rates by 30 to 35% in women aged 50-69 years (Abraham & Seremetis, 1997; Snider, Beauvais, Levy, Villeneuve & Pennock, 1996). However, the benefits of MAM remain inconclusive for women aged 40-49 years. Furthermore, the MAM screening recommendations for women aged 40-49 years continue to change creating much confusion (Abraham & Seremetis, 1997; Klabunde, O'Malley & Kaluzny, 1997). Despite the purported claims of effectiveness in reducing breast cancer mortality, current compliance with breast cancer screening guidelines is less than optimal (De Grasse, O'Connor, Perrault, Aitken & Joannise, 1996; Gentlemen & Lee, 1997; O'Connor, 1993). With the risk of breast cancer threatening women's daily existence, practising secondary prevention strategies suggests a rational means of effectively reducing women's personal levels of breast cancer risk.

The objective of this research is to explore women's personal breast health behaviors and experiences. This research will be guided by the New Public Health (NPH) conceptual framework (Petersen & Lupton, 1996). This model emphasizes health promotion which includes three interrelated concepts: risk, surveillance and the self. Originally, the NPH model was embraced by the medical community and people of diverse academic backgrounds; however, recent research has been more critical. Recent feminist research has identified several implications of the NPH for women and health. They include: 1) the recognition that women have cared for both themselves and their families which results in the individualization of health problems and the solutions to them; 2) the social control of women's "risky" health behaviors;

3) a lack of research on the gendered nature of the determinants of health; 4) the social construction of risk factors; 5) the creation of social divisions between conformers of health and non-conformers of health; and, 6) the notion of women's bodies as health indicators (Foster, 1995; Nettleton, 1996). An examination of women's breast health behaviors and experiences guided by the NPH framework will allow for the identification of implications of the NPH for women engaging or not engaging in breast health. In summary, the study will reveal a clearer understanding of the acceptance or resistance of breast health practices.

Women today are exposed to a variety of messages concerning BCSPs such as media advertisements with a Rap beat (Ehmann, 1993), media articles in popular magazines (Rennie, 1993) and many informational pamphlets. Current rates of compliance with these messages or more accurately with the breast cancer screening guidelines indicate that nearly three in four Canadian women perform BSE. However, only one in four perform BSE on a monthly basis (O'Connor, 1993: 170). Compliance data indicate that although the majority of women over 40 have had at least one MAM (Gaudette, Gentlemen & Lee, 1998: 22), women in the age group 50-69 years of age seldom engage in MAM, with low adherence to the bi-yearly guideline recommendations (Gentleman & Lee, 1997: 26). Despite intense efforts by health promoters to encourage women to engage in BCSPs, the epidemiological evidence indicates that a sizable number of women do not comply with the recommended guidelines. Consequently, research that examines women's own experiences with breast health messages is called for. Using the NPH model as a conceptual framework

for investigating women's breast health experiences, I will conduct a qualitative study consisting of in-depth, semi-structured, tape-recorded interviews.

The purpose of this research is three fold: to present an understanding of how women's social environment, personal beliefs and knowledge affect or influence their breast health behaviors; to explore women's perceptions of breast health messages; and to determine how well the NPH framework explains women experiences with breast health. Offering women the opportunity to express what they are thinking and feeling about breast health and the NPH conceptual framework in a non-threatening venue furthers our understanding about women's decisions to either engage or not engage in breast health practices.

Chapter One provides an extensive literature review of the breast health literature. Chapter Two describes the theoretical framework that will be used, the current public health regime, the NPH. In addition, previous research utilizing the components of the NPH is presented along with the research questions that are informed by the literature. Chapter Three describes the research methods used in this study. Chapter Four provides the findings, including a summary of the women who participated in the study and presentation of the major themes. In Chapter Five, integration of the themes and the theoretical framework are presented, along with strengths and limitations of the research and recommendations for future research. By way of conclusion, I will: examine how this research can contribute to and facilitate change; describe the intersectoral cooperative work currently underway in Manitoba for the provision of breast health/cancer information and support services; and lastly, list the implications for women for breast health under the NPH framework.

CHAPTER ONE: Literature Review

The purpose of this chapter is to examine the current literature on breast health. The discussion begins with the different uses of risk in the breast health literature. Then, an examination of the breast cancer screening modalities and the controversy surrounding the appropriate screening age with MAM screening is presented. Afterwards, the discussion investigates the claims of underutilization of breast cancer screening practices by women of all ages. By way of conclusion, the discussion turns to the lack of theory in the many studies presented in this review of breast health.

I. Breast Health

Understanding Breast Cancer Risk

Breast cancer is a central concern in women's health. Breast cancer is the second leading cause of cancer death among women, however, the incidence of breast cancer continues to increase steadily (Statistics Canada, 1996:15) even though the mortality rates for breast cancer have remained constant. Since the incidence of breast cancer begins to rise after age 30 and the majority of cases are among women aged 60 or older (Statistics Canada, 1996: 45), this would suggest that women possess varying levels of breast-cancer risk throughout their lives. Hence, a woman's personal level of breast cancer risk varies and increases with age.

There are three kinds of risk measures which are commonly reported in the breast health literature. The three kinds of risk measures are; absolute risk, attributable risk, and relative risk. Absolute risk (AbR) is defined as the observed or

calculated risk of an event in a population under study. In terms of breast cancer, it is the rate of breast cancer or mortality from breast cancer occurs in the general population. AbR is expressed in two manners; the number of cases in a specified population (e.g., 240 cases per 100,000 annually for women between the ages of 50 to 59 (Gentlemen & Lee, 1997: 21) or the commonly known phrase that one woman in nine in Canada will develop breast cancer in her life time. This popular phrase is misleading for it describes the average risk of breast cancer in white women only. Also known as the cumulative risk, the one-in-nine figure differs significantly for women from varying ethnic backgrounds. The AbR, according to Dr. Love (1995:178), will over- and underestimate the number of women without and with risk factors respectively. The one-in-nine figure is an average probability and has little predictive power because risk depends greatly on one's own risk factors, notably age (Olivotto, Gelmon & Kuusk, 1996:18). According to Hubbard and Wald (1993: 87) this average probability is used to "jolt" women into practising breast cancer screening.

Attributable risk (AR) is the second risk and is mostly used within public policy. It examines the amount of disease in a population that could be prevented by the elimination or alteration of risk factors. The assumption here is that an association exists between the risk factor and the disease. For example, if women ceased to consume postmenopausal estrogen, there would be an eight percent reduction in breast cancers (Love, 1995: 180). Hence, this measure is unsuitable for estimating individual risks of developing breast cancer.

The third risk, relative risk (RR), estimates the strength of an association between exposure to a risk factor and disease, and suggests the possibility of developing the disease in the exposed group relative to those who are unexposed (Hennekens & Buring, 1987). In other words, it is the rate of a disease in a group exposed to a risk factor as compared with a second group not exposed to that risk factor. Love (1995: 178) states that this measure is more useful for women determining their chances of developing breast cancer. However, careful interpretation is needed since the comparison population needs to be free of the risk factor being compared. There is some discrepancy, however, with how this measure is used. Hoskins and colleagues (1995) maintain that the RR measure is more useful as a population estimate. They suggest that the cumulative risk or the absolute risk be used in a clinical setting since it allows prediction of risk over a defined period (e.g., the next 10 years) or a predetermined maximum life span (often to age 80 years).

Researchers' ongoing struggle to unlock the etiology of breast cancer have resulted in an ever increasing number of factors, known as risk factors, which are statistically associated with the development of diseases. It is hypothesized that the elimination or reduction of a risk factor(s) will lead to a reduction in the incidence of the disease. Investigators have classified these factors as high risk and low risk (Kelsey & Gammon, 1990; Mettlin, 1992), or established and possible etiologic factors (Hulka, 1996; Kelsey & Bernstein, 1996; King & Schottenfeld, 1996).

Since much inconclusive evidence surrounds the risk factors associated with breast cancer, it is simpler to list them. There are many known and potential risk factors associated with breast cancer. The first risk factor category contains

biographical factors: age, sex, family history of cancer, history or prior cancer diagnosis and benign breast disease. The second risk factor category is comprised of reproductive factors. This includes menstruation, reproductive history and breast feeding, menopause and use of exogenous hormones such as birth control pills and hormone replacement therapy. Lifestyle is the third risk factor category and it includes, diet, alcohol consumption, cigarette smoking, physical activity and stress associated with the 'risk' of breast cancer. Environmental factors such as exposure to radiation, organochlorines and electromagnetic fields emitted by microwaves and alarm clocks constitute the last category of risk factors. This list of potential risk factors for breast cancer is not exhaustive. Epidemiologists continue to discover potential risk factors in ongoing research.

Each risk factor's strength of association in the development of breast cancer is typically indicated by its relative risk (RR). A RR represents the magnitude of the association between exposure to risk factors and disease. The RR for each risk factor is in no way implying causality. This is only one criterion of many that is used to judge whether an observed association is likely to be causal [1] (Hennekens & Buring, 1987: 30-51).

According to epidemiological research, all breast cancer risk factors indicate very weak to moderate RRs. The RRs corresponding to each established risk factor range between zero and 5.9 (Henderson & Bernstein, 1991; Hulka, 1996; Kelsey &

1. Other criteria that must be acknowledged and utilised to determine causality are strength of association, biological credibility of the hypothesis, consistency of the findings, as well as other information concerning the temporal sequence and the presence of a dose-response relationship. These criteria constitute Bradford Hill's model of causation (Hennekens & Buring, 1987).

Bernstein, 1996; Kelsey & Gammon, 1990; Kvale, 1992; Longnecker, Berlin, Orza & Chalmers, 1988; Mesko, Dunlap & Sutherland, 1990; Mettlin, 1992; Williams, 1994). Thus, the magnitude of the association between these risk factors and breast cancer is not only low but often inconclusive, thereby making the specification of causality impossible except for being female and growing older (Broeders & Verbeek, 1997). There are, however, several epidemiological studies that have produced controversial results concerning strong correlations between organochlorines and environmental estrogens with the development of breast cancer (King & Schottenfeld, 1996; Wolff, Collman, Barrett & Huff, 1996). Many experts believe that exogenous hormones and organochlorines such as DDT are empirically linked to breast cancer but are minimized by the cancer research community which favours a genetic cause (Batt, 1994; Beane, 1996; Epstein & Steinman, 1997; Hubbard & Wald, 1993; Noble-Tesh, 1988, Williams, 1994).

Upon closer examination of risk factors, there are four obstacles that limit the application of risk factors to primary breast cancer prevention (Mettlin, 1992). First, there is an absence of a primary source of risk with the exception of ageing and being female which combine to explain less than 30% of all breast cancer, other sources of risk are unidentified. In other words, more than 70% percent of all breast cancers are not associated with any specific risk factors (Abraham & Seremetis, 1997; Broeders & Verbeek, 1997; Guillory, 1994; Soffa, 1994). Hence, the source of risk for breast cancer is unknown. Second, there is a long latency period between intervention and effect. Exposures to exogenous hormones (e.g. oral contraceptives, hormone replacement therapies) and radiation illustrate sources of potential risk that precede the

disease by many years (Mettlin, 1992). Third, many known risk factors are impossible to alter, for example, the onset of menses or the exposure to organochlorines. Lastly, there is the controversial evidence concerning the efficacy of controlled trials of low fat/high fibre diet and of prophylactic tamoxifen (Crabbe, 1996; Forbes, 1997; McKeon, 1997). The information regarding diet and tamoxifen remains inconclusive.

Determining one's own personal risk of breast cancer is not an easy task. The risk of developing breast cancer not only increases with being female and ageing, genetics, one's family history of cancer and the environment have come to play an important role. That is, despite the unknown etiology of breast cancer, genetic, environmental and gene-environmental interactions are purported to be possible causes of breast cancer. The medical research community strongly supports the genetic cause, and classifies the risk of breast cancer development by family history of cancer. Three distinct categories which correspond to one's family history of cancer are applied in clinical practice when determining one's personal risk of breast cancer (Hoskins, Stopfer, Calzone, Merajver, Rebbeck, Garber & Weber, 1995; Kelly, 1997; MacDonald, 1997). The three categories are high, medium and average breast cancer risk.

High risk is characteristic of someone with a least three or more, first or second degree relatives (first degree is a mother or sister, second degree is a cousin) with breast cancer or ovarian cancer, particularly if their onset of breast cancer was before menopause.

Medium risk is someone with one or two relatives with breast cancer or ovarian cancer.

Average risk is someone with no family history or breast or ovarian cancer. (Manitoba Breast Advisory Council, 1995: 5-6).

Since personal breast cancer risk is presented this way, the unit of analysis is the individual. In other words, the most that is offered is a genetic/biological specification of risk. The possible environmental causes are ignored. This suggests that all women are at risk of breast cancer and that no one is exempt from this disease. Furthermore, this renders BCSPs as a course of action in the fight against breast cancer since a genetic solution is not forthcoming.

In summary, all ageing women are at risk of developing breast cancer. Assigned to each personal level of risk are risk factors with corresponding RRs determining the association with breast cancer. Although risk factors assume associations with breast cancer and not actual causation, they have limited application for primary prevention. Nonetheless, the knowledge surrounding risk factors and their association with breast cancer is supported as well as promoted by the cancer research community. In light of the current lack of a primary prevention strategy, secondary prevention such as BCSPs are recommended to women. This brings us to an examination of secondary prevention, breast cancer screening practices.

Secondary Prevention: Breast Cancer Screening Practices (BCSPs)

BCSPs play a key role in constructing women as being at risk for malignancy from adolescence to old age. BSE, CBE, and MAM have been extensively publicized as early detection tools for breast malignancy. Some suggest that early diagnosis simply increases the length of time a woman survives after breast cancer has been diagnosed, whether treatment helps or not (Hubbard & Wald, 1993: 73). While early diagnosis can detect the cancer in the earliest stages before metastasis (Whatley and

Worcester, 1992: 200), it cannot prevent the disease from developing (Foster, 1995: 115-116). These three primary modes of breast cancer detection assist in the detection of breast cancer.

Despite being promoted extensively, BSE has not proved to be effective in reducing mortality rates. BSE is considered a means in which women become familiar with their breasts so as to recognize any breast changes (Grady, 1992; Guillory, 1994: 157; Nettles-Carlson, 1995; Whatley & Worcester, 1992: 209). In fact, the research indicates that women find 90% of all tumours themselves (Grady, 1992; Humphrey & Ballard, 1989; O'Connor, 1993: 175) and most self discovered lumps are greater than one centimetre. Whether the tumours are found through BSE or discovered inadvertently during another activity such as bathing remains unknown. However, even with proper instruction and improved skill, BSE remains less efficacious than the combination of MAM and CBE.

The clinical breast examination (CBE) is a second popular breast cancer screening modality. Physicians and other health professionals routinely conduct CBE when women present themselves for their general physical examination. This method of screening permits the potential discovery of suspicious lumps that may appear in the intervals between BSE performance and MAM. The inspection and palpation of the breast is not any different than a self-examination of the breast (Nettles-Carlson, 1995: 682). The CBE is seen as a "gatekeeping" mechanism through which physicians determine which women should be referred for a mammogram.

The third breast cancer screening modality is mammography (MAM). This x-ray of the breast includes two views of each breast, one from above and one angled

from the side. MAM is used for two purposes: screening and for diagnostic assessment. Mammography remains highly controversial as a screening modality. The most convincing, yet controversial, evidence comes from the Health Insurance Plan of Greater New York Screening Project (HIP). The project conducted a randomized clinical trial between 1963 and 1966 [2]. The trial objective was to determine the efficacy of periodic screening with MAM and CBE in reducing breast cancer mortality. The HIP trial screened women aged between 40-64 years and reported a reduction in breast cancer mortality of 30-40% after nine years of follow-up but only for women aged 50 years or older. Women less than 50 experienced no significant reduction in breast cancer mortality after 18 years (Comis & To, 1992; Miller, 1991; Workshop Group, 1989). The HIP and a Swedish Trial results are often quoted results but are controversial because, according to Peter Skrabanek (1988: 971); "The quoted 30% reduction is a relative percentage obfuscating the fact that the yearly benefit was one death fewer in each 15, 000 women screened." This percentage obscures the fact that the small gain in breast cancer deaths was offset by deaths from other cancers such as ovarian cancer. As a result, the overall mortality of the Swedish women in the screening trial was not reduced (Foster, 1995).

The Canadian National Breast Screening Study (CNBSS), a long awaited study, evaluated the efficacy of annual screening with MAM, CBE and BSE in reducing the rate of death from breast cancer among women aged 40-49 and 50-59

2. Other studies have tried to reproduce similar if not better results and have failed, except for the Dom and Nijmegen case-control studies from the Netherlands, which demonstrate a significant benefit from MAM alone (Comis & To, 1992). The three studies Swedish studies Edinburgh, Stockholm and Malmo have shown no significant benefit. The Malmo study also indicates no impact on the rate of death for women aged 40 to 49 (Comis & To, 1992).

years. Designed as a randomized controlled trial, the largest ever, the researchers reported no impact on the rate of death among women in either age group up to seven years following entry into the trial (Miller, Baines, To & Wall, 1992a; 1992b). That is, the efficacy of annual screening with MAM, CBE and BSE in reducing the rate of death from breast cancer among women aged 40-49 and 50-59 years remains inconclusive. Such results have fuelled a mammography guideline controversy and confused women about screening frequency.

Even though breast cancer screening trials testing the efficacy of MAM are inconclusive, Canada and the United States have established somewhat similar breast cancer screening guidelines for periodic screening of asymptomatic women. The recommendations made by the Federal Provincial Group of experts in 1988 are:

Asymptomatic women aged 50-69 or older are offered and encouraged to participate in an early detection program consisting of MAM and CBE, be taught BSE and be monitored for proper BSE practice every two years,

Asymptomatic women aged 40-49 years are not advised to attend an early detection program. They are able to receive a CBE and BSE education from a health professional or a dedicated centre,

Symptomatic or high risk women are welcome to make use of the early detection program, and

No woman is ever turned away (Morrison, 1994; Workshop Group, 1989).

The breast cancer screening guideline similarities between Canada and the United States of America end with American women between the ages of 35 to 50 being recommended to undergo a baseline mammogram, followed by annual or biennial mammograms until the age of 50 and an annual mammogram after 50. The National

Cancer Institute (NCI, 1993) replaced the aforementioned guideline in 1993 giving credibility to the mammography debate. This guideline changed again in 1997 after the CNBSS results. NCI stated that MAM screening benefited women over 50 and that women less than 50 could make their own decisions. The American Cancer Society (ACS) began recommending, after NCI's statement, that women aged 40-49 engage in yearly MAM screening. Shortly thereafter, NCI retracted its statement and issued a new and similar guideline to the ACS guideline. NCI now recommends that women in their 40s engage in routine MAM screening every 1-2 years. Both influential organizations recommend that women aged 50 or older engage in annual MAM screening (Abraham & Seremetis, 1997; Daly, 1994). Hence, the differing opinions of the cancer establishment such as NCI, the American Cancer Society, and the American College of Radiology have kept ongoing the debate as to when to screen and with which modality.

The breast cancer screening guidelines are based on the assumption that early detection of breast cancer will be more effective in saving lives than will later treatment. Breast cancer, according to some (Foster, 1995: 112), is a suitable disease for the application of a screening or surveillance program. For a disease to be appropriate for surveillance several criteria must be met (Beecroft, 1988; Foster, 1995; Hennekens & Buring, 1987). First, a disease should be serious. Second, the treatment given before symptoms develop should be more beneficial in terms of reducing morbidity or mortality than that given after they develop. And third, the prevalence of pre-clinical disease should be high among the population screened. The success of a surveillance program lies with a suitable screening test. A screening test for a disease

should be inexpensive, easy to administer, impose acceptable discomfort on the patients and above all be valid, reliable and reproducible. The validity of a screening test is measured by how well it is able to consistently classify persons attending a screening demonstrating pre-clinical disease as test-positive and without pre-clinical disease as test-negative. The measures of validity are sensitivity and specificity. Sensitivity is the probability of testing positive if the disease is present (the proportion of women with breast cancer who have a positive MAM). Specificity is the probability of testing negative if the disease is absent (the proportion of women who do not have breast cancer in whom the screening MAM is negative) (Forest & Aitken, 1990; Hennekens & Buring, 1987). Desirable as it may be to have a screening test that is both high in sensitivity and specificity, it is not yet possible. Mammography is said to miss up to 10-20% of pathology (Abraham & Seremetis, 1997; Hortobagyi, McLelland & Reed, 1990). Not every women engaging in screening will either be positive or negative. There is a grey zone which is the inability to detect non-palpable cancers.

In short, of the three breast cancer screening practices, mammography is purported to fit the criteria as being the screening modality that provides early and accurate detection of breast cancer. In spite of the resulting controversies in the breast cancer screening trials and its reported 10-20% false-negative rate, MAM alone or in conjunction with CBE are still promoted as effective and rational means in reducing the breast cancer mortality rate. Even though the breast cancer mortality rate has not dramatically changed (Gaudette et al., 1998) women are encouraged to follow these established breast cancer screening guidelines.

Since the three breast cancer screening modalities are highly publicized as effective medical interventions, one would think adherence to the guidelines or the utilization rate of the screening modalities namely, BSE, CBE, and MAM, would be very high. In fact, dissemination of breast health promotion programs encourage women of all ages to engage in these practices. However, all screening modalities are underutilized by women of all ages (Finley, Francis & Lefevre, 1989; Gentlemen & Lee, 1997; O'Connor, 1993; Smith & Haynes, 1992: 1969, 1971). Let us turn to an examination of the underutilization of BCSPs.

Underutilization of Breast Cancer Screening Practices

Breast cancer is the leading cause of death for mid-life women between the ages of 40-55. Incidence increases with age through the 40s and jumps again before age 50. After menopause, incidence continues to increase but at a slower rate (Abraham & Seremetis, 1997). As previously noted, the established breast cancer screening guidelines differ greatly for American and Canadian women. The current discussion will examine Canadian compliance data only; however, the new changes in American guidelines for women aged 40-49 are noteworthy for Canadian women. To reiterate, the Canadian breast screening guidelines recommend that women aged 40-49 engage in BSE and CBE and not engage in MAM unless they are experiencing breast problems. In contrast, the Americans guidelines for this age group have now been expanded to allow women to engage in MAM every 1-2 years. Women aged greater than 50 are recommended to engage in annual (US) and biennial (Canada) mammograms. Compliance with current Canadian guidelines is less than optimal

(Gentlemen & Lee, 1997; O'Connor, 1993).

Statistics Canada reports that the majority (64%) of Canadian women over 40 have had at least one MAM. Women in the two age groups that are targeted by breast cancer screening programs had use rates of 74% for those aged 50 to 59 and 71% for women in their 60s. These rates are a dramatic increase from the results of the Health Promotion Survey 1990 of 58% and 51% for the 50-59, and 60 and older groups respectively (Gaudette et al., 1998: 22; O'Connor, 1993; Snider et al., 1996).

While Gaudette and colleagues (1998) have reported an increase in MAM use, Gentlemen and Lee (1997) state that a large number of women in the targeted age group 50-69 do not engage in their first MAM or engage in repeat mammograms. Dedicated screening centres are where women are encouraged to attend for baseline and repeat mammograms. The Provincial Centres try to obtain a 70% compliance rate in the 50-69 age group in order to reach a 25% decrease in mortality by the year 2000 (Gentlemen & Lee, 1997). Thus far, the breast cancer mortality rate had fallen to 28.4 per 100,000 in 1995. It is the lowest ever reported since 1950. This decline is not solely attributed to breast cancer screening with MAM. It has declined because circumstances such as treatment advances and fertility patterns which have explained mortality rate decline in the United States are playing a similar role in the declining Canadian rate (Gaudette, Gao, Wysocki & Nault, 1997; Gaudette et al., 1998). Although almost 75% or 1.9 million Canadian women in the targeted age group have gone for a MAM, however, doing so biennially falls short of the recommended screening guidelines (Gentlemen and Lee, 1997: 21). Although the screening rate is high, 25% have never had a MAM. Women of this age group are recommended to

attend every second year. Twenty-four percent of these women who had had a MAM had not done so in the previous two years. As a result, approximately 1.1 million women aged 50-69 had either never had a MAM or had had one, but not according to the breast cancer screening guidelines (Gentlemen & Lee, 1997: 22). Therefore, compliance with current Canadian guidelines is less than optimal because women in the targeted age groups do not follow recommended guidelines when they should and women in their 40s, who are not recommended to engage in MAM, do so.

Engaging in MAM screening is strongly associated with the availability of an organized breast cancer screening centre. All Canadian provinces currently have breast cancer screening centres. Some provinces such as British Columbia and Saskatchewan have the longest running breast screening programs. Newfoundland, New Brunswick and Manitoba, on the other hand, have established centres in the past few years. Women who live in rural Manitoba have screening mobile units travelling to their towns. Canadian women who have ever had a MAM are described as being married women, women in the paid workforce, those with a college or university education and those who had recently seen their physician. Women who do not participate in MAM tend to be older, non-white, poorer, less educated and live in rural areas. (Gaudette et al., 1998; Gentlemen & Lee, 1997; O'Connor, 1993).

Mammographic screening for women in their 40s is very controversial. Still, women in their 40s are encouraged to perform BSE and CBE and engage in MAM if they present with breast pain or complaints. Examining the frequency of BSE, many Canadian women report that they have performed BSE but few report that they do this on a monthly basis. That is, 73% practise BSE, but only 27% do so monthly

(O'Connor, 1993). In the Health Promotion Survey 1990, 27% of women aged 15 and over engage in BSE on a monthly basis, 19% did one every 2-3 months, 27% performed this exam less frequently and 28% never engage in BSE. Women in older age groups are more likely than younger women to perform BSE. However, only about one in three women over age 50 engage in BSE on a monthly basis. In the Health Promotion Survey 1990, about 35% of women aged 45-54 and 55-64 did a BSE once a month (O'Connor, 1993: 171; Statistics Canada, 1995). Hence, mid-life women who are recommended to perform monthly BSE fall short of this recommended guideline.

Annual CBE by a health professional is another screening modality which is specifically recommended to women aged 40-49. Unfortunately, the National Population Health Survey 1994 and Health Promotion Survey 1990 did not allow for questions regarding CBE (O'Connor, 1993, Snider et al., 1996) or for physician characteristics related to screening (Maxwell, Kozak, Desjardin-Deanault & Parboosingh, 1997: 350). However, data from one regional survey are available. O'Connor and Perrault (1995) reported that among Ottawa-Carleton women aged 50-69 (n=383) almost all had had a CBE. Fifty-seven percent responded that it occurred the year before and three quarters intended to have one done within the following year. When examining whether women are having CBE in the appropriate time allotted they found that half are not being screened appropriately. The authors conclude that the CBE rate is low, however, it is not due to lack of physician contact. In fact, 80-90% of the women in the survey reported a visit within the last year to their family physician. Hence, women are not visiting physicians for an annual CBE and/or

the physician does not appear to be performing a CBE. In other words, the physician is not taking the opportunity to perform a CBE when a woman presents herself for an annual examination. This lack of physician compliance may be associated with the low adherence to MAM. It is well known that physician recommendation is cited as the most common reason for having a MAM (De Grasse et al., 1996; Johnson, Hislop, Kan, Coldman & Lai, 1996; O'Connor, 1993; O'Connor & Perrault, 1995).

Similar results regarding CBE have been found for women between the ages of 40-49. In Alberta, the dedicated screening centre discovered that over 90% of the women in all age groups, including women 40-49, had had a CBE at some time (Alberta Cancer Board, 1991). When questioned about future adherence to CBE, 75% of the respondents were quite or very certain that they would do so. In spite of being quite certain that they are going to participate in a CBE, it is not known whether the physician will do this examination upon request. As we saw with the Ottawa-Carleton women aged 50-59, low adherence to CBE is not just about women not asking, but of physicians not performing the test. Burns and colleagues (1996) discovered that male physicians would rather send their patients for MAM than perform a CBE and discuss the knowledge around screening. Therefore, like MAM and BSE, CBE is also underused. It would seem, however, that it is not just women who refuse to engage in screening but their physicians also contribute to the underutilization of BCSPs.

In spite of the potential benefit associated with breast cancer screening, women who engage in breast cancer screening practices face potential harmful side effects. Monthly BSE and annual CBE can generate considerable anxiety in women. Second,

BSE not only detects "true positives" but also "false positives" which are associated with extra medical intervention such as biopsies. The third consequence is the false reassurance from a "false negative" with BSE for women who have had several BSE findings and undergo medical intervention to later be told that the finding is benign (Frank & Mai, 1985).

MAM like BSE and CBE is not without its health consequences (Randal, 1993). The same side effects, namely, psychological effects such as anxiety and fear, false negatives leading to false reassurances, and false positives which can incur further medical intervention. However, other consequences such as radiation exposure, painful/embarrassing examination, overdiagnosis, and financial cost for women living in the United States who are without insurance require careful examination (Howard, 1987; Nielsen, Miaskowski & Dibble, 1993).

Emotional and psychosocial difficulties may occur at any point of the breast cancer continuum (Irvine & Lum, 1997), i.e., at the etiology and prognosis stage, during breast cancer screening, at diagnosis and surgery, and continuing to the long term survival stage. The psychosocial consequences of interest in this review are those experienced at the start of the breast cancer continuum, more specifically, breast cancer screening and pre-diagnosis period. A discussion paper written for Health Canada informs this review. Irvine and Lum (1997) present a study in which the authors report that women at the pre-screening stage displayed greater levels of depression and anxiety than women who were undergoing investigations of breast abnormalities. However, the study reported that 10% responded that screening left them more anxious about having breast cancer, 41% less anxious and 48% reported no

change. Another study reported similar results in which 8% of the women who had engaged in screening reported increased anxiety at a six month follow-up. Compliance with breast cancer screening is highly correlated to psychosocial variables. For example, involvement in a strong social network increased the use of MAM services. As well, when being told of MAM results, women wanted to be told of the result over the phone if they are normal and be told by the physician in person if they are abnormal (Irvine & Lum, 1997).

The psychological and emotional difficulties experienced in the pre-diagnosis period address the severe anxiety associated with discovering a lump, hesitating in seeking care, and waiting for a definitive diagnosis (Irvine & Lum, 1997). The literature indicates that women wait for approximately five to six weeks before seeking medical attention. Benedict and colleagues (1994) and Goldberg and colleagues (1992) reported extremely high anxiety and conflicting emotions in over half of the sample. The women made use of avoidance ego defences such as denial of ideas, anxiety and depression. Another immediate psychosocial response to the detection of a lump is the need for information. Women today have much more information to choose from than women in the 1970s and 1980s. With the increase of information, women are attending their physicians with questions in mind. Waiting for a definitive diagnosis is a very stressful time for women and their families. Benedict and colleagues (1994) report that women coped with the extremely high levels of anxiety by "keeping busy or mentally occupied" (Irvine & Lum, 1997: 12). Both women and their spouses scored above population norms on both anxiety and depression. Women's psychosocial responses to breast cancer screening is an area of breast health

that is relatively under-researched. According to Irvine (1996: 14), “very little is known about which women are most vulnerable for poor psychosocial outcomes following labelling or following attendance at a screening program. Still less is known about how the health care team can respond to ameliorate psychosocial risk and morbidity”.

In summary, adherence to breast cancer screening practices is suboptimal. Many women do engage in screening, however, they do not engage at times which are recommended by the screening guidelines. Still, women do engage in screening even though there are health consequences attached to them. As noted, the emotional and social well-being of women engaging in breast cancer screening and the pre-diagnosis period is threatened. In spite of that, the majority of women do not experience long-term emotional distress (Irvine & Lum, 1997).

Critique

There is much literature in the field of breast cancer from etiology and prognosis, breast cancer screening, diagnosis and surgery, treatment, follow-up to long-term survival and bereavement. Complementing all this information is the knowledge of academic disciplines such as epidemiology, biology, chemistry, sociology, psychology, etc., each applying their knowledge base to help understand breast cancer. Much of the literature on breast health, however, is theoretically void and if a theory is used it is seldom identified (Thurston & Scott, 1995). One exception is the studies that examine breast cancer screening using health promotion’s social psychological models such as the Health Belief Model (HBM) to assist in the

understanding and changing of women's screening/ health behavior. Health promotion relies on models derived from American mass communication developed in 1950s and 1960s. The HBM developed by Rosenstock (1966) and expanded by Becker (1974) is very popular in the breast cancer screening literature. Despite its popularity, the HBM and other social psychological models used in health promotion describe forms of service delivery rather than health education principles. Many of the models are very confusing often making reference to the same model yet using different names (Lupton, 1995). Furthermore, few of the models, including the HBM, have been shown to possess empirical rigor. As well, the HBM is exemplary of a high degree of variability within the operational definitions which makes it an incoherent theoretical framework (Burack & Liang, 1989; Calnan, 1984).

The many models that health promotion researchers apply to health behavior emphasize rationality. That is, model names such as Health Belief Model (Rosenstock, 1966), the Theory of Reasoned Action (Ajzen, 1985) and the Social Learning Theory (Rosenstock, Strecher & Becker, 1988) all denote rational thought. The assumption behind all these models and more specifically with health promotion is that improved health status is brought about by behavioral changes which is a result of knowledge, beliefs and attitudes that once changed will improve your health status. In other words, the more knowledge one has, the better one will act in a rational manner to avoid becoming ill. Another disadvantage to these models is that all assume that the individual is a rational actor. That is, once educated, the person will be influenced to behave in a logical manner. Yet, sometimes more knowledge may incur doubt. For instance, the recent changes in MAM screening in women ages 40-49 in the United

States leaves women on their own to determine whether MAM is an option for them.

Lupton (1995: 57) criticizes the health promotion models by stating,

The models, based as they are on psychological tenets, narrow behaviour to the micro-level of the cognitive functioning of the individual, who is represented as behaving almost in a social vacuum. While some models recognize the importance of 'social norms' in shaping behaviour choices and attitudes, this overwhelming concern with the individual fails to account for the complexity of the socio-cultural world in which subjectivity is constructed and reconstructed. In their obsession with personal skills and self-efficacy, the models over-simplify and provide facile solutions to the problems they identify. They suggest first that lifestyle habits are amenable to change, and secondly, that most people, if rationally told the risks will make the effort to do so. Alternatively, individuals who possess knowledge about the health effects of behaviours but continue on as before are represented as requiring further assistance to help them resist temptation and change their ways.

As Lupton notes, individuals do not live in social vacuums and our socio-cultural worlds in which our subjectivity or selves inhabit are constructed and reconstructed on a daily basis as a result of our interactive self. All individuals are managing an array of stimuli in their reality.

Rather than use any health promotional model as its theoretical framework, this research will use the New Public Health (NPH) as a conceptual model. The NPH is increasingly discussed in Australian literature on women's health, although not breast health to date. North American literature seldom explicitly utilizes the NPH framework. This model is appropriate because it is a psycho-social-environmental/epidemiological model taking into account the individual's whole social context.

CHAPTER TWO: Theoretical Framework

The ideas of today's public health movement emerged over 200 years ago. Within these 200 years, four regimes evolved, namely quarantine, sanitary sciences, social medicine and the 'new' public health (Armstrong, 1993) (see Figure 1 in Appendix A). The history of public health is classified within four time frames: pre-Enlightenment, Enlightenment, modern public health and late-modern public health (Lupton, 1995). This discussion will focus strictly on the 'new' public health classified in the late-modern public health classification. This classification assisted the organizing and describing of four public health regimes (see Appendix A for the other three regimes and classification). An examination of the New Public Health regime will address characteristics such as Armstrong's (1993) "boundaries and spaces" within public health, the theories of disease causation, the focus of public health interests, the surveillance and regulations developed to manage these problems, and the issue of responsibility for health and social consequences. The NPH conceptual framework, that is risk, surveillance and the rational self, will inform this research. Using the NPH as the theoretical framework offers the research greater scope in which to understand the context in which women experience breast health. By way of conclusion, I will examine previous research utilizing the components of the NPH and present the research questions which are based on the literature.

I. The New Public Health: Late-Modern Public Health: 1970 - Present

Biomedical practices experienced a growing popularity in the twentieth century. By the 1970s, however, biomedicine was under attack. Several countries

who had adopted a curative model of health and illness were now experiencing immense financial crises in health care costs (Ashton & Seymour, 1988: 20). Therefore, the origins of the NPH are located in writings of many critics who questioned the efficacy and costs of biomedicine. One of the first critics was Thomas McKeown (1976) who demystified biomedicine's role in decreasing the mortality rates. He concluded that the control of infectious diseases was not due to biomedical efforts but to smaller family size, better nutrition and the proper engineering in the delivery of clean water and disposal of waste. Another influential writer was Ivan Illich (1976) who argued that biomedicine was the problem and not the answer for achieving a healthier population. He maintained that biomedicine assumed control over the person's body and health, and as a result, medicine was responsible for iatrogenic (medically induced) illnesses. Illich (1976) stated that the health risks of modern medicine and its institutions far outweighed the benefits. This view was strengthened by the growth of feminist ideas, especially the very popular handbook for women's health, *Our Bodies, Ourselves* (Boston Women's Health Book Collective, 1982). Further support for Illich's perspective came from those experimenting with alternative treatments and those who reclaimed health as an area for lay and self-help groups (Ashton & Seymour, 1988; Illich, 1976; Lupton, 1995).

Another notable critique was the Lalonde report (1974) from Canada. This document is said to have changed profoundly public-health activities (Vayda, 1978). The report marked the initiation of the fourth or current regime of public health. Favoring McKeown's analysis, Lalonde (1974) argued that the health of Canadians could be improved by changes to lifestyle and the environment, while curative

interventions would take on secondary importance. Since lifestyle was seen as being the cause of disease, Lalonde (1974) introduced the term “health promotion”. He advocated that the promotion of health practices would ameliorate the health of a nation. As a result, Britain and the United States followed with equally influential governmental documents. All three documents emphasized the individual’s responsibility for maintaining his/her health (Ashton, 1992; Ashton & Seymour, 1988; Lupton, 1995; Petersen & Lupton, 1996).

Many developed countries looked to the World Health Organization (WHO) for leadership with the emergence of a ‘new’ health regime. A series of documents from WHO sparked the movement’s momentum, starting in 1977 with the Alma Ata Declaration advocating the importance of a reappraisal of primary health care in the developed countries. Accepted in 1981 by the World Health Assembly was the document, *Global Strategy for Health for All by the Year 2000* (WHO, 1981). The ideas of both documents were: first, to focus on the living conditions of the poor; second, to redirect the enterprise of medicine from hospital care towards primary health care; third, to involve the public in its health; and, fourth, to nurture a partnership between the public, private and voluntary sectors. Many countries adopted the ‘Health for All’ strategy that culminated in the Healthy Cities Project in 1986. The Healthy Cities project was the trial attempt to regulate urban space by applying “new” health promotional philosophies (Ashton, 1989; 1992; Ashton & Seymour, 1988; Martin & McQueen, 1989).

The NPH is defined as “...[a]n approach which considers environmental change as well as personal preventive measures and appropriate therapeutic

interventions with a renewed focus on public policy and intersectoral cooperation” (Lupton, 1995: 53). Within the NPH, the entire body is considered (Armstrong, 1993: 404-405). The theory of disease causation within the NPH is one’s lifestyle. In other words, the outcome of economic and social activity has rendered individuals at risk of becoming ill. The focus of interest for the NPH became, then, the prevention of endemic diseases such as cancer and cardiovascular diseases. The NPH focused primarily on those risk factors which prove a direct association between lifestyle and disease causation. Furthermore, there was a renewed focus on public policy and intersectoral cooperation (Lupton, 1995: 53; Petersen & Lupton, 1996).

Health promotion has become the NPH’s central strategy of surveillance and social regulation. Health promotion is the vehicle by which the public becomes informed on how to ameliorate their health status. The focus of health promotion is not only to encourage positive health but to prevent illness rather than treat it, develop performance indicators, use the mass media to distribute information, and get communities working together to improve their environment through intersectoral collaboration. Furthermore, health promotion makes use of health education to teach people about the proper use of health services. As a result, health promotion targets all individuals and engenders a strong emphasis on self-management. Characterized by multi-sectoral cooperation, the NPH prides itself on cooperative relationships among state institutions, agencies and organizations in the private sector, and voluntary organizations to promote health for all. The multi-sectoral nature of NPH has moved health care from the hospital out into other social spaces such as schools, workplaces and malls. Consequently, many social issues are health problems for health promotion

to assess, manage, communicate and confront (Leviton, Needleman & Shapiro, 1998: 5-9). Health promotion, therefore, presents itself as a late-modern medicine (Bunton & Burrows, 1995; Lupton, 1995; Petersen & Lupton, 1996). This sets the stage for a closer examination of health promotion's three interrelated concepts, risk, surveillance and the rational self.

i. Risk

The conceptualization of risk is very complex. Beck (1992; 1995) and Giddens (1991) both see risk as central to modern culture and pivotal to the development of the self. Castel (1991 [1983]), who is inspired by Foucault's ideas on governmentality and the power of experts to define and regulate subjects³, focuses specifically on the new preventive strategies that have emerged under NPH. Earlier conceptualizations of risk (Douglas, 1990; 1992; Douglas & Wildavsky, 1982) addressed the symbolic or rhetorical role of prevention and risk in the re-interpretation of social problems and/or in regulating boundaries between the self and other (Petersen, 1996: 48).

Originally, the term risk was seen as neutral, suggesting the probability of an event occurring. This conceptualization of risk was employed in the field of economics and mathematics (Lupton, 1993: 425). While present society has become very conscious of the health risks associated with technology and lifestyle habits, the current usage of risk abandons the neutral meaning and replaces it with danger (Lupton, 1993: 426). Thus, an individual with high risk is in great danger of poor

3. Both, Beck (1992; 1995) and Giddens (1991) overlooked Castel's work in their discussion.

health, if not death. Events become risks because they are socially and politically constructed by experts as such. Risks include moral judgments of blame and the discourse of risk can be used as a political strategy (Lupton, 1993; 1995).

Health promotion and public health equate risk with danger and a discourse of risk emerges with each new health risk. The disciplines of epidemiology and statistics construct and facilitate the understanding of risk by employing percent or probabilistic terms. Risk implies that no individual is ever risk free of developing an illness.

Instead, as noted by Castel (1991: 288), the individual as a unit of measure disappears and is replaced with factors of risk derived from a population. Experts working within this perspective now have an endless array of targets. When determining the risk for any illness, epidemiology applies the population as the unit of analysis and can report the relative risk for a target population. The cumulative risk, on the other hand, is the measure for individuals in a clinical setting. The number, like the word risk, takes on the meaning of danger as levels of analysis are confused (Douglas, 1990; Ewald, 1991; Lupton, 1995).

This approach ascertains which groups need targeting. They need not show actual symptoms, and are instead, identified through risk factors. This is termed risk profiling (Giddens, 1991: 119). Risk profiling is the act of analyzing what the risks are in a targeted population. What makes this an ongoing project is that risk profiling is not static. The risk profiles of a population are under constant revision and require management from health promotion. Risk profiling replaces the gaze of experts. As a result, the physician-patient relationship is predicted to collapse as physicians become health consultants (Castel, 1991). Much of the health promotional strategies are

practised at a distance, subtle, and not intended to be coercive. Therefore, health promotion assists in managing the population risks with many strategies ranging from risk assessment for individual cases to community wide programs.

According to Lupton (1993; 1995: 78) the risk discourse in public health is divisible into two main perspectives: external and internal risk. External risk is a health danger for the population (e.g. global warming), and an external hazard over which the individual is unable to exercise any control. Internal risks are lifestyle choices made by individuals, hence, individuals can and are able to exercise self-control. Certain lifestyle choices such as smoking and drinking alcohol are risky behaviors and individuals have the control to exercise restraint to manage the 'self' (Lupton, 1993; 1995).

Risk is also conceptualized as moral danger (Douglas, 1990). Douglas (1990: 7) asserts that "being at risk" is similar to sinning. This view stresses the danger of external forces upon a person instead of the dangers a person may put on a community. She goes on to argue that risk has a 'forensic' property (Douglas, 1990). That is, risk not only operates to clarify past risky events but is able to anticipate future events as well. This conceptualization of risk is similar to the political use of the term when considering environmental dangers: individuals have no control over and are at risk of environmental hazards. Hence, the individual is said to be wronged when the risk is an external risk. When this assumption is applied to health problems where individuals are thought to have control and be responsible for their health, they then become the "sinners." The relationship between sin and risk is inverted when examining internal risk (Lupton, 1993: 429). As a result, individuals who take on risk

because of moral weakness subject themselves to being seen as sinning and have not been sinned against. The one committing the sin does not have enough self-control to abate that risk (Lupton, 1993: 429).

Overall, risk involves the notion of danger, as well as an overwhelming sense of morality and personal responsibility. Those individuals who take their internal risk seriously and comply with health promotion strategies are said to be highly moral and responsible individuals. Individuals who are risk takers and cause harm are described as irrational, self-deluding, irresponsible and immoral (Lupton, 1995).

ii. Surveillance

Surveillance is the second factor within health promotion which assists in the control and social regulation of the population. The unit of analysis that undergoes surveillance is the population and this is done quite unsuspectingly. Health experts use biographical information and statistics to document and calculate the factors of risk in a population. They are able to diagnose a target population by determining its risk profile and, thus to offer ways of managing and confronting the health risk (Leviton et al., 1998; Lupton, 1995).

Diagnostic testing as a form of screening is a means of managing one's internal and external health risk (Lupton, 1995: 78). Diseases are unexpected and thus call for innovative methods of early detection. The reasoning adopted here is that the pattern of risk through profiling needs to be deduced before the disease can be managed rationally. Diagnostic testing is thought of as providing control to individuals in a population who have some knowledge about the diseases they may develop at some

point in their lives (Lupton, 1995). The solution to protecting one's self from unexpected diseases comes in the form of diagnostic screening or secondary prevention.

Seen as a rational solution for detecting unexpected diseases, diagnostic screening is not objective or value free. On the contrary, it is subject to the physician's and patient's social contexts, human error during the screening event, and misinterpretation by professionals during the interpretation of tests. All these can undermine whether or not screening is helpful to the patients. The entire screening experience is an emotionally laden process and the consequences of participating are seldom discussed (Foster, 1995) and under-researched (Irvine & Lum, 1997). Health promotional campaigns tend to play on one's fears, anxiety and guilt feelings in order to make screening attractive (Worcester and Whatley, 1992: 3). However, the psychological cost for a symptomatic individuals is thought to be great (Foster, 1995; Lupton, 1995). For the first time in the history of public health, asymptomatic individuals have to consider that they may have developed a disease and as a result, diagnostic screening is presented as the rational means for detecting the growth of a silent disease (Lupton, 1995).

Surveillance is prominent in women's lives and they will encounter surveillance at three sites. The first site is the general responsibility women have towards themselves since the general health promotion message is directed to individuals. The second site is "lifecycle screening activities" (Nettleton, 1996: 42) which implies a woman needs constant surveillance because of the biological changes her body experiences: menses, childbirth, and menopause. These qualities put her in contact

with more surveillance techniques than men. The third site is the home in which she is made responsible for immediate and extended family members (Nettleton, 1996: 42-43). Overall, identifying risks through the act of surveillance will occupy experts and offer many ways of managing or confronting that risk through diagnostic screening. It is also a fact that women are in a pivotal position as targets of surveillance. Let us now examine the last concept under health promotion, the self.

iii. The Rational Self

The intended result of the discourse of risk and surveillance within health promotion is the construction of a specific person possessing a rational self. The self is defined as a sense of self identity. The self (i.e., one's identity) is developed through social interactions with others. One's sense of self is not static. It is highly subjective to language and discourse in its construction and reconstruction. Recently the body has become a symbol of self-identity, that is, the body is the basis for the construction of one's social and individual selves. Consequently, the body has become an enterprise for risk analysis. The body as an ongoing project suggests that it is malleable and can change to suit its owner's needs and wants. Paying attention to the body is not only about achieving health but about how our body is perceived by both ourselves and others. The body, therefore, is another means through which we develop our sense of self and, because of the influence of others, individuals are not free and unrestrained in developing their sense of self (Lupton, 1995: 6-7; Petersen & Lupton, 1996).

The idea that the body is an unfinished project that can be shaped is appealing

to health promotional strategists. These experts view the body as a writing surface (Petersen & Lupton, 1996: 23). The concepts of the body in health promotion are grouped around personal aesthetics, the avoidance of illness and disease, and the focus on the perfect slender, healthy body. Health promotional experts aim to create individuals who are compliant with many self care regimes and who live their lives as projects under construction seeking perfection (Petersen & Lupton, 1996). Therefore, the individual body and the self are never constant but always in flux.

Individuals are able to manage the self through self care or by adopting the lifestyle theory (Petersen & Lupton, 1996:15). This theory postulates that individuals adopt rational attitudes towards health and danger. The individual adopts rational attitudes by accepting self care practices into daily routines such as exercising, eating properly and, in particular, undergoing diagnostic screening. The individual works towards being a healthy citizen whose rational choices are in line with pre-defined truths about healthy behavior. Good, healthy citizens are seen as governable since they are responsible and dutiful persons. An individual is able to control her body and emotions and as a result, becomes a rational self within a rational body.

A healthy body indicates moral worth (Petersen & Lupton, 1996: 25) since the physical body, which mirrors the self, assists in distinguishing those individuals who do and do not practice self care regimes. The individual is required to practise prudence such as self-control, self-discipline, and self-denial. The managing of the self is a requirement to being considered normal and healthy. The individual who refuses to live a prudent life, calculating and being aware of risks is considered to be immoral, irrational, irresponsible and lacking self-discipline.

Health promoters and experts focus on risks individuals can control. As we have seen under the discussion of risk, the behavioral risks are highly dependent on self-control. Under the NPH, disease is a state we can prevent by developing a prudent and rational lifestyle through risk reduction (i.e., adopting the lifestyle theory). This suggests that we choose to have a healthy life, and that individuals are free and rational agents. The dutiful citizen develops a rational self not through coercion, but through the belief that one is free to choose among health knowledges and practices that will bring them well being (Petersen & Lupton, 1996).

While a detailed description of each concept: risk, surveillance and self, is necessary, it is important to acknowledge that these concepts are interrelated and not isolated terms within NPH. Together they are a unit of strength driving the NPH. Together, these terms offer the NPH its power in health promotion. Studying these key terms separately undermines their interrelatedness and their strength as a unit and obscures what the possible overall implications are for women. By way of conclusion, I examine previous research that have considered risk, surveillance and the self.

II. Previous Research

With the exception of the Australian literature on women's health, there are few researchers who overtly identify their use of NPH as a conceptual framework for their investigations. Many researchers have applied the three interrelated concepts of health promotion either singularly or in some combination to a variety of health topics such as reproductive technologies (Beaulieu & Lippman, 1995; Becker & Nachtigall, 1994; Queniart, 1992), genetic disorders (Parsons & Atkinson, 1992), breast cancer

(Chalmers & Thomson, 1996; Gifford, 1986; Tessaro, Eng & Smith, 1994) and cervical cancer (McKie, 1995). Having said this, let us examine a study by Chalmers and Thomson (1996) which incorporates concepts such as risk, surveillance and the self.

The authors inquired into and described the meaning of the risk experience of women who have primary relatives with breast cancer. According to the breast health literature, these women are at greater risk of developing breast cancer than women without a family history of cancer. Employing semi-structured, in depth interviews the authors collected data from 55 women. The results indicated that time is a major component in assisting women in being able to resolve the risk of breast cancer. Throughout their work, a pattern emerged and three interdependent, interacting phases were identified: 1) living with the breast cancer experience; 2) developing a risk perception; and, 3) putting risk in its place. These phases which were informed by the symbolic interaction model and provided the authors with a rich view on how women come to terms with the risk of developing breast cancer. Each phase characterized variables or processes that moved the participant through the process of dealing with the perception of risk (Chalmers & Thomson, 1996).

This work contributes to the risk literature on breast cancer. The pattern discovered by Chalmers and Thomson (1996) addressed women's way of developing individual risk perception, and is insightful due to the lack of qualitative literature on women's breast health experiences. The authors use components of the NPH framework, however, do not name it as such. The study only examined the genetic risk factor and ignored all other possible risk factors that may contribute to the

development of a woman's risk perception. It has been noted that risk perception is influenced by a myriad of risk construction, most importantly one's social context. Another criticism of this study is that the issue of responsibility for one's health is ignored. This is unfortunate because the addition of other risk factors and responsibility would contribute to women's risk perception and provide an insight into how a rational self develops. Furthermore, this article did not address those women who have not developed a risk perception or an other-directed, rational self. These would be those women who rely on lay knowledge or other medical or non-medical sources of information in order to develop their perceptions of risk. In addition, the authors did not examine how the state of "being at risk" imposes self-control and social regulation on women.

As stated at the outset, the NPH has undergone little criticism in terms of women's health. The time has come to examine in-depth what implications may arise for women who do or do not engage in breast cancer screening practices using the NPH as a theoretical model. Researchers who write on the NPH have only just begun to examine the impact of breast health on women, this research is of considerable importance and a contribution to the literature on women's health. Women have been exposed to or are engaging in breast health for some time now. Using a qualitative method will benefit women by allowing them to share their breast health experiences to help identify and examine implications which may be unknown.

III. Research Questions

My research proposes to address the lack of research and knowledge about

women's experiences with breast health using the NPH as the theoretical framework.

Drawing on the NPH framework, the specific research questions guiding this study are:

- 1) How do women's social environment, personal beliefs and knowledge affect or influence their breast health behaviors?
- 2) How do women perceive breast health messages?; and
- 3) How well can the NPH framework explain women's experiences with breast health?

Thus, to complete this research, it is imperative to understand how women perceive being "at risk" and what impact this has on their health behavior. Furthermore, we need to know about the women who do not perceive themselves "at risk" and decide not to engage in health promotional strategies. Specifically, we need to explore the implications for these women when rational compliance is "assumed" in the NPH.

This research is expected to provide insight into the implications surrounding women's breast health behaviors. Hence, a qualitative approach will allow us to understand the context and the subjective experience of women's experiences with breast health.

Making use of the NPH as the theoretical framework will allow for a greater context or arena to make sense of women's BCSPs. As Peterson and Lupton (1996) suggest, the NPH is a comprehensive framework taking into account all aspects of the individual's life. That is, it may be that each woman's particular social environment such as ethnicity and economic class, will lead her to practise different prevention strategies, which may contradict the assumed need for women to engage in positive health behavior. While women who do not follow rational health directives are labeled as irrational or ungovernable citizens under the NPH model, it may be that these

women develop a rationale that is informed by many sources such as personal experiences and media sources in order to learn about their health and make behavioral decisions. The prevention information these women choose to rely on may reflect their individual psycho-social setting.

CHAPTER THREE: Research Methods

The purpose of this study is to explore women's personal breast health experiences. This chapter discusses the methods used to answer the research questions guiding this study.

Research Design

i. Method

The qualitative researcher is concerned with process and interested in the meanings people assign to everyday realities. To achieve this, the researcher participates in fieldwork to collect data, utilizes observations and interviews as the primary vehicle through which data are collected and analyzed, and builds abstractions, concepts, and theories from the details, in order to use an inductive approach to the research process (Glaser and Strauss, 1967; Strauss, 1987).

This study is an inductive study using person-centred interviewing. I conducted 16 in-depth, semi-structured interviews. Open-ended questions guided the informal interview. This open-ended question format allowed the participants to share their ideas, concerns and experiences in the interview and the research. As a result, this method "maximizes discovery and description" (Reinharz, 1992: 18) of each participant's responses. The responses to the interview questions revealed differences among participants' experiences. These differences are respected and were sought, since participants assign different meanings to everyday realities.

ii. The Participants

Women with no prior history of breast cancer were invited to participate in this research. English speaking women who were between 40-65 years of age with no prior history of breast cancer were interviewed. This age group was chosen for several reasons. First, according to the medical literature breast cancer increases with age. Second, the NPH framework assumes that all women should be engaging in BSE on a monthly basis. Third, women in their 40s in Manitoba are discouraged from obtaining a MAM and yet the literature informs us otherwise. Lastly, women in their 50s are to commence MAM screening. Overall, the selected interviewing age group depicts the age at which breast cancer screening is recommended (Manitoba Breast Advisory Council, 1995).

iii. Locating Participants

Participants were recruited through two methods. The first method of recruitment involved contacting several women's organizations in the city of Winnipeg and asking if they could post the recruitment ad in their facility (see Appendix B). The women's organizations included the Fort Garry Women's Resource Centre, Hope Breast Cancer Information and Resource Centre, Jewish Community Centre, Klinik, Mount Carmel Clinic, Native Women's Transition Centre, National Council Of Jewish Women, Women's Health Clinic, the Y.M.C.A--Women's Resource Centre/Women's Program, and Youville Centre-St.Vital. The second method was through a sampling technique known as snowballing. Once women had been interviewed, I asked them if they knew of anyone else who would like to participate in the study. The snowballing

method proved to be the most successful means of recruitment. Efforts were made to recruit women from other ethnic backgrounds, however, these efforts were in vain.

iv. Consent

Interested participants were able to phone me and arrange an appointment to meet. The initial contact over the phone assisted with screening the potential participants for accuracy of age and any prior history of breast cancer. The participants were able to ask for details of the study. At the scheduled appointment, the participants received a full explanation of this study along with an information sheet (see Appendix C). The participants had the opportunity to ask questions, and have all of their concerns addressed. Once they were informed of the study, I obtained their commitment to this research project with a consent form (see Appendix D). A consent form is viewed as a contract between the researcher and the participant. It outlined the procedure of the study, and the amount of time they would have to commit to the interviewing process. This consent form also outlined the participants' right to withdraw from the research process at any time and to refuse to answer any questions. In order to protect the identities of the women involved, pseudonyms were used in the reporting of the results. The pause or stop button of the tape recorder was in full view to each participant in an effort to make the participant feel comfortable that she could stop the interview at any time. The participant was able to be herself and decide whether or not she wanted to be recorded. Once the consent was signed by both the researcher and the participant, the interview began. The participants received a written summary of the results upon completion of the study.

v. The Interview

The in-depth, semi-structured interviews took place in non-disruptive environments. Women were given the choice to be interviewed in their home or make use of an interview room at the Youville Clinic--St. Vital branch. Interviews were tape-recorded, and the participant and I each had access to the pause or stop button. Developing a good rapport with the participants was essential. The interviewing process allowed for the development of ideas and feelings that were shared between the researchers and the participant. The interview was like a conversation where the participants had the occasion to share concerns during the interview. Therefore, the participant was not a passive contributor, but an active contributor to this research process given that her breast health experiences were the focus of this research.

During the entire research process my biases, ideas, and beliefs, known as “conceptual baggage” (Kirby & McKenna, 1989: 66) were recorded in a journal. This is very important to the research process, since it is the bond that “glues” the researcher to the participants when attempting to establish a good rapport. The threat of breast cancer and the perceptions of risks are a reality for the researcher as well as for the participants. As I myself try to make sense of the information surrounding the risk of breast cancer, the participants were able to add to my understanding of breast cancer prevention, as I hope I was able to contribute to theirs. Any notes taken in the interview were made available to the participant for corroboration. After each interview, I recorded field notes about my perceptions and key points which stood out. These notes were recorded off site where they could be properly labeled and stored awaiting coding. The note taking process was used to keep the research process

focused on content and reflections. My reflections provided me with insight while organizing and analyzing the data.

To ensure that women's experiences were documented correctly, I randomly selected five participants to discuss and verify the main themes I had identified to confirm the accuracy of their "lived" experiences. The five participants were accepting of the thematic analysis. This step in the research process ensures a full understanding of their experiences with breast health. This is seen as a form of internal validity. As a result, the participants were involved in all phases of the research. This stage in the research process is essential considering the need to accurately document women's experiences with breast health.

vi. Interview Questions

Questions focusing on women's breast health experiences are of interest in this study (see Appendix E). More specifically, women's perceptions of breast cancer risk, surveillance and the development of a rational self were at the core of the interview. Questions were developed from the literature, media, my own personal reflections and conceptual baggage. The unstructured, informal interview guide assisted in engaging the participants in profound conversations.

Divided into four sections, the interviewer first asked why the women were attracted to the ad. The probes included the location of and reaction to the ad. Then the socio-demographic and biographical questions were posed. The participant was asked her age, birth date, where she was born, place of residence, relationship status, number of children, children residing with her, ethnic origin, economic class, education

and employment status. These questions not only acted as a place to start the interview, they assisted in describing and better understanding the participant's psycho-social environments.

The second section of the questionnaire focused on the participant's general sense of health, doctor-patient interaction regarding breast health, chances of developing breast cancer and the knowledge surrounding the many risk factors known to be associated with breast cancer. They were asked to describe their overall health, any family history of serious disease, their perceived risk of developing these diseases and their reactions to developing a disease. These questions assisted me in describing their overall sense of health along with their perception of inherited diseases.

Next, I inquired about access to a regular physician. I probed with questions on what kind of doctor they see, if they have ever discussed their chances of developing breast cancer with their physician and, if so, when was this first discussed. I then probed further by asking what that conversation meant on a personal, behavioral and interpersonal level. No response lead to further probing. I then asked them to describe their first experience with BSE and CBE and any changes over time, and their level of confidence in performing these tests. This provided information about the doctor-patient relationship and how accepting the woman is of breast health information from her physician, and the women's perception of the propensity of the physician to share breast health/cancer information.

Questions then turned to their overall chances of developing breast cancer, risk level, and reaction to the often quoted statistic that one in nine Canadian women will develop breast cancer in her lifetime. I further asked them what this means on a

personal, behavioral and interpersonal level. This series of questions allowed for the understanding of what and how the participant felt about her chances of developing breast cancer and perception of breast cancer risk. The participant's view of the causes of, and risk factors for, breast cancer were ascertained, followed by details of any actions undertaken to lessen the chances of developing breast cancer. These questions helped set the stage to discuss surveillance practices.

The third section of the questionnaire examined the act of surveillance and in this case, the act of engaging in breast cancer screening practices. Here I asked for engagement in any form of breast cancer prevention and if none, why? Questions explained the experience of MAM by probing about equipment, staff, waiting for results, the meaning and implications of those results and support questions. Similarly, BSE or CBE were explored as were the personal, behavioral and interpersonal meaning attached to these experiences.

The final section addressed where women have obtained their knowledge about breast health. Questions included the sources and type of information sought and their reaction to it. I also asked for their opinion of the information they receive and whether they find the information accessible in Winnipeg. Understanding women's search for breast health knowledge provided a larger context in which to understand their perception of breast health.

Overall, these questions addressed breast health using the three major concepts in health promotion, risk, surveillance and the rational self as the conceptual theoretical framework. The three concepts of health promotion: risk, surveillance and self, are interrelated and offer greater insight together in bringing to light the

implications of breast health for women than they would separately.

vii. Transcriptions

Transcribing all the tapes afforded me the opportunity to “live with the data.” All transcribed interviews were assigned numbers and participants were given pseudonyms. On closely examining the first few interviews to verify the suitability of the questions to the responses, I found the need to clarify the wording on a few questions to add a question on hormone replacement therapy. Since the participating age group was 40–65 it became evident that hormone replacement therapy would be an issue for these women. Once two interviews had been completed, the analysis of the data began.

viii. Ethics

I was obligated to respect the rights, needs, values and desires of the participants. As a result, I was guided by the principles of informed consent which included a full explanation of the procedures involved, a description of any attendant discomforts and risk that can be expected, a description of any benefits to be reasonably expected, a disclosure of any appropriate alternative procedures that might benefit the participant, an offer to answer any questions and instructions that the participant was free to withdraw consent and discontinue participation at any time without prejudice (Baker, 1994; Neuman, 1997). This research was approved by the Department of Sociology Research Ethics Review Committee.

ix. Analysis of Data

Analysis of the data is an interactive process between myself and the data. In making sense of the data, I used the constant comparative method within grounded theory (Glaser & Strauss, 1967; Kirby & McKenna, 1989). Comparison of the first two interviews initiated the coding procedure and allowed for the linking of the data. Coding is a process whereby the researcher labeled, separated, compiled and organized the data. The participants' responses were coded line by line then paragraph by paragraph. The characteristics of the pieces of information coded emerged into categories. In other words, when certain pieces of information or concepts continually arose out of the data, it was identified as a category. The second step in the analysis was to write a description of the categories. Known as memoing, written descriptions of the categories were not completed until all the interviews had been transcribed and coded. A category reached the point of saturation when new pieces of information did not reveal any new understandings. With the data in categories, the third step was to examine the relationships between the many categories. While examining the relationship between the categories, diagramming the relationships between the categories assisted in the development of the major themes (presented in Chapter Four). Hence, the categories found to have links were organized into major themes. While immersed in the data, observations arose in contrast or in likeness to the NPH theoretical framework. These observations appear in the discussion chapter (Chapter Five). I then proceed to the next phase of the research, the reporting of the data (Corbin, 1986a; 1986b; Glaser & Strauss, 1967: 105-115; Kirby & McKenna, 1989; Lofland & Lofland, 1995; Strauss & Corbin, 1990; Swanson, 1986). Therefore, by

constantly comparing the pieces of information, developing categories and diagramming to assist in the emergence of themes, I have been able to present women's breast health experiences.

II. Summary

In sum, the objective of this research is to explore women's breast health experiences using the NPH model. Hence, this research explored the experiences of 16 women with their breast health.

The following chapter provides the results of this study including a summary of the women who participated and the presentation of the major themes.

CHAPTER FOUR: Research Findings

This chapter is divided into two sections that present the findings of this study. The first section describes the sixteen women who participated. The second section addresses three themes which emerged from the data. The three themes are: **Breast Cancer Risk: Family Matters; Breast Cancer Prevention: Peace of Mind?; Rational Self: Under Construction.** These themes capture the main experiences arising from analysis and interpretation of the interview transcripts.

I. The Women Who Participated

The women in this study shared their unique and common experiences with breast health as well as socio-demographic and health information. These latter data are organized and presented in Table 1. At the time of the interview, the women's ages ranged from 41 to 65 years with a mean age of 53. The average years of education were 11. A majority had entered business college or enrolled in a few courses at a University to obtain employment. One participant was near completion of a graduate degree. Fourteen participants were employed either part-time or full-time, and two participants were retired. One retiree volunteered in her community. One half of the sample were married, five were divorced, two were single and one woman was widowed. Thirteen women had borne children and two were single parents. All the women who volunteered to participate in this study were Caucasian and of European descent. All had known someone who had experienced or died of some form of cancer. Fifteen participants had lost an immediate family member to some form of cancer. The remaining participant's best friend had died of breast cancer and a

Table 1.
Socio-demographic Characteristics
of Study Participants (N=16)

Age	Respondents*	Education in years	Employment	Marital Status**	No. of Children	Ethnic Group	Family History of Other Cancers
55	Trudy	10	Full-time	M	2	Scottish	Brother terminal with prostate cancer.
60	Joy	12	Full-time	D	3	English-Canadian	Sister treated for bladder cancer.
65	Olivia	12	Retired	W	2	Irish- Welsh	Father deceased-lung cancer. Sister deceased bone cancer.
40	Wendy	12	Full-time	M	-	Ukrainian	Uncles deceased-leukemia.
59	Jane	11	Part-time	D	2	English	Father deceased-bone cancer.
61	Gloria	11	Part-time	D	3	English	Father deceased-bone cancer.
56	Stacy	12	Full-time	M	4	Anglo-Canadian	Cancer on father's side of the family.
65	Lynn	12	Full-time	D	2	Ukrainian	Mother deceased-stomach cancer. Sister deceased-liver cancer.
42	Joyce	10	Full-time	S	1	Ukrainian -Dutch	Parents deceased-lung cancer.
42	Lori	12	Full-time	D	-	Czechosllovakian	Father deceased-type unknown.
41	Lee-Ann	12	Part-time	M	3	German	Cancer on father's side of the family.
53	Heather	12	Part-time	M	3	English	Mother and aunt deceased-breast cancer.
46	Dec	10	Full-time	M	2	Italian	Maternal aunt-cyst removed.
63	Marie	10	Retired-Volunteer	M	3	Irish-French	Father deceased-colon cancer.
53	Tammy	11	Full-time	S	1	French	Father deceased-colon cancer.
46	Penny	12	Full-time	M	-	English	Girlfriend deceased-breast cancer.

*Names are pseudonyms

**M=Married, D=Divorced, S=Single, W=Widowed

distant relative had recovered from a mastectomy for breast cancer.

As seen in Table 2, the breast health history of the participants varied. Twelve out of the 16 women stated they had experienced breast problems. Eleven presented themselves to their physicians with various breast problems such as breast soreness, sensitivity, lumpy glands, rash or suspicious lumps over the years. Of the 11 women, five had experienced breast surgery such as the removal of a cyst, a biopsy of a lump or the draining of a gland. Three of these five women have a family history of breast cancer. Of the remaining two women, one had no history of breast cancer in the family and the other woman's family history was unknown as she is adopted. Returning to the 11 women who had presented themselves to their physicians, six did not require surgical treatment. A rash was treated with antibiotics and the others were investigated with both a CBE [4] and a MAM [5]. Five of these women were without a family history of breast cancer while one woman's aunt had had a cyst surgically removed.

There are four women who had not presented themselves to their physicians with breast problems. Of these four women, one participant's mother died of breast cancer. The remaining three reported no family history of breast cancer.

Overall, two-thirds of the sample presented with breast problems. Only five had a family history of breast cancer. Four women had surgery performed on their breasts. Only three women were without both breast problems and a family history of breast cancer. No one woman thought she was risk free of breast cancer.

4. CBE denotes clinical breast examination.

5. MAM denotes mammogram.

Table 2.
Health Characteristics
of Study Participants (N=16)

Age	Respondents	Self-Reported Breast Problems	Family History of Breast Cancer	Self-Rated Breast Cancer Risk	Other Self-Reported Health Concerns
55	Trudy	-	Mother deceased.	Unknown	Skin cancer. High blood pressure.
60	Joy	-	-	Low	Diabetes, arthritis.
65	Olivia	Sore left breast.	-	Low	Arthritis.
40	Wendy	-	-	Medium	-
59	Jane	-	-	Low	Arthritis.
61	Gloria	One breast larger than the other.	-	Medium	Arthritis, Asthmatic, Hemorrhoids, High blood pressure.
56	Stacy	Benign lump removed.	Sister deceased.	Medium	Skin rashes.
65	Lynn	Cyst removed from nipple area. Sore left breast.	-	Medium	Osteoporosis, Asthmatic, Esophageal hernia.
42	Joyce	Breast sensitivity.	-	Low	History-cervical cancer.
42	Lori	Rash, breast sensitivity.	-	Low	Several allergies to cosmetics.
41	Lee-Ann	Lumpy breast.	-	Low	Osteoporosis.
53	Heather	Several lumps drained.	Mother and aunt deceased.	High	Breast implants. Considering a double mastectomy.
46	Dee	Lumpy breast.	Maternal aunt-cyst removed.	Low	Kidney stones.
63	Marie	Benign lump removed	Maternal aunt-radical mastectomy.	Unknown	-
53	Tammy	Cyst removed.	Unknown.	Unknown	-
46	Penny	Breast sensitivity.	-	Low	-

Collectively, the women considered themselves relatively healthy even though each had other unique health concerns. These socio-demographic and health characteristics provide the context for examination of the three major themes which emerged from the data.

II. Major Themes

In analyzing the transcripts, three major themes were identified that capture the participants' reported meanings of, and experiences with, breast health. The first theme examines women's breast cancer risk perception by examining three categories: inheriting family diseases, personal breast cancer risk, and the opinions of health professionals. The second theme reflects experiences with, and meanings of, breast cancer prevention. The third theme inquires into the participants' selves. These themes are not mutually exclusive and together they offer a clearer, if not a different view of women's breast health choices. Figure 2 offers a delineation of themes.

Figure 2.

Theme Delineation

Theme Title	Sub-Category Title
Breast Cancer Risk: Family Matters	Inheriting Family Diseases Breast Cancer Risk Perceptions Experts Discussing Breast Cancer Risk
Breast Cancer Prevention Strategies: Peace of Mind?	Breast Self-Examination Clinical Breast Examination Mammography Diet and Exercise Breast Health/Cancer Information
The Rational Self: Under Construction	Ways of Knowing Powerful Others Taking Charge

i. Breast Cancer Risk: Family Matters

The title of the theme reveals women's over-reliance on breast cancer not being in their family which for them translates into a low breast cancer risk. Breast cancer risk is always clinically derived from one's family history of cancer (Chapter One). More specifically, the medical research community adamantly supports the genetic cause of breast cancer development and consequently classifies the risk of breast cancer development by family history of cancer. Therefore, family history of cancer contributes to one's risk level of developing breast cancer.

Inheriting Family Diseases. Understanding the participants' perceptions of inheriting family diseases lays a foundation for interpreting personal perceptions of breast cancer risk development. Considering the differing viewpoints on inheriting family diseases is important because of the increased risk of developing breast cancer if it appears in one's family. For these respondents, family histories of diseases included some form of cancer including breast cancer, heart and respiratory diseases, diabetes, Chrono's disease, osteoporosis and/or arthritis (see Table 2).

For those women with no history of breast cancer in their family, the risk of inheriting family diseases was expressed in terms of a known and present family disease. For example, Lynn's mother died of stomach cancer and today Lynn (age 65) has a variety of health problems including similar stomach problems. When asked about the risk of developing family diseases, she stated:

They watch my stomach very closely and particularly now with the esophageal hernia, it is frightening. You can't help but wonder if it is going to be the next thing that will happen.

Similarly Gloria (age 61), who suffers from severe arthritis in her knees and has undergone one knee replacement surgery, and whose father died of bone cancer responded:

It does run through my mind with all the aches and pains [that I experience]. That is how Dad went through it, you know. It started out with pain in his shoulder that was unbearable. They eventually found it [cancer] in his left knee. When the doctor talks to me about arthritis I always question that. It reminds me of him. It is ironic that the knee that was replaced is my left knee.

A few women recited family diseases as a check list and then stated that breast cancer was not in their family. To illustrate, Wendy's (age 40) grandfather died of late life onset leukemia as did every one of his sons. Her mother and her remaining female siblings were viewed as so healthy that they "[could] run the Boston marathon." Wendy stated with certainty that there was no chance, "not really" of developing any of the family diseases. She took comfort in the fact that only the uncles became ill in their later years, while her aunts remain very healthy. Likewise, Joy (age 60) stated that cancer "...[was] so far removed." However, the family was astounded when her sister was diagnosed with benign bladder tumors, as their family history included only diabetes, arthritis and heart disease.

For three women, breast cancer was part of their family health history. When asked about developing family diseases, their responses ranged from accepting to not accepting the family risk of breast cancer. Heather's mother and aunt died of post menopausal breast cancer long after Heather (age 53) had had breast implants at the age of 40. She was realistic about her chance of developing breast cancer:

Well...it scares me. I have implants and it is a different game for me. I don't think I would have gone for the implants had I known.

Conversely, Marie (age 63), who discovered her own benign lump many years ago, practised an avoidance technique, i.e., not thinking about it. She preferred to ignore her family risk of breast cancer.

I really don't think of it. If I get it, I get it. If I don't, I don't. You know, I just don't think about it.

Stacy (age 56) demonstrated another avoidance technique, i.e., not talking about the risk of developing breast cancer but speaking of some other disease. Stacy and her two siblings had experienced a breast biopsy. Stacy's youngest sibling died of breast cancer. However, Stacy's response had no mention of breast cancer as a family disease.

Heart disease worries me somewhat less than cancer because my diet is somewhat different than my parents would have been. Although that may be counterbalanced by the effects of pollution, additives, chemicals, etc.

An adopted woman with an unknown family disease history had a religious view about inheriting family diseases. Tammy (age 53) demonstrated her spirituality:

I don't worry about it. Everybody has to die of something, someday. It could be cancer, heart attack. When God is ready for me He will come and get me and it'll be of something or other but we all have to go, one way or another, that is my philosophy. I don't anticipate that it is going to happen tomorrow, you live for today.

Lastly, two women demonstrated their suspicions about relying on a family disease history when determining the inheritance of family diseases. Lori (age 42) who lacked specific health information about her father, other than he died from an unknown type of cancer, offered her view:

In terms of the heart problems, certainly. That seems to be running through the family so, aside from that there doesn't seem to be, I mean it is always a concern whether cancer runs through a family. It doesn't mean you can't

develop it. So there is always the fear and the older you get the more of a concern it becomes.

Penny (age 46) voiced similar skepticism. Describing her family as healthy, she also revealed that her father had just been treated for prostate cancer and that another family member had bowel cancer. However, she believed that the two cancer episodes were brought on by life choices. She said this about the risk of developing family diseases:

I hope not. You do all the right lifestyle choices that you can but if there is something in your system you know? I really don't know where cancer comes from sometimes but I strongly believe it is lifestyle choices that help prevent it.

Therefore, like Lori, Penny did not depend on family history when considering whether she would develop any known family diseases. She explained that the two episodes of cancer were related to lifestyle.

To summarize, women with no history of breast cancer in their families claimed that they would likely inherit other family diseases. For those few women with breast cancer in their family history, accepting the family risk of breast cancer was acknowledged in varying ways. Religion played a role in one adopted participant's life. Two women voiced their skepticism regarding the inheritance of family diseases. The above differing perspectives on the risk of developing family diseases offered insight as to how these women perceived the possibility of developing known family diseases. Although few participants reported a family history of breast cancer, the majority reported being at risk for other types of cancer such as liver, stomach, colon, cervical and bone. Hence, breast cancer, for a majority of these participants was not a familial disease.

The next category to examine is personal risk perception of breast cancer development. More specifically, at what level would these participants rate or describe their personal risk of developing breast cancer? This next category is linked to the previous category because one's personal breast cancer risk perception is determined, in part, by considering one's family history of cancer. This supports the medical research discourse that breast cancer is a genetic disease. A few participants expressed caution even though breast cancer was not in their family. This subsequent category examines what women perceive in their psycho-social environment as contributing to their personal breast cancer risk. Psycho-social environment is defined as taking into account the individual's whole psychological, social and physical contexts (Petersen & Lupton, 1996). Furthermore, this category is linked to the theme label because the majority of the participants do not have breast cancer as a family disease, while for five participants it is a looming reality. What other factors are the participants considering when assessing their personal breast cancer risk?

Breast Cancer Risk Perceptions. Identifying and understanding the participants' personal perceptions of breast cancer risk are central to this study. Better comprehension of women's breast cancer perceptions may offer a clearer understanding of their breast cancer screening behaviors. In response to the open format question, "What do you think your chances are of developing breast cancer?", the responses were organized into four risk categories: low, medium, high and do not know.

Half of the sample ranked their personal breast cancer risk as low and did so

for a variety of reasons. For four participants, knowing that breast cancer had not appeared in their family history of diseases was comforting and offered a sense of security. For example, Joy (age 42) stated:

Low, I am not trying to sound overconfident or anything. There is only one incidence of it [sister treated for bladder tumors] and it seemed almost minor. I don't think cancer is ever minor but it was there and it was gone with my sister. And besides it was never breast cancer.

The second reason was offered by two women who combined absence of breast cancer with a healthy lifestyle. For example, Jane (age 59) rated her chances as low:

....because so far no one in my family has had breast cancer and I am not doing anything that I shouldn't be doing. I don't drink and I quit smoking.

A third reason introduced a degree of doubt into the positive ratings of the others.

Two women found little comfort in knowing that breast cancer was not part of their family history. They both noted:

I suppose there is always a chance. It isn't something that is prevalent in my family. Low, for all I know it may be there. You can't rule it out because it isn't in your family. (Olivia, age 65)

I think there is a chance everybody can. But being realistic, anybody can develop breast cancer so basically I am just hoping that it's low. I can't say that I have any comfort level on thinking that it is going to be low. There is no woman who is not at risk. (Lori, age 42)

Olivia was aware that breast cancer can be present for approximately seven years before mammography can detect its presence. Lori, on the other hand, was conscious that carcinoma of the breast is a non-discriminatory disease and that no woman is risk free. Therefore, these two women stated low breast cancer risk based on their individual psycho-social contexts. However, they were not entirely comforted by their stated low risk because “there is always a chance.”

Being at medium risk for personal breast cancer was identified by four respondents. Among the many known risk factors associated with breast cancer, four different risk factors were used as support for their ratings. The risk factors identified were smoking, taking estrogen, stress and undiagnosed breast soreness. For example, Wendy (age 40) recognized the risk of smoking cigarettes and stated:

....I am not a heavy smoker but the fact that I smoke bothers me because I wonder to myself, "O.K., could it develop somewhere else and go into the breast. I don't know."

Likewise, Gloria (age 61) who is a long time user of Premarin [6], is aware of the dangers associated with taking hormones for menopausal symptoms. Although she expressed concern, Gloria was not willing to experience the side effects of menopause. As she articulated, "...there are also good points of being on estrogen. The trade off is better." That is, she is trading off or exchanging menopausal symptoms such as bone density loss and the possibility of bone fractures for the possible risk of developing endometrial and/or breast cancer (Foster, 1995). Thus, some women tried avoiding certain risk factors by trying to quit smoking and avoiding stressful situations. Another participant traded one risk for others. As noted above, the women who identified themselves as being at medium risk for breast cancer related their rating to their own psycho-social contexts.

Only one woman identified herself as being at high risk. Not only had she had a first degree relative die of breast cancer, she also has had breast implants. Since she has had many lumps drained and removed, she said this of her risk level:

....all lumps have come back benign. I think one day I will....get breast

6. Premarin is an oral estrogen supplement commonly prescribed to women to prevent menopausal outcomes such as osteoporosis (Foster, 1995).

cancer. Family history and my own history, I think that one of these days one of these lumps is going to be malignant. I don't think the implants help. I would be playing a different game if I [had] known about my mother and aunt. (Heather, age 53)

In order to reduce her risk of developing breast cancer, Heather has considered and has spoken to her physicians about undergoing a double mastectomy.

The remaining three women were unable to rank their personal risk of developing breast cancer. Tammy (age 53) who had a cyst removed from her breast when she was 19 and has had no other breast problems since stated she had “no idea.” Tammy is adopted and has an unknown family history. Despite giving birth to a child in her 30s, being an ex-smoker and experiencing post-menopausal obesity, she was unable to assess her risk. Aware of some risk factors, this participant paid little attention to them when explaining her risk level.

The other two remaining participants who declined to assess their risk of developing breast cancer reported having breast cancer in their families. One woman, whose mother died of breast cancer, depended on her physician to monitor her risk.

No, I don't think a whole lot about it. If I dwelled on it, it would drive me crazy. As long as I have my regular examination and both myself and my doctor and the mammogram I feel confident that if anything is going to happen it will get picked up. If the doctor is not worried then I am not worried. (Trudy, age 55)

Although Trudy did not provide a risk “score,” she is taking action because she feels some risk and is hoping for an early stage diagnosis. The other participant who had had a benign lump removed placed her faith in God and revealed that:

...I like to think positive and that doesn't mean I am not going to [develop breast cancer] but I don't think in those terms that you are asking. I have faith in God and I trust Him and I know if it happens, it doesn't mean because

I have faith I am not going to get it, but I trust and believe He would not have me dwelling on it. (Marie, age 63)

Marie did not dwell on either breast cancer or her breast cancer risk. Therefore, the three participants who claimed they were unable to assess their personal breast cancer risks were willing to either rely on powerful others whether it be a religious supreme being or a medical doctor, or to “claim” disinterest. Awareness and interest in acquiring knowledge about breast cancer risk factors appeared to be of little importance to these women.

Overall, some women relied on the lack of breast cancer in their family to rate their chances as low. These women obtained a sense of comfort or security knowing that breast cancer was not in their families. Other women who rated a low risk combined absence of breast cancer in their family with a healthy lifestyle and caution with their “low risk” rating because as Olivia stated, “...for all I know it may be there”. A few more women identified with specific breast cancer risk factors (e.g., estrogen, stress) and acknowledged a medium risk for themselves. Only one woman saw herself at high risk of developing breast cancer. Three participants were unable or unwilling to assess their breast cancer risk but took action by engaging in CBE and MAM for early-stage diagnosis. Not one participant thought of herself as being risk free of breast cancer. This even included the three who were unwilling to rate their breast cancer risk. Hence, indirectly, those three women who were unwilling to assess their breast cancer risk did see themselves at some risk of developing breast cancer and hoped for an early diagnosis.

The final category of this theme is the reported opinions of experts such as

physicians on the participant's risk of developing breast cancer. This subsequent category is linked to the previous category because what physicians have to say may or may not influence the participants' perception of breast cancer risk development. More precisely, the physician's knowledge is based within a genetic/hereditary frame of reference. This sets the stage to examine the final category of this theme, experts or physicians talking about breast cancer risk with their patients.

Experts Discussing Breast Cancer Risk. In addition to the role of family disease and the perceived personal risk of breast cancer, the reported opinions of experts such as physicians were solicited from the women. What physicians had to say regarding the participants' breast cancer risk is of interest because it may or may not influence the women's perceptions of breast cancer risk. The breast cancer risk discussion between the participants and their physicians is another aspect of the participants' psycho-social environment which needs consideration. Using data from an open format question, three responses were identified: no discussion, no discussion with examination and discussion alone.

Four women reported they received no discussions of breast cancer risk; all have no history of breast cancer. It was suggested by the women that such a discussion is unnecessary since no one has had breast cancer in their family. Tammy (age 53) who is adopted stated:

....I have never discussed chances with the doctor. The doctor is aware of the removal of the cyst at 19 years of age. It [risk] doesn't mean much to me because I don't think I am at high risk of it. I am sure if he thought I was he would have done something. The doctor is pretty good to me.

For two women in this group, not having a regular physician resulted in no discussion about breast cancer risk. Dee (age 46) noted:

....I don't have a steady doctor and I am not one of these people who runs to the doctor every second day. I have not had the chance to speak with a physician regarding my risk of developing breast cancer. (Dee)

Therefore, not having a family history of breast cancer and not having a regular physician were seen as the reason for no discussion of breast cancer risk between the participant and her physician.

Three women in the second group, no discussion with examination, were all given a clinical breast examination (CBE) by their physician and sent for a mammogram if the physician thought it necessary. Olivia (age 65), who has lived many years with a constant sore left breast, had little discussion time and yet the physician sent her for a mammogram. Olivia stated with frustration:

It is always the same breast that is sore. She sends me for a mammogram every two years. They never find anything.

Similarly, Joyce (age 42) has had breast problems in the past. Her physician of many years had not discussed risk with her and yet did not hesitate to perform a CBE. It is unlikely that Joyce will force any discussion time given her concern for her doctor rather than for herself:

No, we have never discussed breast cancer risk. He is a very busy man.

Therefore, the women in this group who presented with breast problems had their complaints met with an examination by the physician. A discussion of breast cancer risk did not ensue.

The third and last group included nine participants who received discussion

time alone but no breast screening. This group was comprised of four women, each who had a first degree relative die as a result of breast cancer. Each of these four women had discussed breast cancer risk with their physician; however, only one had an in-depth discussion. Heather (age 53) who has breast implants stated that she had spoken of breast cancer risk with both her family physician and plastic surgeon. The last time the same lump was drained for fluid build up, she asked her surgeon what he thought of removing the implants and the breast tissue. He replied, “....you won’t get an argument out of me.” However, she was also reminded by the surgeon that just because she would then not have breasts, it did not mean that she would not develop breast cancer. That is, breast cancer sometimes appears in the chest wall and not necessarily in the breast itself. Heather is thinking of lowering her breast cancer risk. Her physicians have given her their professional opinions and have shared their knowledge. The discussions with her physicians assisted her in making an assessment of her personal breast cancer risk as being high.

The remaining five women in this group engaged in discussions with their physicians only when they presented with a breast problem. For example, when Lori (age 42) presented with a breast problem, her physician only then took the time to discuss breast cancer risk.

....Breast cancer has been brought up only in passing. Not a really long in-depth discussion.of course when I went to her with the rash and so we talked about it. She suggested a mammogram at the time because she was not 100% sure it was a rash.

When Jane (age 59) decided to take Premarin once she had her ovaries removed, the physician spoke to her about the breast cancer risk associated with taking estrogen.

She stated:

....that is when he told me, make sure you always examine your breasts. And if you feel a lump, phone me right away. So far I have been lucky.

Therefore, these five women reported that discussions took place when they presented with breast problems or when the risk of developing breast cancer was heightened with the use of Premarin.

Overall, those women with no family history of breast cancer reported not receiving discussion time with their physician about breast cancer risk. The women with a family history of breast cancer and those with breast problems received discussion time coupled with a breast examination by the physician. Allowing the women to speak about what their physicians have told them regarding their risk of developing breast cancer is another facet of the participants' psycho-social environment which influences their perceptions of breast cancer risk.

Summary. Collectively, women with no family history of breast cancer claimed they would likely inherit a different, known family disease. Those women with a family history of breast cancer either accepted or rejected their family history. All but three women considered their psycho-social contexts or environments such as family history and risk factors when ranking their risk of developing breast cancer. No one saw herself as being risk free of developing breast cancer. Participants with no family history of breast cancer did not engage in/or were not engaged in/or did not discuss risk. Those women with a family history of breast cancer and breast problems received a discussion coupled with an examination. These data suggest that women's thoughts on inheriting family disease and the physician's words and advice can have an

impact or influence women's perceptions of breast cancer risk. The three categories which describe the theme label, **Breast Cancer Risk: Family Matters**, suggest that women find great comfort in knowing that breast cancer is "not in their family." This mode of thinking is further encouraged because their physicians have not told them otherwise through a discussion and more poignantly, that breast cancer is not part of their family history. Hence, this may be construed as those women with no familial/genetic link to breast cancer may conclude that they have a low risk of developing the disease.

ii. Breast Cancer Prevention Strategies: Peace of Mind?

The second theme examines what the participants did for themselves in terms of breast cancer prevention. As previously noted, all women are at risk of developing breast cancer, some more than others. The title of this theme reveals that through breast cancer prevention strategies the participants procured a questionable sense of "peace" or equanimity in how they engaged in monitoring the development of breast diseases. This theme addresses the participants' experiences with breast cancer screening practices such as BSE, CBE and MAM. Additional prevention strategies such as diet and exercise patterns are also examined, as is how breast health/cancer information impacts on the women in the study. Having understood what contributes to women's breast cancer risk perception in Theme One helps us appreciate their behavior towards breast cancer prevention.

Breast Self-Examination (BSE). Women of all ages should engage in monthly BSE since it is a means in which women become familiar with their breasts so

as to recognize any breast changes. However, the frequency of BSE among the women in the sample was low. The participants' responses were organized to reflect three levels of practice; frequent, infrequent and no BSE. There were only three women who practised frequent BSE. All three women had incorporated BSE as part of their hygiene regime. One woman adopted BSE in her personal hygiene routine immediately after receiving breast implants. Heather (age 53) stated:

....The really first time that I did it was after the implants. And the reason why? When you had them [implants] done at first and for the rest of your life you had to manipulate the implants. Squeeze them every single day to keep them from hardening and keep the scar tissue from forming and encapsulating them. I incorporated BSE into the routine care of the implants.

Dee (age 46) became aware that her breasts were sore and lumpy at adolescence. She was frightened by enlarged glands and saw her doctor immediately. Since being taught, Dee practises BSE as often as she can. She noted:

I was always aware of it and I always made a point to checking often and not just checking in here, but actually in the armpit which I was never aware of that before. I check a lot of times at night before I go to bed or after a bath or shower.

Consequently, these three women demonstrated how easy it was for them to engage in frequent or monthly BSE. However, all three participants had experienced problems with their breasts. As a result of their individual experiences, BSE was routinely practised. As Tammy (age 53) noted, "....[BSE] is like washing your face, you go to bed and do it automatically."

The majority of women stated that they practised BSE infrequently. Many of these women stated they felt "silly," "clumsy," "hope I am doing it right," "confused over how things should feel," "I don't know what to look for," and "I have no idea

what I am doing” when they first started practising BSE. Despite several years of practising BSE infrequently, these women continued to have mixed feelings about the practice. Some commented that they are still confused over how their breasts should feel. For example, Gloria (age 61), who had been taught how to do BSE by her physician of many years stated:

...I know we are supposed to do BSE often but I don't. I don't know why. It could be in there and you may not even feel it.

Lynn (age 65) echoed similar words:

....I honestly feel that I don't necessarily know what I am doing or what I am looking for. You know your body has so many lumps and bumps anyway. I don't feel it's [BSE] necessary. (Lynn)

Other women from this group stated a positive change from their first experiences.

....the experience is much better now. The nurse who has taught me over the years is excellent. (Trudy, age 55)

....I would say that I am getting better at it. For sure. (Wendy, age 40)

....Well I think over the years...you get to learn what you are looking for because you know how things are suppose to feel. (Joyce, age 42)

Two more women spoke of sharing the responsibility of doing BSE with a spouse.

Wendy (age 40) stated that she would sometimes relinquish the act of examining her breast to her spouse while they were intimate. Jane (age 59), who is divorced, stated with uneasiness that she would find her own lump since she did not have “a male companion in her life.” This seems to imply that there is only one person and not two who could find the possible lump. Hence, her chances of lump discovery are potentially lower since she is single. Jane also noted her insecurity on doing BSE:

....I keep thinking I hope I am doing this right. And to me, well, if I do find a lump, I wouldn't know, or something strange, I don't know what it is suppose to feel like.

Although the women at first reported feeling incompetent and confused engaging in BSE, time for comfort with practising BSE and education have resulted in positive attitudes. However, this has not translated into regular compliance.

The remaining three women in the study stated that they did not engage in BSE for reasons based on other factors. For example, Joy (age 60) is struggling with two arthritic knees and is financially unable to take time off work for knee surgery. In addition, she is diabetic and does not eat well and as a result has difficulty controlling her sugar levels and ultimately her weight. She noted:

I feel silly doing it and [would] rather concentrate on other more important health matters and besides breast cancer is not in my family.

Stacy (age 56) whose younger sibling died of breast cancer, shared that she used to frequently engage in BSE, however, no longer does so. She believes that now she understands what generated the breast discomfort and BSE is no longer necessary.

Stacy suggested that she would rather understand what generated the breast discomfort and make adjustments to her diet, stress and exercise regime than worry about practising BSE. She stated:

I did for a period of time, I confess I don't anymore. I finally, together with the doctor, decided that it was due to caffeine; that was causing all the tightness. And since then, with a decent intake of coffee, [it] doesn't appear anymore.

Knowing these women's psycho-social environments in which their decisions to no longer engage in BSE were made allows us to better understand their breast cancer

screening behaviors. The decisions to not engage in BSE varied from other health concerns taking priority, educating oneself, to not wanting to do BSE.

Factors which promote and/or inhibit the practice of BSE emerged in the women's responses. For example the level of confidence in one's ability to practise BSE appeared to strongly affect reported performance levels. Women's degree of confidence for doing BSE was solicited and the responses varied from having no confidence at all, to low, medium and high. Levels of confidence were combined with the aforementioned adherence categories. Accordingly, the three women who reported that they practised frequent BSE also reported high levels of confidence. For example, one woman stated:

I have found all of my lumps. I do know what they feel like. I feel very confident. (Heather, age 53)

The other two women were taught by health care professionals during their late adolescent years and have since always engaged in BSE. Tammy (age 53) stated:

I was 19 years old when they showed me how to do BSE. I feel very confident, I do it every night. It is like washing your face, you go to bed and I do it automatically.

Factors such as breast problems and being taught BSE by a health professional appeared to promote the practice of BSE. Furthermore, high levels of confidence contributed to these women's continued and frequent practise of BSE.

The level of confidence with the ability to do BSE varied greatly for the majority who stated an infrequent level of BSE practice. This group's responses ranged from no confidence at all to high confidence. One participant stated a low level of confidence, four moderate confidence, two high confidence and three stated no

confidence at all. For example, three women who claimed no confidence at all in doing BSE noted:

I don't do it half the time. I'll do it if my breast is bothering me. I know I should check more often. (Olivia, age 65)

I know we are supposed to [do BSE] often but I don't. I don't know why. (Gloria, age 61)

The two women who responded high confidence with the ability to do BSE but infrequently practised stated:

I do it when I remember to do it. I don't have any menstrual period so its when I remember. I should be more on top of things. (Trudy, age 55)

....you will see in a magazine or something and it will click in your head again so you know you make sure you do everything that they are saying. The doctor says you should do self-examination. So I try to do that on a regular basis. (Penny, age 46)

Low or high levels of confidence were found to either inhibit or promote the practice of BSE. Forgetting to do BSE was a common response for all the women in this group. Levels of confidence could be construed as inhibiting for those women who all had been taught BSE by either their physician or a mammography technician. Their responses suggested that BSE teaching from a health professional often did not carry influence for the subsequent practice of BSE.

The three women who do not engage in BSE reported varying confidence levels with the ability to practice BSE. Two of the three women stated they had no confidence while the third had moderate confidence. In addition, a third variable which influenced the use of BSE amongst these women emerged. All three non-BSE practising women transferred the responsibility of breast examination to a powerful

other such as the physician to perform a clinical breast examination. Joyce (age 42) noted:

...I don't do it on myself. Just yearly during my physical at the doctor's office. I have no confidence at all.

To summarize, the majority of the women did not adhere to monthly BSE despite having been taught by a health professional. Some women have incorporated BSE into their personal hygiene routines. Others were still confused with respect to their own breast structure and relied instead on their physicians for a CBE. One woman shared the practice of BSE with her spouse. Lack of confidence, forgetting to do BSE, and over-reliance on physicians were found to limit or inhibit with BSE practice. In contrast, women who experienced a breast problem and were taught BSE by a health professional, were found to practise BSE. The participants were aware of the benefits of practising BSE and the screening recommendations, but only some have translated their knowledge into action. Hence, practising BSE for a majority of the women did not evoke feelings of peacefulness, but of confusion.

The related category to examine is women's experiences with clinical breast examination (CBE). This next category is linked to the BSE category not only because it is the second modality for breast cancer screening, but some women preferred not to engage in BSE and thus rely on a health professional to perform a CBE. This and other experiences will be uncovered in the next category. This CBE category is linked to the second theme label because, like BSE, few women developed feelings of peacefulness or reassurance when having a CBE performed. Although the CBE is often done in a medical environment such as the physicians office or in a breast

cancer screening clinic by health professionals, it left a majority of the participants feeling vulnerable.

Clinical Breast-Examination (CBE). All the women in the study had experienced CBE in routine physical examinations by their physicians. Almost half of the sample had presented to their physicians with breast problems and had a CBE done outside the realm of a routine medical check-up. Participants were asked to describe their first experience with CBE. They responded:

....I was pregnant. I was embarrassed and I was too young. (Jane, age 59)

....of course it was embarrassing. You are sort of vulnerable laying there.
(Gloria, age 61)

...I sat there closed my eyes and turned red. It is quite embarrassing.
(Joyce, age 42)

These women stated that over time the CBE experience had improved for them.

However, a few commented that they just stare at the ceiling and talk about something until it was over. Although all the women have had several examinations done by their physicians, the experience still leaves them feeling vulnerable.

The concept of “thoroughness” emerged while women discussed their CBE experiences. Thoroughness had various meanings for the participants in the study. For some, a lengthy relationship with the physician and the extensive examination, such as palpating the under arms to feel the lymph nodes and in the chest area to feel the breast bones were characteristics of thoroughness. For example, Trudy (age 55) who practised infrequent BSE, has had the same physician for many years and said:

....he just covered every square inch of my breast and he was far more thorough than I was myself.

Similarly, Lee-Ann (age 41) who concurrently was participating in a menopause study felt that she had access to the best information and physicians. She noted:

...My doctor is always thorough and gets me in at periodical times.

Conversely, the CBE experience for Penny (age 46), who is in search of a permanent family physician, found the examination incomplete. For Penny, the CBE was performed too quickly:

...to me, I would do a better job than she would...she seemed to rush through it pretty quick compared to when I do it myself. I go under the breast and into the armpit.

The data suggest that to these women, a thorough CBE is characterized by having a lengthy relationship with one's physician and the physician paying in-depth attention to the examination.

Another meaning of thoroughness was the pain that could be associated with doing a CBE. Two women associated thoroughness of a CBE with experiencing pain during an examination. They stated:

...yeah, she pressed really hard I remember. She [the doctor] probably was making sure she was going to do it thorough. I do have fairly large breasts. (Wendy, age 40)

I find that when the doctor does it as opposed to when I do it myself it is quite painful. Obviously they press on tissue considerably more than I do. I don't do it to cause me pain; obviously I don't do as thorough a job of it as they do it. (Lori, age 42)

Even though both women indicated moderate confidence when they perform BSE, not experiencing pain was considered an inadequate or incomplete examination since, in their minds, thoroughness equals pain. The intensity of examination for both of these participants in their 40s may indicate that the density of the breast is much greater

and thus physicians need to press harder to feel beyond the breast tissue.

Two other women raised the issue that the gender of the physician performing the CBE determined the thoroughness of the examination. Stacy (age 56), who has had a benign breast lump removed, has consulted both male and a female physician for her breast health and said this of her experiences:

...she had been excellent in that she was very, very thorough with the breast exam. I always appreciated that and my present doctor is good too...I don't have too many complaints. I think I really do feel that female doctors have satisfied me much better than a male doctor in certain respects. (Stacy)

Penny (age 46) did not speak of thoroughness, but rather her comfort level with the gender of her physician.

...yeah, I feel more comfortable with a female physician than with a male physician. I did have a male gynecologist and I wasn't comfortable with that.

As described, for some the thoroughness and comfort level with a CBE was dependent on the gender of the physician. Women's first or continued experiences with CBE left them feeling vulnerable.

Overall, no participant had ever refused to have a CBE performed by her physician. All the participants received a CBE. Yet the thoroughness of a CBE meant different things for the women. For some women it was a lengthy relationship with their physicians and the trust that had developed over the years that determined a thorough examination. For one woman, participating in a Menopause study offered her a sense of thoroughness in all aspects of her health. For two women, it was the gender of the physician performing the CBE which made the difference between a thorough and an incomplete CBE. The data suggest that the method or the technique used to examine the breast was unimportant. Only the trust that was established

between the physician mattered. With another two participants, thoroughness of a CBE was feeling pain with the performance of a CBE. For the remaining participants, it was simply part of the physical in which they ignored the procedure. Even though some participants reported thorough CBE, the experience left them feeling vulnerable and not at peace with their actions towards breast cancer screening.

Mammography (MAM). Mammography is recommended to women 50 years and older and to those women who present with breast complaints. Of the 13 women who engaged in MAM, attendance was varied, that is, either every six months, annually or biannually. Seven women had seen their physicians with various breast complaints; five participants had resulting MAMs. For two participants, breast soreness continued to persist even though the MAM results were negative.

Engaging in a MAM took on various meanings for the women. Some related this preventive practice to emotional well-being by providing peace of mind (Joy, age 60), while for others it was a form of empowerment. For Penny (age 46), it provided a sense of control. In contrast, for Stacy (age 56) who has a family history of breast cancer, the process was a disempowering experience. She noted:

....it is the usual, it hurts, it's darn unpleasant but you do it, period. It is very depersonalizing, dehumanizing to have the breast crushed between these metal plates.

While Stacy found that a MAM is “darn unpleasant” and felt she is at “medium risk,” she continued to attend regularly for her MAM.

Although women “of a certain age” are encouraged to have MAMs on a regular basis, the respondents who complied with this advice shared some of the

negative aspects of this procedure. As Trudy (age 55), whose mother died of breast cancer noted:

....they are terrible, they are very painful for me. I have small breasts and dense breast tissue. I complained bitterly and the technician said to me that the tissue was dense. I dread it, it really hurts me.

Similarly, Dee (age 46) reported being bruised by an overzealous technician. She explained:

....the technician was very rough. When she put my breast on the plate and they bring the other one on top, when they brought it part way down, she reefed on it from one end to pull it in more and, like, she got right into my arm pit and it really hurt.

Not all the respondents had such negative experiences and their approval of the event is best summed by Jane's (age 59) words:

....I was kind of scared. Well I was scared. I went and I was shocked that it wasn't as bad as I had anticipated. It didn't hurt. The machine squeezed to a pinch but it did not hurt.

Jane has a history of bone cancer in her family not breast cancer. She thought of herself as being at a low risk for developing breast cancer. The reasons she engages in MAM is because she is taking Premarin and is past 50.

As noted above, all but three of the women had engaged in mammography. These three women provided unique reasons. Wendy (age 40), who had all her uncles die of leukemia and whose aunts were alive and well, did not fit the official age criterion to receive a MAM and furthermore had no breast problems. She demonstrated her lack of enthusiasm for when such a day would come. She explained:

....When I turn 49 and 364 days I'll go. Three hundred and sixty-four days past then I'll go for a mammogram.

Gloria (age 61) is overdue for a MAM but relates her delay to her concern with other more important health problems. She stated:

....I've never been for a mammogram. The doctor has never mentioned it. My mother has. I guess I should go. I just feel other things [other outstanding health problems] are more important things.

Although Gloria did say at the start of her interview that her health was fair, she further stated that she suffered from high blood pressure and is asthmatic with the seasons. She was, at the time of the interview, waiting to hear from a physician she had been referred to for hemorrhoids. Lori (age 42) had been scheduled by her physician for a MAM when she developed a rash on her chest. Lori did not keep the appointment and explained:

....I decided that it was a rash and that is all it was. There was no lump and the rash cleared. I was certain that it was a rash and that it was external. It was not internal.

These three women made the decision to not engage in a MAM for specific reasons; two women did not fit the official age criterion while the other woman was more concerned with other existing health problems. In addition, Lori believed that the rash was external and not requiring a MAM. Hence, Lori and Wendy will have to give mammography more thought when they reach the recommended age requirement. Conversely, Gloria has other health problems which she felt deserved more attention at the time of the interview.

Another experience which is part of engaging in MAM is obtaining the results. Women were asked for their thoughts on what it was like waiting for the results of the MAM. The participants' answers suggested that "peace of mind" and "feeling empowered" for engaging in MAM may not be the same feelings generated around

waiting for results. For instance, although it is standard practice in a physician's office, some participants were not told of their results until one year later after the examination. The women were told of their results during their subsequent check-up with their physician. Joy (age 60) who stated that she gained "peace of mind" with a MAM stated that it did not bother her to have to wait a year to get results. Similarly, Penny (age 46) expressed that she felt empowered by engaging in a MAM, that is, she felt in control. However, when asked about waiting for the result, she stated:

....No one called me, as long as they don't call you, I guess everything is o.k. I kind of feel weird about that. Even if they [the films] were o.k., I would like a phone call to hear that everything is fine, then you can relax.

Penny disliked the practice of having to wait a year because you cannot move on psychologically. Furthermore, she is not about to know what the result of that one MAM is because her physician has moved out of the province. She is now searching for a new physician and is not looking forward to having to start over. Well over half of the participants reported that they waited for a year to learn of their MAM results. Seven of these participants have had breast problems while three reported a family history of breast cancer. These three participants reported that they "didn't think about it [results]" and placed their trust in the physician's office to notify them.

A few women reported that they were told about their results approximately one week after the MAM. All have had breast problems, however, two of these participants have a family history of breast cancer. In particular, Heather (age 53), who has breast implants and breast cancer in her family, reported that she experienced a lengthy follow-up visit one week after her MAM. She explained:

....she [told] me in the office. She reads me the results. And she also doesn't get the written results and read it and say you are fine. She always asks for the X-rays and she has them up [on the viewing box] when you come in. They [the radiologists at the clinic] read them and send her the results and films and she does her own afterwards. She is very thorough.

Heather's comprehensive follow-up visit is the only one of its kind reported in this sample. The other two women met with their physicians a week after the examination, however, neither of them reported such a comprehensive follow-up.

The data suggest that Heather and the other two women may be the only participants who may have some end or closure to their breast cancer screening experiences, that is, until the start of the breast cancer screening cycle repeats itself (e.g., monthly BSE, next the CBE with the check-up and then the annual or biannual MAM). However, these participants may have been able to move on from the MAM experience because they know their results. The women who have not experienced one week follow-ups may have a little more difficulty in obtaining closure or feeling at peace with their breast cancer screening behaviors. Therefore, not knowing the outcome of a MAM for one year may not be conducive to feeling "empowered" or obtaining "peace of mind" with one's actions towards breast cancer screening behaviors. Such emotions may even influence the cessation of BSE and the over-reliance on physicians to perform CBE.

To summarize, all were aware of the purported uses of mammography as a means of detecting breast cancer. Thirteen participants had received a MAM. Furthermore, in terms of adhering to the mammography screening guideline, 10 women were found to comply with the guideline. Of these 10 women, five have a family history of breast cancer, and eight were greater than 50 years of age. This is

seen as contributing to such a high compliance rate to MAM in the sample. The experience held positive and negative meanings for each woman. Some participants felt “peace of mind” and “empowered,” while another participant felt “disempowered.” Waiting for results evoked feelings of indifference and dread. That is, of the thirteen women who engaged in MAM, 10 left it up to the physician’s office to call if the results were unfavorable. Three women were told their MAM results within a one week period. The data suggest that “peace of mind” is a short lived emotion and that the participants would rather forget about the results or leave it up to the physician’s office to call instead of obtaining them themselves to gain closure.

Diet and Exercise. The fourth category to examine are the diet and exercise patterns of the women who participated in the study. This category is linked to the previous categories in that following the *Canadian Guidelines for Healthy Eating* (Health Canada, 1992) and exercising are additional prevention strategies for breast cancer. The subsequent category is linked to the theme label because it ties into the concept of what actions can be done to reduce the risk of breast cancer development. Moreover, eating a proper diet and exercising three times a week for thirty minutes are possible influences on reducing one’s risk of breast cancer. The participants reported making a conscious effort, however, this may not be translated into obtaining “peace of mind” for their breast cancer prevention behaviors. Let us turn to the second last category of this theme, diet and exercise patterns.

Following the *Canadian Guidelines for Healthy Eating* (Health Canada, 1992) and exercising three times a week are considered to be additional preventive strategies.

The participants were asked what they ate and if they exercised to lessen their risk of developing breast cancer. The *Canadian Guidelines for Healthy Eating* (Health Canada, 1992) promote healthy food choices. Altogether, the women stated that they did try to make a conscious effort regarding what they ate, often paying attention to cholesterol levels and fibre:

....I watch my diet because I have high cholesterol. I watch the fat content, I eat a lot of fruit, vegetables, lean meat, chicken and fish. (Jane, age 59)

....I eat fibre, make bran muffins and I drink milk and water. I can't resist caffeine. I don't eat breakfast but I will have a good lunch. (Wendy, age 40)

Some of the participants supplemented their diet with vitamins because of their belief that the vitamins and minerals disappeared while cooking. Therefore, taking a daily supplement guaranteed them their adequate level of vitamins.

As part of the *Canadian Guidelines for Healthy Eating* (Health Canada, 1992) exercising half an hour daily is recommended to maintain one's weight. Very few participants exercised on a regular basis. Some raised the issue that they are too busy to exercise and that "coming and going" about the house would suffice. As Wendy (age 40) explained:

....I don't exercise per se. I used to do aerobics. Now I just keep busy with work. I do the stairs at work and on the weekend I look after my yard.

Others like Jane (age 59) and Olivia (age 65) also incorporated exercise into their daily routines. Jane danced twice a week and Olivia did a little tae-bo in her home. Two participants stated that they would like to exercise, however, specific health problems prevented them. For example, Joy (age 60), who is waiting for knee surgery and her mobility is restricted noted:

...I wish I could walk more but my arthritic knees won't allow me.

Overall, the women in the study reported making a conscious effort to eat well. That is, they were all aware of the low fat and high fibre recommendations and attempted to comply; some indulged in sweets. A few were aware of the benefits of exercising and tried to do so on a regular basis. However, other participants did not exercise because they were too busy and/or have existing health problems preventing them from exercising. The data suggest that the participants did not necessarily translate their actions of diet and exercise into another method of reducing their risk of breast cancer but simply for their general well being.

Breast Health/Cancer Information. The next category examines breast health/cancer information with regards to where the information is found, the type of and why information is sought, and how women feel about the information they receive. This category is linked to the previous category along with the breast cancer screening categories because breast health/cancer information is seen as a possible means of influencing behavioral choices. Breast health/cancer information assists women in acting upon their breast health if they choose to do so. This category is linked to the theme in that although the participants stated that breast/cancer information is found everywhere and a large majority had had breast problems, very few sought information. Hence, this fits with the theme that the majority of the women's actions are counter to developing and feeling at "peace" with their breast health behaviors.

How women perceived breast health/ cancer information is of interest in this

study. Perception of breast health/cancer information not only influences the development of the self but also can affect preventive practices such as breast cancer screening, diet and exercising behaviors. The information found on breast health/cancer was encountered in various places such as the physician's office, by experiencing a death in the family, through the media such as television and radio, and at places of employment. Although few women reported having searched for information on breast health/cancer, many answered that their physician would be their first source. For example, these are a few comments from the participants:

...He is excellent. For a family physician you won't find one better. I can ask my doctor anything. (Trudy, age 55)

...at the clinic and with the doctor. (Lee Ann, age 41)

...the doctor gives me some [information] and the technicians. (Marie, age 63)

The data suggest that physicians are seen as a primary source of information due to their extensive knowledge.

The four women who had a family member die of breast cancer stated that experiencing the family member's death led them to seek information about breast health/cancer. For example, Trudy (age 55), whose mother died of breast cancer, stated:

...speaking to my physician about mother's cancer diagnosis and what Paget's disease is has helped me understand. Knowing now that Paget's disease is not hormonal is important.

Whether Paget's disease of the nipple is hormonal is very important for Trudy since she is taking Premarin. She stated she would be switching over to plant estrogen even though her physician told her taking Premarin was fine. Similarly, Stacy (age 56)

whose younger sibling died of breast cancer reported gathering information in a similar way. She offered these words:

Well I have read some literature but I don't go into it deeply. And then[there is] the information that came to us during my sister's illness and during my own short history with the benign cysts. (Stacy)

A first hand experience with a breast lump or the loss of a family member to breast cancer placed these participants in a position to gain information. As stressful as these experiences are, information is still key to successfully making proper choices for the management of one's health. Information can influence the development of the self and consequently health choices.

Other sources of breast health/breast cancer information are television, books and magazines, and the radio. For example, Olivia (age 65) who reads alternative health journals learned from a health program on television that by the time the mammogram detects breast cancer it has already been in the breast for several years.

Olivia stated:

... You know it is so minute if they would find it at the first stage. What you think are first stages, it has already been growing for a long time. Couldn't they find it sooner? What about MRI?

Lori (age 42) spoke of how the information on breast health/cancer is everywhere in the media. She stated; "...it is in your face." She feels she cannot escape breast health/cancer information. It is everywhere, from magazine covers in the grocery line up, to the changing rooms in women's clothing stores.

Four women stated they were able to find breast health/cancer information at their places of employment. Working with health professionals offered them the opportunity to converse with physicians, nurses and pharmacists. For instance, Penny

(age 46), who suffered from intense breast pain after her physician prescribed Premarin after her hysterectomy even though her ovaries remained, offered these words:

.... I had the opportunity to speak with a co-worker who is a pharmacist about estrogen use and dosage. He stated that being on Premarin was not necessary.

When Penny saw her physician at the following visit she told them she had stopped taking estrogen. Penny noticed the difference immediately and no longer complained of sore breasts. The information from the pharmacist proved to be very helpful for this participant. Similarly, Tammy (age 53) who works in a health care setting is able to get information at work. She explained:

....there are many pamphlets on the ward. And besides I have nurses and doctors to speak with everyday.

Both Penny and Tammy are in privileged positions where health information abounds. Working with health professionals has allowed these participants to have greater access than most of the participants to breast health/cancer information.

Other women said they would go to the public library, consult the phone book, search the Internet, and ask at their local hospital for information. One woman was aware of the newly funded Breast Cancer Comprehensive Centre in Winnipeg, Manitoba. Only three women were aware of the Hope Breast Cancer Information and Resource Centre. However, these women were unfamiliar with what the Centre offered. Public libraries, hospitals and centres dedicated to offering cancer information/support were a weak secondary source of information.

Breast health/cancer information is very important to have when making

decisions pertaining to breast health. Most of the women had experienced breast problems but only a few had actively sought information. The information that was sought pertained to breast health maintenance and hormonal therapy (e.g., Premarin use). For example, Lynn (age 65) and Lee-Ann (age 41) sought information for breast soreness and a suspicious lump respectively. They stated:

....I want to understand the soreness in the left breast. (Lynn)

....At one time, it was for a lump. I wanted to know data. The chances that it was malignant or benign. I wanted to know. (Lee-Ann)

These participants sought information to help them understand what was happening with their bodies.

Comprehensive breast health information was sought by only one participant. Heather (age 53), who is considering a double mastectomy, has sought information from her physicians. Having had the same lump drained several times she has become more concerned about her health. Heather has received information and consensus from her physicians that a double mastectomy would be in her best interest. At the time of the interview she was still reflecting on the information she had been given.

Other women sought information regarding hormonal therapy. Since Trudy's (age 65) mother died of breast cancer, hormonal therapy information is vital because certain breast cancers are hormone dependent while others are not. Similarly, Penny (age 46) was also looking for hormonal therapy information. Having experienced a high degree of breast sensitivity upon taking estrogen, Penny had questions. She explained:

....Because the other doctor told me I had dense breast tissue and I should go more often [for a mammogram] because of that. I am going to check with

this new doctor and see what her thoughts of it are. Now that I am not on estrogen anymore I feel much better. My breast tissue doesn't seem as dense. Does that make sense?

As for Penny, taking estrogen was not necessary given that during her hysterectomy her ovaries were left intact and functioning giving her the necessary hormones her body needs. Those participants who were nearing menopause were also in the process of seeking hormone replacement therapy information.

The data suggest that seeking breast health/cancer information served two purposes for the participants in the study. The first was the possibility of helping themselves and the second to assist others. Two women stated that they sought information so that they could help others. For example, Jane (age 59) stated:

....I can't say I wanted to know more. It is a fact that I would like to know more about it to see if I could help somebody else. You know, get them on the right track. Pass the information on.

As much as the above few participants have sought information, Lori (age 42) reported that it was unnecessary. She stated:

I don't think it is a case of actively pursuing information or knowledge on that topic. It is just the fact that you cannot avoid it. Every magazine you open up has something in it. It is not necessary that I am actively seeking information. The information is there.

The participants expressed various feelings about breast health/cancer information. For instance, Joy (age 60) was neutral about the information she received. She noted:

....It doesn't make me feel one way or the other. Because if I happen on something on the radio I will listen to it then it is out of my head because it has never really been a major concern. And this is just like saying how well your car is running and the next day it needs to go the garage. I'm afraid I am jinxing myself. It has not been a high priority for me just because of the lack in my family and it is not hereditary.

For other participants such as Gloria (age 61) and Lynn (age 65), they felt informed and comforted.

Some participants expressed contrasting emotions towards the breast health/cancer information they received. For example, Marie (age 63) does not like all the technical medical jargon that comes with breast health/cancer information. Olivia (age 65) a reader of alternative health journals, felt that the information changes too often and she expressed feelings of skepticism. Stacy (age 56) stated she “...ignored all the trendy stuff [information].” Joyce (age 42) stated she had become doubtful. She explained:

...I have to take some of the information with a grain of salt. How much of it is absolute fact. How much of it is truth? (Joyce)

Breast health/cancer information continuously changes due to ongoing research and professional opinions and debates. Consequently, reactions such as skepticism and doubt can be inherent in the dissemination of information.

A few more participants expressed anxiety over the breast health/cancer information. Jane (age 59) noted that the statistics are rising and it concerned her.

Another women stated concern with receiving too much information:

It is not good to get all this information. ...we overload and it may make you anxious and life is too short to be that paranoid and it is not worth it. (Tammy, age 53)

For Lori (age 42) knowing about breast health/cancer information was inevitable. She commented:

....it is very scary. You can't stick your head in the sand and avoid it. You have to be realistic.

Feeling anxious regarding the breast health/breast cancer information was inescapable for some participants.

Overall, the women reported being exposed to breast health/cancer information on a daily basis. The information is readily available through physicians, places of employment and the media. The participants sought different types of information such as the impact of hormonal therapy, ways to maintain breast health and factors related to breast sensitivity. They reported that they sought information to help either themselves or others. The women in the study expressed feelings of comfort, discontent, or anxiety with the information they received. One participant remained neutral. The women all agreed that the breast health/cancer information is very available. As Lori expressed, "It is in your face." As noted by the above description, very few women actively sought breast health/cancer information, however, several knew that their physicians were a primary source of information and knowledge. In addition, few knew about services offered by the Canadian Cancer Society and the Hope Breast Cancer Information and Resource Centre.

Summary. Primary prevention strategies for breast cancer are unavailable. Consequently, the secondary prevention strategies such as the three breast cancer screening practices are highly promoted by the medical research and the public health communities as early detection tools for breast malignancy. Collectively, few of this study's participants adhered to monthly BSE, however, everyone had had a CBE. The women may be described as neglecting to do BSE and therefore having an over-reliance on their physician to perform a CBE. Mammography had been experienced

by 13 of the 16 participants. In addition, over half adhered to the MAM guidelines. However, in all, there were only two women who reported that they complied with all three breast cancer screening guidelines. Feelings of indifference and dread were expressed with regards to obtaining MAM results. Over half of the participants reported that they waited one full year to be told the results of their MAM. Three were given their results within one week of the x-ray being performed. As for the additional preventive strategies, such as eating according to Canada's Food Guide and exercising, a few women adhered for their well being and not specially for reducing their breast cancer risk. Breast health/cancer information, although available, was sought by a few participants from their physicians and not from any dedicated centres which disseminate breast health/cancer information such as the Canadian Cancer Society or the Hope Breast Cancer Information and Resource Centre. The women reported feeling both comforted and anxious about the breast health/cancer information they received.

Women's thoughts and experiences as to their participation in breast cancer screening practices are of importance to this study. The categories of this theme indicate that adherence to the Canadian breast cancer screening guidelines is suboptimal for the study participants. There are only two participants who reported adhering to the breast cancer screening guidelines precisely. Furthermore, any attempts to derive benefit from exercise and to follow Canada's Food Guide were for general well being and not to reduce the risk of breast cancer. Breast health/cancer information if needed was obtained from their physicians. Therefore, the women engaged in sporadic breast cancer screening practices, made somewhat of a conscious

effort to eat well and exercise and did not search for breast health/cancer information. Despite these shortcomings they reported having “peace of mind” and “feeling in control” with their breast cancer prevention choices. The theme label, Breast Cancer Prevention: Peace of Mind?, implies that women are able to experience such emotions although it is questionable as to the accuracy of their comfort. The data suggest that the equanimity that is sensed is an ephemeral emotion and is not due to compliance with the breast cancer screening guidelines or with information gathering. That is, the participants are confused over BSE, feel vulnerable with the CBE, have grown to be tolerant of MAM, are indifferent towards the results of their MAM and do not search for breast health/cancer information. Moreover, eating healthy and exercising do not factor into the equation or recipe to reduce the risk of breast cancer. As a result, a majority of the women’s actions are counter to obtaining “peace of mind”. Such emotions are at best falsely gained emotions.

iii. The Rational Self: Under Construction

In this study, self is defined as a sense of self-identity. The self is constructed and reconstructed through social interactions. Consequently, there are innumerable influences shaping the self. Under the NPH, the body has become a symbol of self-identity, that is the body is the basis for the construction of one’s social and individual selves. The influence of others and our body are means through which we develop our sense of self. Hence, the self is malleable. Using this definition of the development of the self, the self complies with health promotional messages/ information that affect the body.

The participants here reported selves which have been influenced by social interaction. The title of this theme suggest that the participants, selves are malleable but not in the way the NPH framework assumes a self develops. What we clearly see is the movement or action between the evolving selves versus the malleable selves. Through various influences of social interaction, the self will always be under construction. This theme consists of three categories: ways of knowing, powerful others and taking charge. The first two categories are singled out as elements which influence the development of the women's selves. The third category acknowledges the action of the participants to take some control of their health. In particular, taking charge illustrates the advocating self. Let us start by examining the first category of this third theme.

Ways of Knowing. The participants' ways of knowing were shaped through various social interactions. In the data, there emerged four ways of knowing through social interaction which influenced the self. They are personal, work, family and friends' experiences. For these women, personal experience emerged as a primary way of knowing. One's own experience is always first hand knowledge. Four women spoke of how personal experiences had contributed to their way of knowing about breast cancer and consequently influenced their self. For instance, when discussing breast feeding as a breast cancer risk factor, Joy (age 60) shared her beliefs:

....I don't believe in those things. Now I haven't read up enough about it; I just know it. It isn't what I have experienced.

Joy reported a low risk of developing breast cancer and did not identify with any breast cancer risk factors. Breast cancer is not in her family and she focused on other

more pertinent health problems such as her diabetes and arthritis. For Joy, diabetes and arthritis are the diseases which have greatly influenced the development of her self. The issues concerning breast cancer are secondary to her prevailing ill health.

Similarly, when asked about her thoughts on breast cancer screening Lee-Ann (age 41) implied that screening for arthritis was more important than for breast cancer. She explained:

....breast cancer is not as alarming as they are trying to portray it to be. There are more people with arthritis. There are people out there that have other things that I think are much more, how should I put it. I look at my own experience and family and what has happened with arthritis and hardly anything [funding] goes into arthritis. That is just a debilitating disease that is just.... My mother, her knees, wrists and now her shoulders. They want to operate on her shoulders now. I look at my mom who was in rehab for a year with arthritis and my husband was extremely debilitated and now my daughter, and... why is that happening? You know I see more people with arthritis. It is much higher than, you know, breast cancer.

Lee-Ann's display of frustration is a reflection of the high incidence of arthritis in her family. Her own experiences and those of her family have influenced the development of her self. Personal experiences for these women were their ways of knowing and in turn influenced the development of their selves.

Work experiences are the second way of knowing. Three women discussed how work experiences influenced their way of knowing. For example, Trudy (age 56) shared a work experience which caused her much concern:

...I am more worried about ovarian cancer than I am of breast cancer. That really scares me. [Why?] Because I worked on a Gynecology ward at a [local hospital] and they die of terrible deaths. It is so silent by the time you have symptoms it is too late for a majority of them and they suffer terribly and I still have my ovaries. Did you know there is no test for ovarian cancer?

Trudy's work experience educated her about ovarian cancer yet it has caused her much anxiety because she still has her ovaries. This knowledge gained through work experience is very much part of her self. Similarly, Penny (age 46) conducts exercise classes for elderly women. One participant is a breast cancer survivor of many years. She stated:

....one of them is 93 years old and she has had both breasts removed back when she was in her forties and she is amazing. She is 93 and pumps weights.

Penny expressed the wish to be as vital as the ladies she teaches exercises to when she becomes a similar age. This work experience contributed to Penny's knowledge that breast cancer is not a death sentence based on this 93 year old woman who is a breast cancer survivor and is still vital. Social interaction within a work experience contributed greatly to both participants' sense of selves.

Family experience is another way of knowing that also influences the development of the self. Joyce (age 42) spoke of the factors which contributed to her parents' deaths. She told her story:

My mom died of emphysema and lung cancer. My dad died of lung cancer. They were both mild smokers. There were two separate incidences in both of their lives which I believe contributed to the fact that they got lung cancer. My father had a brick wall fall on top of him in 1958 and was rushed to the hospital. He walked out; my father was not a hospital man. His lungs were severely damaged and because he worked in construction, you know the type of chemical they use. I am not saying that smoking doesn't do it, it is an additive. I think that [the accident] contributed to the fact that he got sick. My mom always kept a very clean house. She always mixed household liquids. She had lysol, javex, laundry detergent all poured into the pail and took hot, hot boiling water that she heated on the stove and poured over top and the steam came up and from that moment on she couldn't breath properly, ever. I think she probably fried her lungs by inhaling the fumes. She was a part time smoker, same with my dad. Not half a pack a day, four or six a day and they were home rolled.

Events that had occurred during adolescence set the tone for many beliefs. When asked about developing any family diseases, Joyce was certain that she would die of lung cancer. Her parents' experiences have influenced the development of their daughter's self.

Likewise, Lynn's (age 65) mother's and sister's health outcomes and actions are of concern for her. She explained:

...My sister died of liver cancer and my mother died of stomach cancer. They watch my stomach very closely and especially now with the esophageal hernia. I have always had gas. I live on Gaviscon [7] and peppermints. That is exactly what my mom and sister did. Of course it is a concern.

As noted above, both Joyce and Lynn expressed that they would die of the same cancers that had claimed the lives of their first degree relatives. Their similarities in experiences with their family are not only of concern to these participants but have been interpreted by them to mean a similar demise for themselves. Hence, the development of their selves was influenced by family experiences.

Friends' experiences are another and final way of knowing which emerged from the data. What friends experience contributed to two participants' knowledge.

Lori (age 42) spoke of a friend's experience with discovering a lump:

.... they didn't know what it was and sent her for a mammogram. They couldn't find the lump on film so they kept trying and trying. They took about 16 films and at the end of it they said don't worry about it because we can't find it.

Lori was unsure at the time of the interview what her friend was going to do. Even though Lori had refused her MAM when she had a rash on her chest, she fully understands the purpose of a MAM. As well, the likelihood of engaging in a MAM

7. Gaviscon is an over the counter preparation that offers relief from indigestion, heartburn and gas.

has been influenced by her friend's experience. Hearing such stories did not encourage Lori to engage in MAM, although she had discussed the ultrasonic method of breast examination with her physician to avoid a MAM. Similarly, Penny (age 46) spoke of a friend's experience regarding a surgical decision:

....they first said, "Well let's take off the breast." She got comfortable with that idea and at the next appointment she saw him and he said, "You know we could probably do a lumpectomy." She replied, "Well you already told me that I should have the breast removed and I have gotten comfortable now you are telling me not to." So my friend was very confused and she decided to have the breast removed.

At the time of the interview Penny was concerned that her friend had not sought a second opinion. Both Lori and Penny have incorporated their friends' experiences to build their knowledge and influence their behavior. Lori's skepticism towards MAM is partly grounded in a friend's experience and Penny who is in search of a physician practises caution. A close friend's experience was, in this instance, as valid as their own experiences.

Overall, each participant's way of knowing was shaped and influenced by various forms of social interaction which impacted on their sense of knowledge and self-identity. Personal, work, family and friends' experiences are ways in which we learn and know things which in turn result in the development of the self. There are many ways which we as interacting individuals consume lay knowledge. How one consumes what one knows takes on an important role in how the self is developed which translates itself into behavioral choices. This ties in well with the theme label, *The Self: Under Construction*, because the self is not static. It is always undergoing change with the knowledge one consumes and change can be either small or large.

Powerful Others. Through everyday social interactions we are in contact with a variety of individuals. Some of these individuals play a bigger role than others in how they influence the self. Emerging from the data as being powerful others who play a contributing role to the development of the participants' selves are individuals such as health care professionals, spouses and God.

Health professionals such as physicians are seen as contributing greatly to women's selves in terms of their breast health. Nine women had trusting and lengthy patient-physician relationships. One woman in particular described the special bond she had with her physician:

...I am very comfortable with the doctor. He is not only my friend, I was one of his very first patients. He is not only my doctor he is also my friend. I trust him. (Tammy, age 53)

Furthermore, when discussing why her physician had not spoken to her about her breast cancer risk she demonstrated the trust she holds:

...It doesn't mean much to me because I don't think that I am high risk of it [breast cancer]. I am sure if he thought I was, he would have done something. The doctor is pretty good to me. (Tammy, age 53)

Similarly, Heather (age 53) spoke of how fortunate she was to have had the same physician for several years. Heather described what her physician meant to her, particularly given her breast implants.

...in my mind he is excellent. He told me, "We will check you closely, let's hope we catch it early."

Physicians were seen as powerful individuals by these women. As previously discussed, the reliance on physicians for CBE by the women was great and underscores the influence physicians have over their patients.

Certified mammography technologists also played an important role in the participants' development of the self. Performing MAM and reinforcing the knowledge on breast health, they are seen as an important source of breast health/cancer information. For example, Penny (age 46) was surprised by one of her technologist's knowledge:

....the second last technician asked me what I did for a living. She said I had a lot of muscle in the chest wall. She said, "I can see that you are very strong." This impressed me.

Similarly, Heather (age, 53) noted her amazement with the technician's manner:

....the technician was very open in talking with me. She examined me first and asked when she felt the scar whether I felt pain there. She was able to detect a scar on top of another scar. I was quite shocked. She made me sit in front of a mirror with my arms like that and tell her if I saw anything different today and then she told me what I might see if I saw something different. I have never had them talk to me like that before.

The technicians displayed in-depth knowledge and professionalism which offered these two participants the reassurance of a thorough examination. The MAM technician may have more time to teach and reinforce knowledge involving breast examinations than do physicians. The interaction with the technician is very important for it is a means of securing and ensuring the next breast cancer screening appointment.

Another individual in the married participants' lives who is seen contributing to the development of the self is a husband. One woman in particular who has been married for 18 years described how her husband participates in breast health:

You are going to laugh but whenever my husband and I are intimate I always say to him, "Make sure you check." I always whisper in his ear, "If you feel a lump let me know." (Wendy, age 40)

Wendy trusted her husband with breast examination and only infrequently practised BSE herself.

Another factor in influencing the development of the self for two participants was religion. Marie (age 63) spoke of God and the impact her faith has had on her health. She said this about her breast cancer risk:

...I am the way I am is because I have faith in God and I trust him and I know if it happens, it doesn't mean because I have faith I am not going to get it, but I trust and believe and I don't believe he would have me dwelling on it. Not to be foolish, you should check yourself.

At an intellectual level Marie knows that God cannot help her but at a spiritual level she believes that God would not want her to worry. Tammy also spoke of God. She offered these words in reference to having an unknown family history:

I don't worry about it. Everybody has to die of something, someday. It could be cancer, heart attack. When God is ready for me he will come and get me and it'll be of something or other but we all have to go one way or another. That is my philosophy. I don't anticipate what is going to happen tomorrow; you live for today.

God is seen as a powerful other contributing to these women's lives. Their faith has given them peace and hope and this has influenced the development of their selves.

Altogether, through daily social interactions, certain powerful individuals such as health professionals, spouses and God, were seen as contributing to the development of the participants' selves. This category links up to the theme label because the powerful others are seen as influencing the development of the self and contributing to the participant's way of knowing. These key individuals are seen as contributing to their knowledge.

Taking Charge. The last category of this theme illustrates an additional dimension of the self. Women offered examples of when they advocated for their health in various manners. This subsequent category is labeled “taking charge”. A take charge attitude about one’s health is fostered by the way one learns and the powerful people in their lives. Some participants advocated for their health in various ways. The first method of advocating for one’s health was demonstrated by going against medical advice. For example, Olivia (age 65) who possesses a strong personality and suffers from arthritis spoke of a disagreement she had with her physician:

....I have had both hips replaced. Still have a bad knee but it doesn't bother me as much since I had the hips replaced.I know one doctor was very concerned with my spine, I would eventually have a poker spine. He was more concerned with that. I then said, "Listen, my back doesn't hurt. Let's not worry about it at this point in time."

Similarly, Lori (age 42) refused to have a MAM. She explained:

....I went to her with the rash and so we talked about it. Actually she suggested a mammogram at the time because she was not 100% sure it was a rash. But I didn't go. I decided that it was a rash and that is all it was. It was an external problem, there was no lump and the rash cleared with the antibiotic cream.

Both these participants displayed resistance and their reactions to their physicians’ advice demonstrate the take charge or the advocating self. Olivia is aware of her health needs and reads many health journals. For Lori, because there was no lump and the rash cleared, the breast problem did not warrant a MAM. Both participants took charge of their health and thus exercised their advocating selves.

A second method of advocating for one’s health was demonstrated in a

participant's skepticism towards MAM screening. Again, for Olivia (age 65) the breast pain she continued to experience makes her skeptical. She explained:

....I do BSE if my breast is bothering me. It [the pain] moves around it is never bad enough but it concerns you. When it gets a little sore she [the doctor] always sends me if I mention it. The mammogram has never coincided with the episodes of pain. To me there must be something or it wouldn't bother me.

Stacy (age 56) spoke of radiation emissions:

I am a little bit afraid of all kinds of rays going into my body. I guess that is what a mammogram is. I have read some articles that suggest that those who go for mammogram are more likely to get cancer of the breast.

Undiagnosed breast pain and radiation emissions are only a few consequences of MAM screening. Olivia is skeptical of the MAM technology because she still has breast pain and it remains undiagnosed and undetected by MAM. Stacy (age 56) has read that radiation emissions from mammograms caused breast cancer. Skepticism is characteristic of the advocating self.

A third and final manner or action which falls under the heading of "taking charge" is engaging in alternative health practices. Three women engaged in alternative health practices. For example, Trudy (age 55) said this about taking estrogen:

....My mother had Paget's disease of the nipple, an irregular form of breast cancer. The doctor said it was not hormonal and I am able to take Premarin but I am switching over to a natural plant estrogen.

Although Trudy's physician did encourage her to take Premarin she is choosing not to and will take instead a natural supplement. Trudy also takes daily vitamins and eats as healthy as she can. Similarly, Olivia (age 65) who is a subscriber to various alternative health magazines stated:

...I think you probably need both conventional and alternative medicine. I don't go along with the medical profession in particular and I think there are a lot of alternative things out there they don't even know about and that they don't want to know about and are very closed minded towards it. I think if you use it with a bit of common sense that can be to your advantage. A lot of the stuff has been around for a lot of years and it works. But I wouldn't say I would go alternative treatment if I knew I had cancer rather than going to a medical doctor. I might do some of them or both.

Olivia takes vitamins on a daily basis and has applied knowledge that she has learned in alternative magazines to her health. For example, Olivia has learned from the journals that she reads not to take her cholesterol medication with certain foods. Olivia described herself as an open minded person and sees the benefit of both conventional and alternative medicine.

Overall, refusing medical advice, skepticism towards medical technology, and engaging in alternative medicine are means through which the participants displayed the advocating or "take charge" dimension of their selves. The take charge dimension of the self is constructed as a result of how one knows what they know and the influence of powerful others in their lives.

Summary. The participants' selves were shaped and influenced in numerous ways. Everyday social interactions at work and with family and friends are means by which the participants acquired their lay knowledge. These various and continuous social interactions are also seen as influencing the development of the self.

Furthermore, there are certain individuals, such as health professionals, husbands and God who have had a great impact on the participants. Hence, the way we know and the aforementioned powerful others shape or influence the continuous reconstruction of the participants' selves and ultimately behavioral choices. This theme further

explained the multi-dimensional self which “takes charge” that is, the advocating self. Here the women are described as resisting medical advice, engaging in alternative medicine and being skeptical of the purported effectiveness of mammograms. This last theme label indicates that the ways of knowing and powerful others may result in an advocating self. In addition, since these elements are always in flux, the advocating self would also fluctuate along with behavioral choices. Hence, the self is constantly under construction. As individuals we do not live in a social vacuum and our psychosocial environment in which our selves inhabit are under daily construction as a result of our interactive selves.

III. Conclusion

In summary, this chapter examined the unique and common experiences of the sixteen women with breast health. Three themes which emerged from the many categories were identified. The first theme, **Breast Cancer Risk: Family Matters**, revealed that a majority of the participants perceived their risk of breast cancer development as low because there have been no cases of breast cancer in their families. The second theme, **Breast Cancer Prevention: Peace of Mind?**, examined women’s experiences with breast cancer prevention strategies. The data brought to light that women’s actions are counter productive to obtaining “peace of mind” and “feeling in control”. The data suggest the danger or falsehood of such feelings due to non-compliance with the screening guidelines and the lack of information gathering. The third theme, **Rational Self: Under Construction**, examined the interactive multi-dimensional selves of the women and the data revealed that the many ways of knowing

and powerful others result in the construction and reconstruction of the self. Due to these influences in our psycho-social environment, the women's selves through their behavior were found to be non-compliant with health promotional messages/information that affect the body. This chapter sets the stage to a discussion of the integration of the themes and the NPH theoretical framework .

CHAPTER FIVE: Discussion and Conclusions

Through the analysis of in-depth interviews with 16 self-selected respondents, three themes were identified which depicted these women's experiences with breast health. The three themes are: Breast Cancer Risk: Family Matters; Breast Cancer Prevention: Peace of Mind?; The Rational Self: Under Construction. The purpose of this chapter is to integrate the three themes with the New Public Health's conceptual framework. This chapter will address the three questions guiding this research, discuss the strengths and limitations of the study, and offer directions for future research. By way of conclusion, I will discuss opportunities for change, the intersectoral collaboration efforts underway in the area of breast health/cancer services, and list the implications for women's breast health under the NPH.

The objective of this research was to investigate women's breast health experiences under the current model of public health, the NPH. This model emphasizes health promotion that incorporates three interrelated concepts: risk, surveillance and the self. The study sought to unveil a clearer understanding of the acceptance of, or resistance to, breast cancer screening practices by women over the age of 40, and to provide insight into the implications surrounding their breast health experiences.

I. Integration of Themes and Framework

Question 1:

The first research question asked, "How do women's social environment, personal beliefs and knowledge influence their breast health behaviors?" Overall, it

was clear from the data that breast health behaviors are influenced by a number of factors related to the NPH framework. These include: the social and personal levels which are exposed to the tenets of the NPH framework.

Lack of Genetic Information. As we have seen, social environments, personal beliefs and knowledge influenced the participants' breast health behaviors. Like the three concepts of health promotion, these factors are interrelated and not isolated elements in an individual's life. As a result of the interrelatedness of women's social environment, personal beliefs and knowledge, a strong majority believed that breast cancer is hereditary. Hereditary for these women meant being transmitted from a parent to an offspring. The genetic component of breast was not mentioned. Few considered lifestyle to be a contributing factor to the cause of this disease. This is somewhat ironic since the New Public Health framework views disease causation as an outcome of economic and social activity (i.e., lifestyle). With a majority of participants believing that breast cancer is a hereditary disease, many women expressed relief knowing that breast cancer was not in their family. All but a few women relied on the lack of breast cancer in their family to assess their personal breast cancer risk as low. This belief is paramount in understanding the participants' breast health behavior and the development of the self under the NPH.

According to the literature, these participants appear to be misinformed about the genetic classification of breast cancer. As Susan Love (1995:186) discusses in her book, breast cancer occurrences are divided into three groupings. The most common group is known as sporadic and it accounts for 70% of all patients with breast cancer

who have no known family history. The second group is known as genetic in which one dominant gene (BRCA1 or BRCA 2) is passed on to one or more family members. This accounts for 5-10% of all breast cancer. The third group, known as polygenic, occurs when breast cancer is in one's family, however, the dominant gene skips a generation. The majority of the women in the study sample are unaware or unsuspecting of the sporadic group which accounts for 70% of all known breast cancers. Based on the literature the study participants ought not to find comfort from the knowledge that breast cancer is not in their family, as they are still at risk of being in either of the two groups, the sporadic or the polygenic group. Despite this, a majority of the women found themselves with a false sense of security because breast cancer was not in their family. Only a few participants expressed doubt because for them "...there is always a chance." These women recognized their risk as low but also believed no woman is ever risk free, including them.

When determining their individual breast cancer risk, the women did not speak of the possible genetic connection of one type of cancer (e.g., lung cancer) to breast cancer. However, all study participants have had a family member die of some form of cancer such as lung, stomach, liver, colon, prostate and bone. These types of familial cancers were not considered by these women to be associated with their risk of breast cancer. Rather, several stated that they would most probably develop a similar cancer already present in their family history. This sense of security would seem to be misplaced given the ongoing research examining the issue of other cancers in one's family and the association to breast cancer (Love, 1995: 190). For example, research has identified that daughters of men who have prostate cancer are at higher risk of

breast cancer. These women mostly supported the hereditary cause of breast cancer without recognition of the difference between hereditary and genetics.

Medical Professionalism. The participants' belief systems favoring genetics over lifestyle were reinforced by the medical profession in several ways. First, physicians are educated and work within a genetic/hereditary framework. They prioritize "family history" to help set a genetic history and only later are lifestyle questions posed. Second, given the way medical practice is established in Canada most physicians are paid by the government on a fee-for-service basis (Edginton, 1989:120-121; Rachlis & Kushner, 1989: 35-37). The more patients they see, the higher their income. Therefore, the fee structure for physicians does not encourage non-billable health education in the office. Consequently, when these women presented with a breast problem, they always received a CBE, a less time consuming billable procedure compared to non-billable answering questions. Physicians are not obligated to incorporate health education into their practice style but some physicians sometimes refer women to a dedicated centre such as the Hope Breast Cancer Information and Resource Centre (HBCIRC). Although many of the study participants had experienced breast problems, they were not referred to the breast health/cancer information centre which offers services in Manitoba. The HBCIRC has a provincial mandate to disseminate breast health/cancer information and support services to Manitobans. The newly built Breast Health Centre is a rapid diagnostic centre where women are able to self-refer if breast problems are urgent. The HBCIRC has limited personnel to address concerns and needs of their clientele, and nurses at the

centre are paid on salary. Consequently, not only is the fee structure for physicians not conducive to the delivery of health for women, but women who work in a health profession are negatively affected by the unfair payment structure.

A third means of reinforcing the confusion regarding genetic information is how physicians exercise power and control over their patients. The data revealed that physicians are “powerful others” having great influence over some of these women’s lives. A majority of the study participants spoke of the great trust they have in their physicians. The trust and influence are of such magnitude that a large majority does not practise BSE, preferring to submit to a CBE even though it leaves them feeling vulnerable. Consequently, the physicians are seen as experts and the primary source of breast health/cancer information. Hence, the women’s knowledge regarding breast health/cancer is not increasing and the women continue to frequent the same physician. As well, no challenge to the expert’s method of medical practice is made and no change occurs for other women.

The false sense of security derived from the belief that breast cancer is not in their family is detrimental to lives of women. This false sense of security is alarming especially since some participants sought breast health/cancer information to inform not only themselves but other women. Since the majority of participants stated they see their physicians on a regular basis, it is alarming that no efforts are being made to correct this false notion. Several explanations can be offered for this omission. It may be that the physicians are too busy or too closely tied to the fee for service model that they do not make the time to educate their patients. Alternatively, the physicians may have themselves been educated before the NPH notions of self-management became

part of medical education and thus have not incorporated the tenets into their practice styles (Guldan, 1996: 689-691). Or as noted by Foster (1995: 4-5), the relationship between the health care industry and women is an “unhealthy” relationship. There is much evidence that medicine is practised in a sexist/patriarchal manner which designates power and control to the physician and expects the patient to be a passive recipient (Daly, 1978; Doyal, 1979; Oakley, 1980; Roberts, 1985). In addition, the female body is used as a site for profitability (Dreifus, 1977; Foster, 1995). There also could be some physicians who still believe that their female patients are unable to cope with much information and thus are selective as to what they say (Foster, 1995: 181). The issues of sexism and patriarchy persist alongside the notion that health promotional strategies are organized to regulate women’s lives without the consumer realizing that such healthy choices regulate individual and collective behavior. The structure of post-modern medicine is ineffectual in ameliorating women’s health needs and thus intensifies the “unhealthy” relationship.

Summary. The women’s social environment, personal beliefs and knowledge have enormous influence on their breast health behaviors. The NPH’s nature to promote regulatory public health strategies will exist alongside the biased breast health/cancer knowledge, a medical care system that serves women’s health needs in a sexist/patriarchal manner which continues to discover ways to profit from the female body. Consequently, this will cause women’s experiences within the current public health model to become very complex.

Question 2:

The second question guiding this study is, “How do women perceive breast health information or messages?” Altogether, the data indicated that women perceived breast health/cancer information with caution. This was illustrated through the hierarchical ratings of health conditions, the practising of selective acceptance of health information and the competition between the developing and malleable self.

Rating of Health Conditions. A startling factor was uncovered with the first interview and then confirmed in some other interviews. Many of the study participants truly felt they were unable to contribute to this study. Several participants had not given any thought to breast cancer and were surprised that their stories were still important enough to be recorded. The participants shared their stories even though some were skeptical that they were of any value to the researcher. In contrast, other participants welcomed the opportunity to dialogue about their breast health experiences.

Many women believed that their breast health experiences were not worth documenting because they felt they had other more important health problems. One woman was concerned with controlling her diabetes and her weight in order to lessen the stress on her arthritic knees. Breast cancer was not an important health issue for this participant. Another woman who suffered from stomach and esophageal problems truly felt she had nothing to offer in terms of a breast health experience. Yet after proceeding through several questions she reported that she had a cyst removed from one of her breasts. She, after all, did have an experience to share. These two

examples indicate that for these women breast health was secondary to other more pressing health problems. In addition, it would seem that the NPH framework does not allow for personal experience to be of any value to understanding health matters. The framework is preoccupied with statistics and narrowing down population rates to an individual/collective setting whose profiles are similar. It is no surprise that the women felt their breast health experiences were not of value to the study because the overall health system denies their experiences.

Selective Acceptance of Information. Several participants stated that their interest in the study was for informational purposes. Yet, according to the data, much of the information they examine is incorporated into their social and personal contexts only if it is deemed applicable. It would seem that the messages that filter through are what the women choose to apply in their lives. That is not to say that these women are in denial or taking the information for granted, however, the point is they truly believe that the information does not apply to them. For example, when discussing the well known statistic of “1 in 9 Canadian women will develop breast cancer in their lifetime,” few women actually knew what this meant. As noted in Chapter One, the “1 in 9” statistic is more of a scare tactic than a real statistic. For several, the statistic was judged to be too high, others had never heard of this statistic and one woman believed in the statistic. This one participant had worked in health care for many years and stated that she had “...seen the statistic.” One woman believed that the “1 in 9” phrase is a misrepresentation that is, falsified by statisticians. She knew how numbers could be manipulated. A few other participants might not have known about the “1 in

9” statistic but expressed worry for their daughters when informed. This expressed worry for their daughters emphasized the caregiver role assigned to women.

According to Nettleton (1996: 37-38), although health education material is directed at women and mothers, it is not for their health needs but for the health needs of their families. In this instance, the women expressed concern for their daughters’ breast cancer risk.

The inattention paid to the “1 in 9” statistic is ironic since the NPH framework has built health promotional campaigns and strategies on this one statistic alone and yet the women disregarded the meaning of the number. What clearly matters to the participants is the fact that breast cancer is not in their family and therefore, they perceive their breast cancer risk as low.

The Developing Self Versus the Malleable Self. Participants’ knowledge obtained through personal experiences revealed that the NPH messages of self-management or adopting the lifestyle theory are competing with many other messages. According to the NPH, it is assumed that all individuals want to be healthy and this is done by practising self-management. Despite the model’s assumption, individuals’ ways of knowing or life experiences compete with health promotional messages. The data revealed that personal experience is a primary means of developing and confirming beliefs that result in the development of the self. The arena where messages compete impacts on the development of the self. This debate is described as the developing self versus the malleable self.

Knowing that the self is not static and is under constant development, the NPH

model views the self as malleable. For instance, the many personal experiences that the participants spoke about had influenced the development of their selves. When discussing risk factors, one participant stated that she was unsure of the risk factors for breast cancer. We discussed two potential breast cancer risk factors, not breast feeding and giving birth to a child later on in life. She stated that she did not believe in those risk factors because it had not been her experience. For this woman, her own experiences superseded public health messages. The source of development of her “self” lays outside of public health information and messages. Expecting the self to absorb health information that results in behavioral changes such as improved self-management appears to be an impractical expectation. In addition, for these women risk factors were a product of social values and ideologies rather than facts. The risk factors are not free of wider patriarchal values and encourage a way of behaving and shaping one’s life.

Within the NPH, it is apparent why and how risk factors and risk profiling are used as tools to develop health promotional strategies which in turn regulate or control all health/social behaviors, especially women’s. Social behaviors are included because we live in a risk society (Beck, 1992) and disease causation for the NPH framework is lifestyle. Hence, the NPH may seem ideal in that it examines one’s psycho-social environment, however, it does so to regulate all social behavior since social behaviors renders us ill. In fact, the NPH resurrects the notion of victim blaming.

Summary. Overall, breast health information is everywhere and is competing in an arena with many other messages. The women judge what is important to their

individual social contexts and establish their hierarchy of needs often in contrast to the so-called non-coercive health promotional strategies of the NPH. Although purported to be non-coercive, health promotional strategies are an intrusion into our everyday lives and have the potential to regulate all aspects of social behavior.

Question 3:

The third and last question guiding this research is, "How well can the NPH framework explain women's experiences with breast health?" Overall, the NPH framework can be used to explain women's lack of breast cancer screening practices; however, it does so in opposition to the intended direction. Women's experiences with breast health oppose the NPH framework. Furthermore, the framework is punitive, relying on uncertain pre-defined truths and denying women their breast health experiences.

Opposing the Model. In this study, almost all of the women's breast health behavior oppose the NPH model. The intent of the whole model is to promote individual responsibility and consequently curb health care system costs (Lalonde, 1974). In the NPH framework it is rational to engage in self-management of one's health because it means less frequent use of medical services. However, these data revealed that women have come to rely on a system which discourages individual self-management. The physicians' offices operate under the assumption that if tests results are abnormal only then will patients be notified and patients are instructed to refrain from inquiring. This is an example of imposed reliance on an imperfect system. In the current system, mammography films are not only subject to interpretation by a

radiologist where human error is a possibility, there is also reliance on the human organization of an office to ensure that the results are examined and filed in the appropriate chart. Hence, there is much room for human error. Despite the chance for errors, the NPH model promotes mixed messages where an individual is directed to practise self-management but at the same time to rely on a system that is organized in opposition. This paradox is described later as a policy implication

A Punitive Model. The NPH model is a psycho-social environmental/epidemiological model. It is defined as "...an approach which considers environmental change as well as personal preventive measures and appropriate therapeutic interventions with a renewed focus on public policy and intersectoral cooperation" (Lupton, 1995: 53). The model uses health promotion, risk surveillance and the self, as a central strategy to facilitate changes in health behavior.

According to Lupton's (1993; 1995) analysis of the word "risk", the women who do not comply to breast cancer screening practices are unconscious of their internal risk and are thus "sinners" (Chapter Two). They are inflicting harm or sinning against themselves and other individuals such as immediate and extended family members. Women who are non-compliant are resisting the surveillance of one site of the female body. To follow through with this line of argument, the women display immorality and irresponsibility towards a risk that can be monitored. According to the NPH framework it is irrational not to engage in self-management and become a healthy citizen by taking part in breast cancer screening practices and incorporating health messages into their daily lives. Consequently, the NPH framework is a punitive

model. The NPH is at its core a “moral enterprise” and not a liberating project or movement, and the warnings heeded by scholars need to be taken seriously (Bunton, 1992; Lupton, 1995; Nettleton, 1996; Petersen & Lupton, 1996: xiii, 3).

Nevertheless, the women in the study defined rationality in their own terms. Through their judgment of information, they managed their health through “other” rational means that complemented the context of their lives, for example by practising BSE sporadically. For the majority of the women, breast cancer is not part of their family “health” histories and although they know to comply to BSE monthly, will practise when they remember, or will attend their next periodic physical examination and will submit to a CBE. The women displayed an over-reliance on their physicians for a clinical breast examination. Thus women rely on a system which opposes such reliance.

Uncertain Pre-defined Truths. Adopting the lifestyle theory for the management of one’s health means freely choosing and following rational health options in line with pre-defined truths supporting health promotional strategies. The data indicated that choosing healthy behavior is impossible because the purported pre-defined truths are constantly challenged as knowledge changes. For instance, several women who stated they were on Premarin were unsure whether to continue taking it due to the possible association with the development of breast cancer. Another debate that has received much attention is the efficacy of mammographic screening for women aged 40–49. The knowledge base of this issue is always changing (Chapter One). There is still no definitive answer of what a woman aged 40 is to do regarding

mammography. In addition, there are other debates such as the health risks involved with mammography, drugs which are purported to prevent breast cancer such as Raloxifene or Evista, and the repercussions of genetic testing for the breast cancer gene. This NPH model assumes women will choose to follow the instructions of professionals or pre-defined “truths”. However, belief in the messages of professionals is not given as the women in the study demonstrated.

Denying Women’s Experiences. The NPH model does not acknowledge women’s breast health experiences. The model treats the female body like a clean slate, re-writing the body to become a rational healthy citizen. Through constant health promotional messages the goal is to change behavior to result in a healthy citizenry independent at some point of a national health care system. In this study, women’s stories were both unique and in some ways similar. However, the NPH model is not able to acknowledge their unique experiences. According to the NPH framework, everyone follows the same continuum. Furthermore, because of how information is collected determining cohort differences is impossible. The unit of analysis which undergoes surveillance is the population and that information is then imposed on the individual. A woman is no longer considered an individual part of an age cohort or socio-demographic cohort. The woman as a unit of measure disappears and is replaced with factors of risk derived from a population (risk profiling). The woman’s experiences are not considered but the fact she fits a risk profile does. Consequently, fitting this profile, she is to adopt self-management strategies such as breast cancer screening practices to lower her risk of death from breast cancer.

Furthermore, since women are in a pivotal position as targets of surveillance, it would be rational to have the system work in their favor. Yet, according to this analysis the relationship women have with the new public health model is an unhealthy partnership where one party is exacting behavior from the other. If you examine Figure 1 in Appendix A, you will see that women have been supposedly an issue worthy of public health surveillance since the second public health regime. Moreover, the fourth public health framework is not exempt from previous social values and ideologies which supported the third regime. Therefore, the impact the NPH is having on women's lives is not any less complex than the third regime and yet more because morality is at the core of this new health paradigm. Regrettably it has taken approximately 20 years to identify the NPH as a problematic paradigm of health. Only recently have scholars begun to challenge the framework.

Summary. In summary, women's breast health experiences under the NPH framework attest to the framework's inability to provide women with the necessary breast health care that is wanted and needed. The model can be seen as punitive, not offering women the unbiased information they want and need to make informed decisions about their health, and not respecting each woman's experience with her body and her health. Furthermore, the NPH model is seen as exacting healthy choices from women by making them believe they are doing so freely without coercion. This is facilitated by the notion that the body which is reflective of the self is malleable.

II. Strengths and Limitations of the Study

All researchers must examine the strengths and limitations of their work. One strength of this research is the chosen methodology. A qualitative method offered the opportunity to delve below the surface of these women's lives. A survey would have only collected surface information and would not have reached the unique and similar experiences of these women about their breast health. In addition, a qualitative approach exposed other implications of the NPH for women and their health such as the regulative underpinning of health promotional strategies.

Limitations include sample size, selection and composition. The sample in this study is small and the data are not generalizable to the larger population. The sample is a non-probability sample. The 16 participants are self-selected and participated in the snowball method of identifying other potential participants for the study. The efforts to recruit women from various ethnic groups/communities such as Asian, Aboriginal, and African women were unsuccessful. Their experiences are missing from this study and would have been important for identifying and understanding cultural implications the NPH poses for women who are not Caucasian. In addition, the breast health experiences of women who are physically challenged are missing in the study. Advertisements and follow-up phone calls were placed to different women's organizations where women of visible minorities, Aboriginal women and women who are physically challenged participate; however, no one responded.

At a personal level, my views and the participants' views on breast cancer risk have influenced my reporting of this research. Being told at the age of 21 that I was at risk for breast cancer by my physician really made no sense to me. I was outraged,

for at that time women died of breast cancer. Was I to die? Obviously the delivery of this public health message was harmful and incorrect. Thirteen years later women still die of breast cancer, however, what I have come to understand is that early detection is our best defense. I also understand that the information provided within this study is not accessible to many women due to the technical, statistical and medical language that is used in academic journals. I am in a privileged position to have taken an academic interest in the confusing literature on breast health/cancer health promotion and to have shared it with the participants of the study.

The women in the study might not always practise breast cancer screening but they are hopeful that early detection may save them from an untimely death. The hope they feel is contagious and has allowed me to perceive that there are organizations and much support available in my city. This is not meaning to say that I will engage in mammography. I firmly believe that mammography imposes an unacceptable discomfort and its validity remains questionable. However, like the women in the study I myself filter through the information and judge what is applicable to my own psychosocial context. Hence, I have developed my own "other" rational self. As a woman and with other women, we must always challenge what pre-defined truths we are told. I, as the other two participants who have not engage in MAM, am hoping for better technology for when I turn 50. Until then I will continue to engage in BSE, be apprised of the breast health/cancer literature and make use of the self-referred rapid diagnostic centre if the occasion should arise.

The women's stories were respected and documented accurately for they are

the experts of their lives. As noted in Chapter Three, the interviews were a sharing of ideas and beliefs where a bond developed between the women and myself. It is inevitable that interviewing would have an impact on my views as well as theirs and consequently the study.

This study is unique for several reasons. To date, this research appears to be the first to address the lack of research and knowledge about women's experiences with breast health using the NPH as the theoretical framework. Researchers who write on the NPH framework have only just begun to recognize its impact on women's health. The second reason why this research is unique has to do with the uncovering of NPH implications for women who do not engage in breast cancer screening practices. The NPH model was unable to explain adequately women's breast health experiences. The NPH framework is touted as being new; however, the model is not exempt from past and current social values and ideologies that have characterized previous public health regimes. Furthermore, the NPH framework though the guise of health promotion is socially regulative. This translates into the necessity of further research with female participants to ensure that the NPH framework works on the behalf of women.

III. Future Research

Through excellent qualitative research and women centered health policies, health promotion could become a vehicle in which women reconstruct and ameliorate their present unhealthy relationship with the health care system. Future research into women's experiences with breast health should explore the views of women who are

the least likely to engage in MAM, that is rural women, women of color, women who are physically challenged and Aboriginal women. Furthermore, the research should delve into the differences among age cohorts as well as incorporating the different groups of women who fit the screening guidelines. Also, it is important to interview women about their over-reliance on their physicians when Manitoba has two centres dedicated to breast health/cancer. Interviews with general practitioners to explore their views about implementing health promotion/education into their practice would complement the literature examining obstacles pertaining to community health promotion. These interviews could also investigate the notion of physician-patient relationship as consultative rather than a clinical/directive relationship (Castel, 1991). Conducting any of the above research not only challenges the NPH but improves the model for women.

IV. Conclusions

This study has documented women's breast health experiences under the current model of public health. Although some women felt their stories were unimportant, they were all instrumental in furthering our understanding about women's decisions to engage in breast cancer screening practices. These women helped us understand or made us aware of their developed "risk" perception and how that translates into a breast cancer screening behavior. The NPH model as it stands does not appreciate these unique experiences and could benefit by adjusting the way data is collected by incorporating the lived "reality" of these and other women's experiences.

The women in this study who shared their breast health experiences and their personal stories have contributed to a greater understanding of breast cancer screening behaviors under the NPH strategies. Breast cancer is a disease women seldom speak about; consequently they take five to six weeks before seeking care for the discovery of a lump (Irvine and Lum, 1997). This study can help women to realize that their breast health experiences are equally important as their other health issues. The participants' breast health experiences are a contribution to both the breast health literature and to a growing body of literature criticizing the NPH model as it relates to women's health.

This research can facilitate change in many ways. These data clearly indicate that dedicated centres providing breast health/cancer information and support services must increase their advertising in a variety of ways to increase the chances of being incorporated into women's health routines. It is crucial that accurate, unbiased information be offered to women of all ages. High school programs could ensure that health classes offer information on breast and prostate/testicular cancer. Teaching about testicular/prostate cancer could lessen or deflect the stigma or notion of the imperfect body away from young girls. Such knowledge will stress that such diseases are a reality to adult males and females and that the notion of the imperfect body concept is not the issue at hand but health prevention. This knowledge and understanding may assist younger adolescents in understanding such diseases if either disease becomes a reality for their parents. Furthermore, knowing about these health problems and the importance of early detection will offer "no surprises" to the teenager or young adolescent who presents him/herself to a physician for an annual

physical. Rather it will promote knowledge and consciousness of health care choices.

With regard to the medical profession, physicians' current method of payment, fee for service, should be replaced with a salaried income structure. Once physicians are no longer paid for services rendered it will be to their advantage to have healthy clients who are knowledgeable about prevention. As well, empowering women about their health by taking charge of it could result in improving the unhealthy relationship between women and their physicians. When physicians' offices become more sensitive to the delivery of normal or abnormal results of mammograms in a timely manner and when physicians encourage their female patients to do BSE and not perform a CBE unless it is to reinforce the techniques of BSE, we will know that women have taken charge of their health and the health care structure has become easier to use for the improvement of "health for all". If such research facilitates the above changes, it is exemplary of a start towards addressing several implications of the NPH for women and health. As an example of changes that are happening at the community level within the NPH framework, I will now outline the intersectoral collaborative efforts underway in Manitoba concerning the provision of breast health/cancer information and support services (see Appendix F for a detailed description of the development process).

An Example of Intersectoral Collaboration in Manitoba

In Manitoba, under the leadership of Cancer Care Manitoba, the Breast Cancer Advisory Council (BCAC) and the Hope Breast Cancer Information and Resource Centre put forth a funding proposal to Health Canada with the Model for National

Collaboration (see Appendix F) in mind to facilitate the dissemination of breast health/cancer information and support services in Manitoba. The province of Manitoba has moved towards a regionalization concept of health service delivery and this format ties in with the community capacity building strategy or the cooperation resulting from communities and organization working together for the provision of breast health/cancer information and support services closer to home (see Chapter Two, the Ottawa Charter for Health, 1986, and WHO's Health for All strategy, 1981). The BCAC saw the opportunity to redefine its role to keep pace with other provincial and national breast cancer initiatives. Furthermore, this project advanced the HBCIRC's connection/partnership with communities and Regional Health Authorities and assisted with the dissemination of breast health/cancer information and support services (see Appendix F for more details).

Although I am hopeful that this network will enrich the breast health of women, I am left with a sense of potential dread. It is possible that the consideration of one disease, breast cancer, could be expanded to include, medicalize and regulate additional health conditions of women such as childbirth and menopause. One means of ensuring that the network does not become a regulative structure would be to encourage women, especially breast cancer survivors and breast cancer/women's health advocates to become involved in and oversee the structure. Similar to the NPH framework needing improvement to become user friendly for women, the collaborative network needs to be monitored so that it serves women and their health.

Implications of the Study

In conclusion, the implications of this study with respect to breast screening practices and health promotion strategies are:

- For these women, the delivery of health promotional messages have not been effective. Some women still do not engage in breast health practices. For those who do, the messages have been interpreted as a means to help others rather than themselves. For example, more concern was voiced for daughters' breast cancer risk levels than for themselves.
- If the goal of the NPH is to have women become self-reliant rather than dependent on the health care system, the opposite behavior is occurring. Women are remaining reliant on their physicians.
- The community networking efforts (intersectoral collaboration) have the potential to become a regulating structure of women's health. Once the structure is in place, there may be no limit to the number of public health strategies being promoted.
- Under the current NPH model, lay knowledge is not deemed to be credible. Rather, population health assessments using group statistics are the primary surveillance tool. Women's "lived" experiences are not considered fact in comparison to risk profiling.
- Although within the NPH women are viewed to be malleable and accepting of health promotions messages, women make their own choices, often in opposition to the prescribed "truths." Adopting and strictly adhering to lifestyle theory and self-management practices as defined by "the experts" can be risky, for example, engaging in MAM and Premarin use, and are often judged and rejected.

This analysis, the identification of themes and the integration of the NPH framework address the cautionary warnings from scholars and feminist researchers that the vehicle of health promotion within the NPH needs investigating. The identified implications noted here can be seen as potentially detrimental to women's continued consumption of health services in relation to breast health and other health matters. Furthermore, since the current model of public health is monitoring a

population living within a risk society and is reflective of changing socio-cultural values and ideologies, it would seem that there are many other practical, public and policy implications of the NPH yet to be discovered. The NPH framework has morality at the core of its philosophy and, in its covert coercive ways, defines for us how to live our lives individually and collectively. When considering the NPH tenets, it behooves us to carefully examine the NPH's directives and to question for whom, and what, involvement entails. We as women may want to emulate the study participants by judging the available health information, selecting only that which applies to our own social context, and taking charge of our health when we are told information that is in opposition to our knowledge and beliefs. In other words, we need to rely on our own and on other women's experiences to guide us through the health promotion maze of the New Public Health model.

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APPENDIX A

A Brief History of Public Health

I. Public Health pre-Enlightenment: 1300 - 1689

Quarantine Regime

Pre-Enlightenment public health focused on epidemics and the daily regulation of waste disposal. Although endemic diseases were present, they were often ignored. The public-health strategies of surveillance and regulation during this time were ad/hoc or reactive to the spread of plagues, thus quarantine and isolation were the only two strategies used during this time period. This reactive organization was a form of non-administrative collective responsibility and was usually town based. Basically, the townspeople collaborated to protect themselves. To prevent the spread of disease, much effort went into establishing boundaries between places. For example, trading ships were denied economic transactions between towns because many believed these ships were carrying diseases. A social consequence of these ad/hoc strategies was the categorizing of some groups of people as dangerous. For example, those suffering from leprosy were banished from their homes to live beyond city limits in hospitals or on the street (Armstrong, 1993: 394-395; Lupton, 1995: 18-19).

There are four theories of disease causation that characterize this period and preceding centuries. The first, humoral theory, viewed the individual body as seeking a balance with the four humours, four elements, and four qualities. The second, the miasmatic model, was popular up to the discovery of microbes. Miasmatic theorists argued that bad air, either damp or odorous, resulted in sickness. The third is the contagion model, from which the quarantine strategy emerged. Many held the

position that disease spread by simple contact with an infectious body. The miasmatic model is similar to the contagion model with a slight difference; the miasmatic model identified dirt and smell as the primary causes of disease. When the humoral, miasmatic, and contagion models failed to provide a rational explanation for disease causation, it was deemed to be God's will, the fourth and ultimate theory of disease causation. Many believed that disease was the divine creator's way of punishing mankind for their many sins (Lupton, 1995: 19-21). These theories of disease causation remained influential in the second public health regime, sanitary science.

II. The Age of Enlightenment: 1690 - 1799

Sanitary Science / Social Medicine

Sanitary science or social medicine emerged during the Enlightenment. This period characterized how the creation of knowledge ceased to be for God's sake and became instrumental in human progress. Public health adopted many characteristics of the Enlightenment. Characteristics such as rational thought, social order, education and scientific method would assist in uncovering natural laws. Subsequently, those natural laws could then be applied to the elimination or control of diseases (Lupton, 1995: 21).

The notions of governmentality emerged from rationalization and social order, characteristics embedded in the Enlightenment. Governmentality facilitated involvement of the State in its citizen's lives. Social medicine emerged alongside governmentality, fostering attitudes that the State should be responsible for ensuring the population's health status. The public health movement was also influenced by scientism and hygienism. The supporters of social medicine saw the necessity of

changing from a quarantine strategy to a preventive model by establishing administrative procedures. Social reformists increased and strengthened their authority by emerging as a profession with the tenets of science (Lupton, 1995: 22).

After the development of a public health administration, the focus of public health broadened to include not only epidemics but also endemic diseases, which had previously been taken for granted. The health status of the work force had become very important with rapid urbanization and the onset of capitalism. As a result, two public health interests became prominent. The first interest was the natural environment. Much attention was paid to specific building standards (e.g., houses, schools and hospitals). The second interest was a new concern with the body's excretions within these environments (e.g., blood and urine). The focus shifted to maintain the boundary between the environment and the body, since danger was seen to emerge from nature. Medical policing and inspection became the means through which these public health interests were managed (Armstrong, 1993: 396-397; Lupton, 1995: 21-24).

Foucault (1975; 1984) documents the changes around the regulation and recording of epidemics that lead to the growth of medical administration. He states that documenting patterns of disease and death required a 'multiple gaze' that extended beyond the individual to all areas of social life. Medical knowledge increased as the use of statistics provided a window into the health of the entire population. As a rational technology of surveillance and regulation, the scientific discipline of statistics offered the field of public health credibility. Despite the acceptance of statistics, all four theories of disease causation continued to influence knowledge of the sources of

illness and disease. Many social reformers recognized the need for and invited other experts such as engineers and pharmacists to assist them in compiling statistics about the health of the population (Lupton, 1995: 23-25). As a result, a more comprehensive system of medical administration developed as medicine sought to become proactive and forestall the advent of illness by medicalizing social life and the environment.

The discipline of Statistics within the public health movement facilitated the surveillance of populations. Population surveillance techniques such as demographic estimates, mortality and morbidity rates, marriage and death rates became the measures of choice. A consequence of these developments was the constructed standards of healthy bodies through statistical norms. Statistics assisted in the stigmatization of groups such as the poor and unclean by informing medicine about what was normal and abnormal. The survey constituted a technology that dispersed the medical “gaze” throughout society. It assisted in measuring what was statistically normal and abnormal. With an interest in populations, the “gaze” focused itself upon a sub-population, the family. Population surveillance techniques offered a view of the family’s health by reporting on the number of children per household and the growth and survival rates of children and these statistics fueled the production of child rearing texts. Social reformers believed that making the family responsible secured the well being of children (Lupton, 1995: 25-26). Thus, the family unit would remain an important site of surveillance from this point on. This brings us to an examination of the third regime, personal hygiene.

III. Modern Public Health: 1800 - 1969

Social Medicine / Personal Hygiene

The beginnings of the third public-health movement grew out of a serious concern about the expanding cities and the consequences of capitalist production. Many cities expected problems such as overcrowding, waste disposal and insufficient water supply. Edwin Chadwick, a renowned social reformer, and followers of reform working within the theories of miasma and contagion, anticipated endemic diseases of large proportions which would incapacitate a productive workforce. Chadwick and colleagues believed that money spent on public health measures would ensure a healthy and productive population. They further maintained that industrialization would raise the population's quality of life. Chadwick statistically confirmed in his 1842 report, that current patterns of diseases were the result of improper engineering or lack thereof. The expanding cities all lacked a functioning infrastructure for obtaining clean water, proper housing and sewage and refuse management (Lupton, 1995: 26-28; Noble-Tesh, 1988: 30).

Chadwick's report initiated administrative development of regulations and measures to prevent diseases. As a result, Britain enacted a series of Nuisance Removal Acts in 1846. The authorities were able to prosecute citizens who were responsible for nuisances, such as the improper management of waste. From these Acts emerged the Public Health Act of 1848. This Act led to the development of a General Board of Health whose objective was to empower local authorities to regulate nuisances through inspection. Due to criticisms against its interfering authority, the General Board of Health that operated under the constraints of early capitalist

ideology was forced to dismantle. There emerged with the Sanitary Act of 1866, mandatory conditions for the direction of local authorities. This change, however, was met with much resistance. By the end of the nineteenth century, the 'sanitary idea' or clean cities became a responsibility of the local government. Many of the principles of public health at this time were enforced (Lupton, 1995: 28-30, 44). Public health had developed and implemented an effective medical administration in the prevention of endemic diseases.

The early nineteenth century was not only characterized by securing a clean environment, but also a clean body. Boundaries and spaces were established between bodies, since danger was believed to be associated with individual bodies (Armstrong, 1993: 404). Personal hygiene meant that individuals were forced to regulate the exterior elements (water and food) that entered the body, and interior elements (urine and faeces) that were excreted into the environment. Dead bodies posed a problem and several regulations emerged as solutions. Social groups such as the poor, laborers, prisoners and immigrants were seen as harboring dirt, filth and contagion. The obsession with hygiene and cleanliness even reached the soul of individuals, since Christianity believed the sexual body needed surveillance and regulation. Public health hygienists pointed out all areas of social life that required regulation as an interest of the State (Armstrong, 1993; Lupton 1995: 33-36). Soap, water, education and religion would turn the uncivilized, dirt harboring individuals into productive, clean and lawful members of society.

The late nineteenth and early twentieth centuries were characterized by the discovery of the microorganism. Microscopically identifying bacteria substantiated the

contagion theory and strengthened public health's connection to science. Since the Enlightenment, health reformers and medical practitioners had believed that science would eliminate diseases. In North America, the discovery of the microorganism became the basis for a re-interpretation of hygienic problems. For example, perceiving tuberculosis as a problem of bacteria and not one of poverty is an illustration of how diseases were re-interpreted. Administrations in Britain, on the other hand, who previously believed that lifestyle and sanitary changes were fundamental to one's health, finally adopted the bacteria ideology in the mid-twentieth century. The public health movement in the early twentieth century shifted attention towards the individual body, and placed less emphasis on the individual's physical environment (Lupton, 1995: 36-37). As a result, the discovery of the microbe changed the focus of public health.

Public health in the early to middle twentieth century became dominated by biomedical principles. Emphasis was placed on curing the sick with medically advanced technology. At the same time, curative intervention gained popularity with a notable decrease in infectious diseases and the expansion of ideas about the welfare state. The ideology of the welfare state firmly supported the health of a population as a responsibility of the State. The role of health education was now seen as supporting biomedical practices through mass media techniques and health education materials which instructed individuals on how to care for their bodies. The mass media was seen as a primary source of information playing an enormous role in educating people about their health. As a result, public health experienced a loss in administrative

power and resources, and the ill were now treated in hospital (Ashton & Seymour, 1988: 18; Lupton, 1995: 44-45).

A social consequence of this regime was the stigmatization of the poor, immigrants and certain cultural groups who were believed to be unclean. The importance of individual bodily cleanliness and the regulation of space between individuals especially the rich and the poor became important. Diseases of contact, such as tuberculosis or venereal diseases among the poor, had some health reformists, namely eugenicists, counsel against prevention and treatment in the belief that the poor were genetically unfit. Much effort on educating the public occurred at this time. Consequently, this focus re-confirmed the family unit as a site of surveillance. As a result, mothers were held responsible for the health care of their families. The latter part of the personal hygiene regime was characterized by educating the public and not enforcing public health principles. Health educators and administrators came to the conclusion that disease and illness may be preventable since human behavior was seen as the missing link to good health (Lupton, 1995: 39-45). Human behavior as a missing link to good health will be examined further in the fourth or current regime of public health, the New Public Health.

The above historical overview of public health demonstrates the many changes and developments of public health over three regimes. Recognizing this historical context of public health gives us a clearer understanding of the developments of the New Public Health and its central strategy of surveillance and regulation, namely, health promotion (Chapter Two).

Figure 1

A HISTORY OF PUBLIC HEALTH

Time Period- Regime	Boundaries and Space	Disease Causation	Public Health Interest	Public Health Strategies	Responsibility	Social Consequences
Pre-Enlightenment 1300- 1689 Quarantine Regime	-guard the lines between towns	Humoral Miasma Contagion God's Will	-outbreaks	-quarantine	-unorganized -no administration	-stigmatization of the poor and ethnic groups (Lepers and Jewish citizens)
Enlightenment 1690-1799 Sanitary Science Social Medicine	-guard the lines between body and environment	Humoral Miasma Contagion God's Will	-epidemics -endemic diseases -workers health -body excretions	-medical police -inspection -statistics	-state involvement -administration -concept of statism	-stigmatization of the poor is heightened -gaze focuses on the family
Modern Medicine 1800-1969 Social Medicine Personal Hygiene	-guard the lines between bodies -danger arises from individual bodies	Miasma Contagion	-epidemics -endemic diseases (TB, VD, Cancer)	-hygiene -disinfection -deodorizing -photography -education -vaccination	-state/social responsibility	-stigmatization of the poor, immigrant groups etc. -family is the site of intervention -mother's behavior is scrutinized
Late Modern Medicine 1970- Present NPH	-lines are everywhere -risk society	-Lifestyle	-risk profiling -risk factors -infectious diseases -public policy	-mass screening -statistics -education -health promotion	-state/social responsibility -neo-liberalism	-social regulation -focus on women and the family

APPENDIX B**BREAST HEALTH STUDY**

A graduate student at the University of Manitoba would like to talk to women about their experiences with breast health.

If you are a female between the ages of 40-65 with no history of breast cancer or breast cancer treatment living in Winnipeg I would like to hear about your experiences.

If you are interested in participating or would like more information please give me a call at: 000-0000 and ask for Jo-Ann. Please leave a message if I am not available, and I will return your call as soon as possible.

All conversations are completely confidential. Your anonymity is guaranteed and will be protected at all stages.

This project has been granted ethical approval by the Department of Sociology Ethical Review Committee, University of Manitoba and is supervised by Dr. B. Payne.

APPENDIX C INFORMATION SHEET

My name is Jo-Ann Trudeau and I would like to learn more about your experiences with breast health. This study fulfills one of the requirements of my M. A. program and has been approved by the Department of Sociology Research Ethics Review Committee at the University of Manitoba.

Your participation in this study is entirely voluntary and you may withdraw your participation at any time. Participating in this project does not pose any more risk to you than what you might experience in the normal conduct of your everyday life. However, you will receive the phone number to the Hope Breast Cancer Information and Resource Centre as a precautionary. You will not be receiving any remuneration for participation in this project. If you wish to participate, you do so because you genuinely want to speak about your experiences with breast health.

If you agree to participate in this study, you agree to having the interview audio taped. The interview may last for approximately two hours, however, this will vary with each individual. You are free to refuse to answer any questions you consider too personal or objectionable. You are free to ask any questions concerning the study before and during the interview. The pause or stop button on the recorder will be in full view if you either want to continue or cease answering the questions at any time. If you wish, you have the opportunity to read the transcripts and make changes.

The information you provide to me will be kept in strict confidence. Your identity will not be revealed in published reports of this research. You will only be identified with a pseudonym and an identity code. The audio tapes of your interview will be stored in a locked cupboard and will be destroyed at the end of the project. The computer files will be password protected and the hard copy of the transcripts kept in a locked cupboard. The information gathered in the course of this research will be evaluated for the purpose of a Master's of Arts degree at the University of Manitoba, possibly in other scholarly publications and you will be given a written summary of this work.

If you should have any questions about this study you may contact me, Jo-Ann Trudeau at 000-0000, or Professor Barbara Payne, (my advisor) at 000-0000. Any complaints regarding procedures may be reported to Professor R. Kueneman Head of the Department of Sociology at the University of Manitoba (000-0000) for referral to the Ethical Review Committee.

**Thank you for your time in this matter,
Sincerely,
Ms. Jo-Ann Trudeau**

APPENDIX D
Consent Form

I, _____, agree to participate in the study of women describing their experiences with breast health. I have read the attached information sheet and I understand that my participation in this study is entirely voluntary and that I may withdraw my participation at any time. Participating in this project does not pose any more risk to me than I might experience in the normal conduct of my everyday life. However, if I feel the need to speak with someone I have been given the phone number to the Hope Breast Cancer Information and Resource Centre as a precautionary. I am not receiving any remuneration for my participation in this project.

I understand that in agreeing to participate in the study I will take part in one audio taped interview lasting for approximately two hours and one meeting there after for the purpose of transcript accuracy. I am free to refuse to answer any questions I consider too personal or objectionable. I am also free to pause or stop the recorder and either to continue or cease answering the questions at any time. If I wish, I will have an opportunity to read the transcript and make changes.

I understand any information provided by me will be kept in strict confidence. My identity will not be revealed in published reports of this research. I understand that my identity will be altered with a pseudonym and a code. I further understand that the audio tapes will be stored in a locked cupboard and will be destroyed at the end of the project. I understand that the computer files will be password protected and the hard copy of the transcripts will be locked up. I understand the information gathered in the course of this research will be evaluated for the purpose of a Master's of Arts degree at the University of Manitoba, possibly in other scholarly publications and I will be given a written summary of this work by the investigator. Under these conditions I agree to the interview and to the use of my responses for Ms. Jo-Ann Trudeau's research purposes.

I understand that according to the laws of the Province of Manitoba, a report of any ongoing child abuse or abuse of any vulnerable persons must be made to the proper authorities.

I understand that should I have any concerns about this study I can contact Jo-Ann Trudeau (000-0000), or Professor Barbara Payne, (Thesis Advisor) 000-0000. Any complaint regarding procedures may be reported to Professor R. Kueneman Head of the Department of Sociology at the University of Manitoba (000-0000) for referral to the Ethical Review Committee.

(Date)

(Participant's Signature in Ink)

(Date)

(Researcher's Signature in Ink)

APPENDIX E

Structure of the interview:

Hello,

Welcome and Thank You for agreeing to participate in this exploratory research on women's experiences with breast health. I will be asking you questions on your experiences with breast health. You are guaranteed confidentiality and anonymity and you may stop and end the interview at any time. Thank you for agreeing to have this interview taped. This is the pause or stop button to go off record. Are you ready to begin?

I. First, I would like to start with what **attracted you to the ad or poster**.

1. Can you tell me why you agreed to participate in this study?

Probes:

Where did you see the ad or poster?

What was your reaction to the ad?

2. Can you tell me a bit about yourself.

Probes:

What is your age?

What is your marital status? What kind of work do you do? What kind of work does your spouse/partner do?

Do you have any children? How old are your children? Do your children reside with you?

Have you always lived in Winnipeg? Which ethnic group do you consider yourself to be a part of?

How about your education?

II The second set of questions focuses on your **general health and your thoughts on developing breast cancer**. The questions for this section include:

1. Can you tell me about your health?

Probes:

Overall, what is your health like?

(If 50 or older) Are you on any hormone replacement therapy?

(If 40) What do you think of hormone replacement therapy? Will you ever engage in it?

Is there any family history of serious diseases (e.g. heart disease, cancer, diabetes)

**Do you think you are at risk of developing any of these diseases?
How does this make you feel?**

2. Do you have a physician?

Probes:

What kind of doctor do you see?

Is s/he a family doctor (GP) or a gynecologist?

What has your doctor told you about your chances of developing breast cancer?

When did s/he first discuss this with you?

What does this mean to you on a personal level?

What actions have you taken ?

What does this mean to you on an interpersonal level (and reasons) ?

If nothing, probe —why?

Fear?

Rejection of medical model?

Denial?

Can you describe your first breast- self examination experience?

Has this experience changed over time for you? Better, worst, more confident about test, less confident about test? Why do you practise BSE? Who taught you?

Can you describe your first clinical breast examination experience?

Has this experience changed over time for you? Better or worst?

Did you ask to get this done?

Why was this done?

3. Now, I'd like to focus on breast health. Do you think there is a chance you might develop breast cancer?

Probes:

What do you think your chances are?

Low...why?

Medium...why?

High...why?

How did you come to this assessment?

What are you basing this response on (education, experience/)

What do you think of when you hear the often quoted statistic that 1 in 9 women in Canada will develop breast cancer in their lifetime?

What does this mean to you on an emotional/psychological level?

What actions have you taken?

What does this mean to you on an interpersonal level (reasons)?

4. There are a number of factors that are thought to increase our risk of developing breast cancer. What do you think is most likely to cause breast cancer?

Probes:

How do you know this?

What do you base your knowledge on?

What are the risk factors associated with breast cancer?

Are there any risk factors which concern you? If so... which and why?

If none, probe.....why?

What actions do you engage in to lessen your chances of developing breast cancer?

Probe...Diet? Exercise? Screening? Prevention? If none, probe.... Why?

III. The third set of questions will focus on what women do in terms of **breast health preventive practices**.

1. Do you engage in any form of breast cancer prevention?

Probes:

What kinds of breast health practices do you use?

If none, probe why?

*If mammogram..... Think back to the last (or first) mammogram you had. Tell me about that experience.

Probes:

Equipment, staff, waiting for the results, the meaning and implications of those results, support (family, friends, spouse).

Was it diagnostic or screening? Why?

What was the deciding factor (reason) to engage in MAM?

*If clinical breast examination → What is this experience like?

*If breast self-examination → What is this experience like?

*On any breast cancer screening practice, probe....

What does this mean to you personally?

What actions have you taken?

What does this mean to you on an interpersonal level (reasons)?

Do you take any medication to prevent breast cancer?

Probe:

Tamoxifen, Herceptin

Natural remedies, complementary healing (e.g. reflexology)

2. What is your opinion of breast cancer screening? Please explain.
What can you tell me about breast cancer screening in Manitoba?

Why do you feel this way?

IV. The final set of questions focuses on where women have obtained their knowledge about breast health. These questions include:

1. From where do you get information about breast health practices and breast cancer?

Probes:

Why do you want to know more about this topic?

What type of information were/are you looking for?

How does this information make you feel?

What is your opinion of the information you get?

Is any information contradictory? Explain

2. Do you find information accessible in Manitoba?

Probes:

From where?

How do you get it?

******How do you feel about the questions asked today?**

******Any questions you think I should be asking?**

******Is there anything you would like to add or ask?**

Once the I have the transcript would you be willing to get together to confirm your responses or change what you have said.

Yes_____ No_____

Thank you for your time.

APPENDIX F

Intersectoral Collaboration in Manitoba

The co-sponsoring organizations held a 2-day workshop which brought together Manitobans or stakeholders such as survivors, citizens, health and allied health professionals, volunteers and agencies together with the interest in disseminating breast health/cancer information and support needs. Through the facilitation of the HBCIRC, the stakeholders worked towards identifying what resources were available and not available in their communities, issues and priorities along the continuum of care (wellness/prevention to bereavement). One priority was selected to work through two set of questions which focused on the development of a Local and a Provincial network. All returned to their respective communities with an action plan facilitating them towards; 1) the development of a Local network and 2) developing a process in electing a Regional representative to attend phase II, developing a Provincial Network, in the year to come. The stakeholders have the HBCIRC assisting them developing a local network resulting in a Regional representative. From there the Regional representative will occupy a seat at the Provincial level and then one member at the Provincial level will then hold a seat at the National level. All issues, concerns and priorities regarding breast health/cancer information and support services will travel through this local, provincial and national network horizontally (see Model in this Appendix). This model opposes the usual top-down method of decision making and flow of information.

According to Petersen and Lupton (1996:147) the concept of participation” and “community” are not without it’s problems within the NPH framework. Although the ideas of “community participation” seem democratic, they are not new and are under criticism in the literature and requiring exploration. In light of the literature, the theoretical knowledge underpinning community participation is descriptive of unacknowledge policy implications, there is much potential for discrimination and the notion of involving the community to work within a participatory model suggests regulatory effects. Lets quickly examine these three points using examples from the Manitoba context.

An unacknowledged implication is how participating in your community is nothing more than an act of tokenism (Petersen and Lupton, 1996: 148). Those who participate may be asked to consult, however do not have much influence affecting decisions. They may in fact even be co-opted into the political organization they set out to oppose. Another implication which requires more attention is the idea that the method used to enable and empower a citizenry to participate in their community is the same procedure for all communities. This was clearly seen at the 2-day collaborative workshop in Manitoba where stakeholders from Northern Manitoba who represented Aboriginal communities have to adjust the way things are done for them and thus it be reflective of their cultural context, location and commitment of individuals involved in the process.

The act of belonging in a community conjures notions of discrimination. The word community is restrictive with much emphasis on the neighborhood as the basis for identity. This denies the importance of other communities which see a

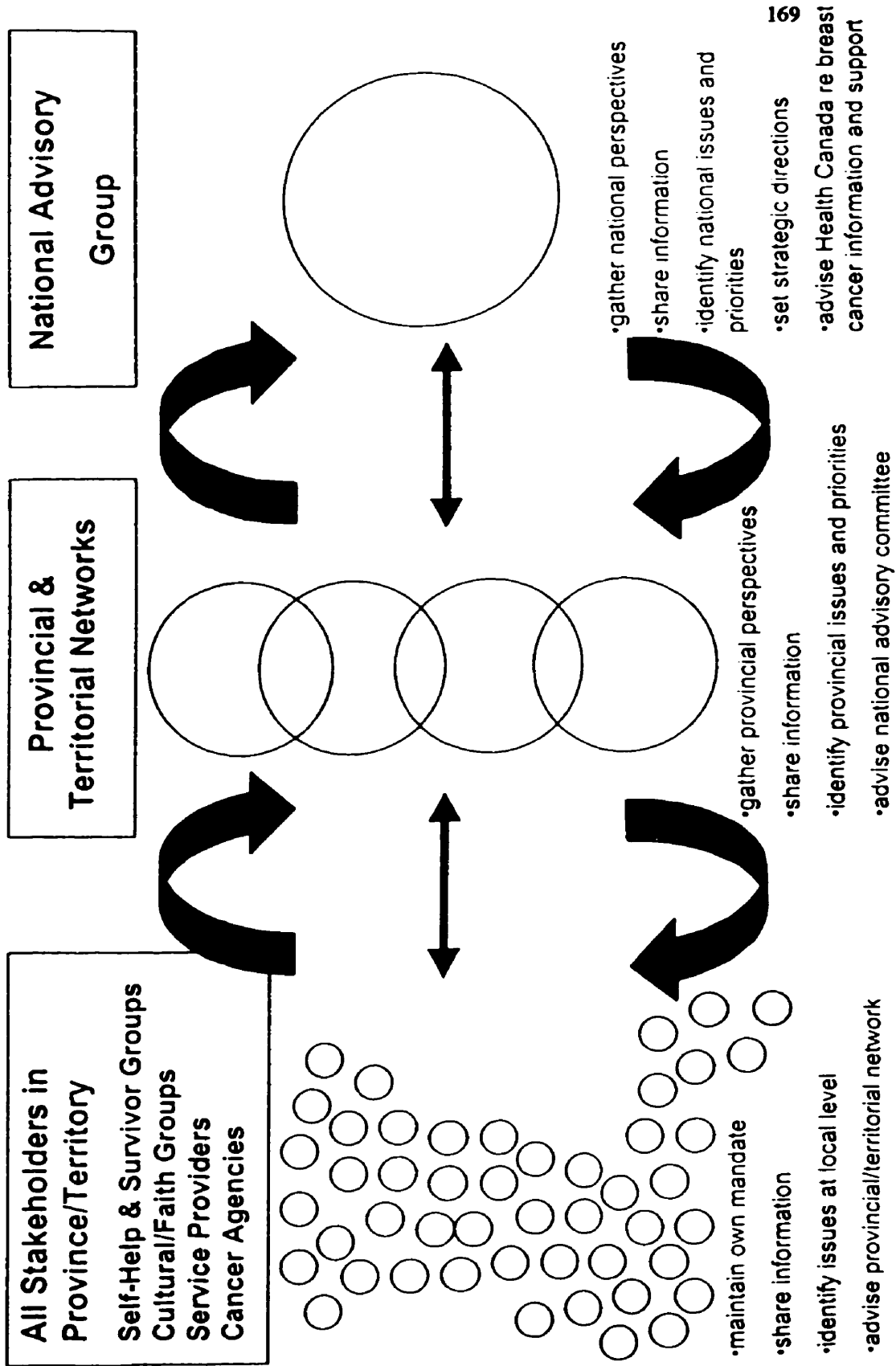
fit or conflict with a community's participation towards improved health (Petersen & Lupton, 1996: xvi, 164). For instance, the conference offered no room for criticism of the drug clinical trials involving Raloxifene or Evista. The workshop agenda was designed to introduce and promote breast health/cancer information and support services in Manitoba and did not allow a critique of these programs.

According to Petersen and Lupton (1996: 146-147) the ideas of enabling a citizenry to participate in their community has regulatory effects. Participation according to the NPH framework is not a right but a duty. The duty concept ties into the discourse of rationality in that a rational person is a dutiful citizen incorporating into their health a repertoire of knowledgeable ways to practise self-control of the body and emotions and thus result in being regulated. The individual is not duped into thinking that personal freedom allowed them to choose the necessary health practices instead the choice is implied by larger socio-cultural and political context. Furthermore, community participation only perpetuates the tenets of the NPH such as rationality, healthism and morality. In reference to the events in Manitoba, one of the selection criteria for inviting stakeholders to the conference was that they have a personal/professional interest in the disseminating breast health/cancer information and support needs. This selection criteria reinforced the concept of duty which implied participation.

On a final note, who is the Manitoba collaborative network for? According to the literature, the network is a means of imposing regulation on a segment of the population. In the Manitoba case, is the network to become a means to regulate women and their breast health? We know that the women in the study

were unaware of the HBCIRC and with this network under construction will women make use of it for learning or will they continue to rely on their varied non-scientific ways of knowing?

Model for National Collaboration Breast Cancer Information & Support



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PROPOSAL REVIEW REPORT

PLEASE PRINT

Principal Investigator(s):

JO-ANN MARIE COLETTE TRUDEAU

Project Title:

WOMEN'S EXPERIENCES WITH BREAST HEALTH

This Proposal, as currently described, has been:

- approved
- approved with modifications (minor changes; no re-submission required).
- approved in principle (research tools have yet to be developed).
- tabled (major modifications or information required).
- found ethically unacceptable.

Comments:

Livante-Pearson

Chair, Research Ethics Review Committee

Nov 7, 99

Date