SURGERY FOR BREAST CANCER IN ST. JOHN'S: THE STATISTICS, THE SURGEONS' VIEW, THE PATIENTS' VIEW

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Surgery for Breast Cancer in St. John's:
The Statistics, The Surgeons' View, The Patients' View.

by

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A thesis submitted to the School of Graduate Studies in partial fulfillment of the requirements for the degree of Master of Science.

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ABSTRACT

Background: Surgical management of localized breast cancer has changed dramatically in the past two decades. Randomized clinical trials of women with stage I or II lesions have shown there is no significant difference in survival rates between women receiving modified radical mastectomy (MRM) or breast conserving surgery (BCS). However, there are substantial regional variations in types of surgery for breast cancer. It would then seem that surgeons and patients' views could help explain such variations. This study aimed to clarity the numbers of MRM and of BCS performed within the Health Care Corporation of St. John's, Newfoundland during the years 1994-1997. In addition, the aim was to contrast the surgeons' view of the different types of surgical interventions for breast cancer with the views of women who had undergone different types of surgery.

Method: The records of all surgeries for breast cancer, irrespective of staging of the disease, were extracted from the Health Care Corporation of St. John's (HCCSJ) for the period of 1994-1997 and coded according to the Canadian classification of diagnostic, therapeutic and surgical procedures (Statistics Canada, 1986). Chart audits were completed to ensure accuracy of the extracted data. All surgeons within the general surgery program of the HCCSJ who did breast cancer surgery regularly and consented to participate in the study completed a short questionnaire and were interviewed about their own surgical practices, their views of the decision making processes of women and which factors they felt impacted these particular patients' choices for surgical intervention for their breast cancer. Four focus groups and one private interview were organized with 21 women who had either

MRM or BCS to provide them with the opportunity to discuss their surgery. The interviews and focus groups were taped, transcribed and common themes extracted.

Results: A total of 363 surgeries were performed for breast cancer within the HCCSJ during 1994-1997. Of these 71.9% were MRM. There was little variation between years at each site but significant differences in rates between sites. MRM was a more common procedure for women from outside the city and for older women. According to the surgeons, most diagnostic visits took place in a hospital clinic and lasted approximately 20 to 30 minutes. They emphasized the importance of the woman's choice and they claimed they always gave women an opportunity for choice. However, a substantial majority of the women were unsure they had been given such an opportunity. The majority of women who underwent MRM stated they did in fact have their minds clearly made up to have a mastectomy regardless of what information the surgeon gave them. They also stated that they chose MRM because they thought of the breast as diseased, were more familiar with this form of surgery and felt it would be better protection from recurrence. Those patients who had received BCS described reaching the decision jointly with their surgeon once all of the options had been described and discussed.

Conclusions: Modified radical mastectomy is the dominant procedure being performed within the Health Care Corporation of St. John's, Newfoundland. While surgeons may advise women of their options during the diagnostic visit, many of the women may " not hear" the options because of their heightened anxiety. Alternate ways of informing women of their options are discussed.

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DEDICATION

This thesis is lovingly dedicated to the memory of my father, **Peter James Walsh** who taught me perseverance and who showed me how to find courage and inner strength in the face of adversity.

CHAPTER 1: INTRODUCTION

The overall level of health attained by Canadians is a meaningful measure of our society's success. Standards of good health facilitate individuals to lead fulfilling, productive lives. For the country itself, a high level of health contributes to increased prosperity and stabilizes our country socially.

Health status indicators are phenomena which can be measured and which serve as indicators of the state of health of individuals and therefore the health of the general population. As a health status indicator, life expectancy provides a meter for measuring a particular aspect of the population's overall health and the extent to which people are able to live a long life through all stages of the life cycle. More often, the measures known as "health status indicators" are really measures of disease or death, rather than measures of good health or well-being. Many aspects of health status can be measured and include the general health and well-being, ability to function, the existence of disease or health problems, causes of death and length of life. The rates at which specific diseases or conditions occur in the general population help identify trends and patterns of diseases or health problems and to determine the need for prevention, treatment, and support services (Advisory Committee on Population Health, 1996).

Since the 1970s, death rates from most major causes have declined in Canada, particularly those deaths caused by heart disease and injuries. The decline in heart disease associated deaths has been due to a combination of factors. The reduction in smoking, the improvement in diets, particularly in the decreased consumption of dietary fat, and improved control of hypertension have seen a decrease in occurrence of heart disease. Deaths caused by injury have declined due to increased safety consciousness and safer behaviors. Often legislating programs aimed at issues of better quality roads, vehicles, impaired driving, child carrier seats, seatbelt use and motorcycle helmet use have added to the improving trends (Advisory Committee on Population Health, 1996).

Information about cancer cases in Canada is compiled through a provincial reporting system which provides a national database for studying trends and patterns of cancer. In 1995, an estimated 125,000 new cases of cancer were diagnosed in Canada. In reviewing the figures for all types of cancer combined, the incidence has remained relatively stable since the mid-1980s. Although the overall rate does not appear to be changing, some cancers are notably decreasing while a few types of cancer are increasing (National Cancer Institute of Canada, 1998).

Breast cancer incidence among women has risen particularly among women aged 50 years or older. This may be due in part to better detection through mammographic screening since the mid-1980s. Although cancer is primarily a disease of the elderly, female breast cancer is occurring more frequently at earlier ages with women aged 40-59 years accounting for approximately one-third of new cases (National Cancer Institute of Canada, 1998). In 1992, an estimated 15,700 women developed breast cancer in Canada and 5,200 died from it (Beatty, 1993). In Newfoundland 252 women were diagnosed with breast cancer in 1994, with the highest number being in the 40-54 age group (H. Bliss Murphy Cancer Center, 1996).

The management of localized breast cancer has changed dramatically in the past two decades. Until the mid 1980s, the treatment for stage I or II breast cancer was total mastectomy or removal of the breast together with removal of the axillary lymph nodes. Since the mid 1980s a second alternative for surgical treatment of breast cancer has been available. This alternative is referred to as breast conserving surgery which involves the removal of the tumor along with a cuff of normal tissue while preserving the cosmetic appearance. As an adjunct to this surgical option, radiotherapy is required. Randomized clinical trials of women with stage I or II lesions have shown that there is no significant difference in survival rates between women undergoing modified radical mastectomy (MRM) and those receiving breast conserving surgery (BCS) (Canadian Medical Association, 1998; Hislop et al., 1996; Goel et al., 1997; Morrow, Bucci, and Rademaker, 1997). The evidence suggests that with long term follow up, BCS followed by radiation of the remaining breast have resulted in equivalent rates of overall survival and local control to MRM (Hislop et al., 1996).

Since there is often a choice between treatments in the early stages of breast cancer, patients are being asked to play a more active role in decision- making regarding surgical treatment options for breast cancer (Lerman et al., 1993; Cotton, Locker, Jackson, Blamey, and Morgan, 1991; Crawley, Kostic, and Capello, 1990). With the present evidence of outcomes well documented, many women are now in a position of having a choice between these two surgical interventions.

Three recent Canadian studies were conducted to examine the variations within two Canadian provinces with the use of either MRM or BCS and the indications of why each was chosen. These studies revealed that BCS rates varied from 23% to 68% in Ontario and British Columbia respectively (Goel et al., 1997; Hislop et al., 1996; Iscoe, Goel, Fehinger, Holowaty, and Naylor, 1994). They also found that high rates of MRM were associated with an older population of women, if the surgeon was not affiliated with a teaching hospital, did not hold an academic appointment and was not a recent graduate from medical school. However, there was little evidence on differences between surgeons and women in their preferences. In the study conducted by Goel et al. (1997) it was noted that although variation in the use of MRM and BCS for early-stage breast cancer has been examined, little attention has been paid to the factors that may influence their selection.

There is a need for ongoing research to determine local variations in types of surgery for breast cancer and the role of the surgeons and women themselves in explaining these variations.

1.1 Aim of the Study

The purpose of this study is to examine the types of surgery for breast cancer performed within the Health Care Corporation of St. John's, Newfoundland, over the period 1994-1997. In addition, the aim is to contrast the views of the surgeons regarding the different types of surgical interventions for breast cancer with the views of the women who had received different surgical interventions.

Specifically, the main objectives are:

1. To determine the rates and types of breast cancer surgery performed within the Health Care Corporation of St. John's, Newfoundland during the years 1994-1997;
2. To describe the views of surgeons regarding breast cancer surgery;
3. To describe the views of patients in regard to their personal experience of having different types of breast cancer surgery;
4. To contrast the surgeons' views with those of the women.

1.2 Literature Review

The extensive amount of literature available on breast cancer can be attributed to the contributions from various disciplines within health care (e.g., psychology, medicine, nursing and physiotherapy).

This literature review provides an overview of the relevant study findings which capture current understandings of the dimensions encompassing breast cancer. Issues pertinent to past and present perspectives on breast cancer have been explored.

1.2.1 Background Information

Surgical treatment for localized breast cancer has changed considerably in the past two decades. Until the early 1980s, the standard treatment for breast cancer at any stage was mastectomy (Health Canada/Canadian Medical Association, 1998). Originally, the mastectomy was termed radical as it involved removing the breast, nipple, areolar area, the chest wall muscle of the affected side along with the axillary lymph nodes. This procedure was also known as the Halsted procedure and was based upon the principles for treatment of breast cancer set forth by William Halsted almost 100 years ago. At that time it was common to see large tumors. Today, it is rare to see the large tumors of the breast as in Halsted's era (Lazovich, White, Thomas, and Moe, 1991).

Twenty years ago, the selection of therapy for primary breast cancer was easy. The diagnosis of breast cancer usually meant mastectomy. This surgery was radical as the idea was to remove any and all tissue in close proximity to the cancer. Not only was this procedure disfiguring, but it also induced mechanical problems due to the loss of muscle and lymph tissue. These mechanical deficits caused such problems as a decreased range of motion with the affected arm due to loss of muscle; or lymphadema of the arm due to the excision of the lymph nodes (Gerber, Lampert, and Wood, 1992). Other problems not well described or investigated before the 1980s were problems associated with body image such as psychological morbidity due to the loss of the breast (Maguire, 1989).

The concept of using breast conserving techniques as a means of surgical intervention is not new. There is evidence in the medical literature that proponents and practitioners of breast conserving techniques began performing these interventions as early as 1920 (Palmer, 1994). During the 1980s, several published trials indicated that breast conserving surgery followed by radiation therapy was a valid alternative for many women (Nattinger, Hoffman, Howell-Pelz, and Goodwin, 1998). Despite the data which has been available in the last several decades supporting the trend toward breast preservation techniques, it appears at present that the most commonly performed procedure for stage I and II breast cancer is still MRM (Palmer,1994).

1.2.2 Staging of breast cancer

The staging of breast cancer refers to the extent of disease that is evident from physical findings and special pre-operative studies. The American Joint Committee on Cancer and the International Union Against Cancer have agreed on a TNM (Tumor, Regional Lymph Nodes, Distant Metastasis) system for classifying stages of breast cancer (Tierney, Mcphee & Papadakis, 1994, p. 571). Table 1 summarizes the physiological characteristics of the three main stages of breast cancer. It also defines the two main forms of surgery.

Table 1 Stages of breast cancer and types of breast cancer surgery

Stage I Breast Cancer: Tumor is 2 cms. or less in its greatest dimension, no regional lymph node metastasis and no distant metastasis present.

Stage II Breast Cancer: Tumor is more than 2 cms. but not more than 5 cms. in its greatest dimension, metastasis to moveable ipsilateral lymph node(s); no distant metastasis.

Stage III Breast Cancer: Tumor is 5 cms. or greater, metastasis to moveable ipsilateral lymph node(s); possibility of distant metastasis.

Modified Radical Mastectomy: Total mastectomy plus axillary lymph node dissection. This procedure removes the entire breast, overlying skin, nipple and areolar complex as well as the underlying pectoralis fascia with the axillary lymph nodes in continuity. The major advantage to the modified radical mastectomy is that radiation therapy is usually not necessary.

Breast Conserving Surgery: Removal of the tumor with confirmed tumor free margins with excision of the axillary lymph nodes. Post-operative radiation therapy is required as an adjunct to this intervention.

Adapted from Tierney, McPhee and Papadakis, (1994). Current medical diagnosis & treatment.

1.2.3 Eligibility for BCS

Before considering which procedure the surgeon should recommend, the nature and extent of the tumor must be precisely established. Once the diagnosis of clinical stage I or II breast cancer has been determined, the options for surgery can be reviewed. For those patients with either stage I or II breast cancer, BCS followed by radiotherapy is now generally recommended (Health Canada/Canadian Medical Association, 1998; Hislop et al., 1996; Goel et al., 1997). There are, however, several reasons which would possibly preclude BCS as a treatment option for breast cancer. Several of the factors that indicate treatment would not be best served by BCS are described by the Canadian Medical Association (1998) which include malignant type calcification visible on mammogram, multiple primary tumors or failure to obtain tumor free margins. A large tumor size in relation to breast size or the patient's clear preference for mastectomy should also be considered before treatment options are discussed.

1.2.4 Psychological consequences

The diagnosis of breast cancer has serious effects upon patients' lives - it may cause disfigurement simply to treat it; there is the possibility that it will recur, and, of course, it may be fatal. However, a breast cancer diagnosis has a psychological, as well as a physical impact upon the patient's life. It has been found that up to 25% of women with breast cancer develop a psychiatric disorder (usually involving depressive or anxiety related symptoms; Glanz & Lerman, 1992). Stanton & Snider (1993) found that the rate of psychological disorder in newly admitted cancer patients was approximately three times that of the general population and twice that of other medical patients with 85% of those receiving diagnoses having depression or anxiety as their central psychological symptoms. However, research has indicated that individual differences in coping styles may play a role in the physical and psychological well-being of breast cancer patients (Carver et al., 1993).

Cognitive factors play a key role in emotion and adaptation, affecting the impact of events that are perceived as stressful (Cohen & Lazarus, 1979). Developing symptoms of illness and undergoing medical treatment can be highly stressful events. Many people take for granted their good health and their ability to function well in society and maintain a sense of independence. Since this view of oneself as being healthy, active and having a relatively normal appearance is central to most people's image and evaluation, illness in any form can be a shock to a person's sense of security and to his or her self-image. Not only does this threaten the conventional view of oneself, but it further accentuates the fact that one is vulnerable and that life is uncertain, that one may have little control over events, and that one's life may be changed in major respects.

Cohen and Lazarus (1979) argue that adjustment to an illness or injury which may be potentially life threatening will require considerable coping effort. The choice of coping patterns relies heavily upon the process of cognitive appraisal which mediates psychologically between the person and the environment in any stressful encounter. Cohen & Lazarus (1979) describe two types of appraisal: Primary appraisal is an evaluation of the significance of an event for one's well-being, and secondary appraisal is an evaluation of coping resources and options. The way a person construes an encounter (appraisal) is basically the psychological key to understanding coping efforts in that situation and to understanding the emotional reaction which tends to change depending on the flow of events and the changes in patterns of appraisal.

Cohen & Lazarus (1979) identified four main modes of coping: information seeking, direct action, inhibition of actions, and cognitive processes. With the information seeking mode, patients try to find out what exactly the problem is and what if anything must be done. Cohen and Lazarus found that in the context of illness, some patients were insatiable in their search for information whereas others avoided it and preferred to place themselves in the hands of someone they trusted. The mode of coping described as direct action included arguing, running away or making decisions on their own. Inhibition of action is the obverse of direct action while the mode of cognitive processes includes denial and avoidance. It appears, the more helpless the person is, the more he or she must depend on such cognitive processes.

There has been a vast amount of research studying the psychological consequences associated with breast cancer. Stanton and Snider (1993) hypothesized that distress would be greatest immediately after diagnosis and would diminish after surgery. They tested this hypothesis in 147 subjects using questionnaires which assessed personality, cognitive appraisal, coping, and mood variables. Assessment occurred before breast biopsy, after diagnosis and, for breast cancer positive women, after surgery. They found that distress and perceived threat were greatest immediately after a positive diagnosis for breast cancer, though it did not approach clinical levels. Also, as hypothesized, tension, depression and confusion decreased after surgery to prebiopsy levels. These results are also supported by the study by Carver et al. (1993) which indicated that distress was greatest prior to surgery and decreased significantly afterwards. Stanton & Snider (1993) also noted that there were no other significant shifts in mood during the year after surgery. Furthermore, none of the distress measured was extreme.

A better understanding of the biology of breast cancer and an increasing awareness of the psychological significance of the altered body image has led to the development of less aggressive breast cancer treatments. Mock (1993) found that women treated with BCS consistently reported more positive feelings and greater satisfaction with their bodies than those treated with MRM. The BCS patients showed less sexual dysfunction, earlier resumption of sexual activities and greater satisfaction than patients who had had MRM. However, in a study conducted by Fallowfield, Hall, Maguire, and Baum (1990), which compared the psychological outcome of MRM and BCS, they found that psychosocial and sexual disturbances were common reactions to the diagnosis and treatment of breast cancer irrespective of type of treatment. Schain, d'Angelo, Dunn, Lichter and Pierce (1994) compared the psychosocial outcomes of women treated with MRM versus BCS. This study revealed there were some advantages in terms of a positive body image in those women having undergone BCS, but there were no significant differences in global measures of psychiatric morbidity between the two groups. It also found that sexual dysfunction over time approached a mean level for both groups. A review article by Moyer (1997) which was a meta-analysis of the literature dealing with the psychosocial outcomes of BCS versus MRM found that many of the findings have been equivocal and typically show a lack of substantial benefits for BCS as compared to MRM.

In a study by Dorval, Maunsell, Deschenes and Brisson (1998), breast cancer survivors were interviewed eight years after their initial treatment to ascertain the level of their psychological distress, physical symptoms, perceptions of their own health, satisfaction with the types of surgery performed and with marital and sexual adjustments. It was concluded that assessed globally, BCS and MRM appear to be equivalent treatments in terms of a patient's long term quality of life. There was evidence to suggest that both short term and long term distress levels after BCS and

MRM may depend on the patient's age at diagnosis. The use of BCS has not resulted in a substantial reduction in psychologic morbidity in the first months after breast cancer diagnosis which may be due to the need for radiation therapy and therefore, a longer recovery period. This study did find that those who underwent BCS were somewhat more satisfied with the type of surgery performed than the MRM patients.

The role of social support has been the focus of some studies. Carlsson and Hamrin (1994) concluded that social support is an important factor for psychosocial adjustment as well as for survival for women with breast cancer. Different sources of support evaluated (partner, family, friends, relatives, and medical professionals and work outside the home) were found to be statistically associated with survival. The study of social support for a women with breast cancer has moved from a global measure of the entire family to a focus on particular relationships. In particular, a focus on patients' partners is essential - the partner provides an important source of emotional support. Pistrang and Barker (1995) have suggested that problematic partner relationships during a breast cancer episode cannot be compensated for by other relationships. This study interviewed 113 women recently diagnosed with breast cancer and assessed psychological symptoms, mood, helping relationship and relationship satisfaction. Findings indicated that good helping by the spouse was characterized by communication about the women's emotions and concern involving breast cancer, high levels of empathy and low withdrawal from open discussions about cancer. Good helping patterns were positively related to emotional well-being and marital satisfaction.

The importance of the spouse to the breast cancer patient's well-being was also studied by Ptacek, Ptacek and Dodge (1994). Coping style, marital satisfaction and psychological adjustment were assessed in 36 breast cancer patients and their husbands. They found that social support and psychological well-being were significantly related to self-reported coping strategies. Husbands who used more problem solving coping and less wishful thinking had wives that were more satisfied with their marriage. Furthermore, the perceived coping of the spouse was positively associated with the patient's psychological well-being and marital satisfaction. These findings of the importance of the patient-partner relationship are further supported by Roberts, Cox, Reintgen, Baile and Gibertini (1994). This study found that breast cancer patients who perceived themselves to be socially desirable and to be receiving good social support from family, friends, and spouse, had lower distress levels. However, when social desirability was controlled for, the correlations between friend and family support and distress levels decreased to below significance; though spousal support remained significantly related to decreased distress levels.

This evidence indicates the importance of the spouse as a source of social support. In fact, how the husband copes has been shown to be related to how well the breast cancer patient copes (Ptacek et al., 1994). Furthermore, patients whose relations conform to a communication pattern in which the woman seeks to discuss the problem and the man withdraws or avoids it, may be more at risk for distress and decreased psychological well-being (Pistrang & Barker, 1995).

The evidence suggests that there are negative psychological consequences for breast cancer surgery which may be alleviated by certain coping styles and social support. There is little evidence that the negative impact is in any way more for those who received one form of surgery over another. This suggests that on both clinical and psychological grounds, women should be offered options of their surgical interventions.

1.2.5 Variations in management of breast cancer

A recent Canadian study by Goel et al. (1997) which compared patterns of initial management for stage I or II breast cancer in two Canadian provinces, revealed that BCS was performed in 43.8% of cases in British Columbia and 67.6% of cases in Ontario. Another Canadian study conducted by Iscoe et al. (1994) studied the variations in use of BCS in counties throughout the province of Ontario. There was an overall percentage of 52.4% of women undergoing unilateral surgery for breast cancer having had BCS. It should be noted that these two studies examined the surgical rates of only node negative breast cancer surgeries. Olivotto (1997) examined the rates of MRM and BCS in British Columbia and found that only 44% of those eligible for BCS received it. He did not distinguish between node negative and node positive types of breast cancer.

These three studies indicate a number of factors which may have contributed to this variation. Given that the prognosis for survival are similar for MRM and BCS, it appeared patient and surgeon preferences play a major role in deciding the treatment option. Iscoe et al. (1994) described that women with families or work commitments and women who must travel long distances to radiation therapy sites may choose MRM over BCS because of the travel time or the time away from work and/or families that radiation therapy would require. If there is a long waiting period for radiation therapy in some areas, this may also influence surgical choices. Two other factors that appeared to significantly affect the choice of MRM were the patient's age and income. The relationship between BCS and income varied by age. The increased odds of BCS with income was most apparent in older women. In younger women there was less variation in BCS with income.

Although there have been several regional studies which looked at the variations in breast cancer surgery there have been no such studies within Newfoundland.

1.2.6 Decision Making

Patient participation in their care is a relatively new concept. The term "patient participation" is similar to and often used interchangeably with patient collaboration, patient involvement, and patient partnership (Cahill, 1998). The historical assumption regarding patient participation and health care was that illness could only be effectively diagnosed and treated by experts. Patients were regarded as passive recipients of care and decisions dealing with their treatments were the domain of the physician (Roberts & Krouse, 1990).

Many factors have led to the change from the physician dominant approach to the philosophy of patient participation and their great inclusion in their own care. One such factor described by Cahill (1998) was the growth of consumerist beliefs which have led to patients becoming more actively involved in the provision of health care. This approach presented a challenge to the health care professionals' power and authority. A second factor which caused a change in modality and practice by health care providers was the development of new epistemologies which sought movement away from biomedical domination towards a patient-centered approach to care (Beardshaw and Robinson, 1990). According to research the majority of oncology healthcare professionals believes that patients should be provided with the necessary information they need to actively participate in treatment decision making (Northouse & Worthman, 1990).

(a). Surgeon's Perspective

Cegala and McGee (1996) assessed doctor-patient communication within the medical interview. They found it to be characterized by two communicative functions:(1) information exchange and (2) relational development. They described a positive relationship as one that facilitates obtaining an accurate medical history, describing the medical problem, providing information about diagnosis and treatment, and understanding prescribed procedures and their rationale. Though the majority of patients indicate they are interested in receiving as much information as possible, physicians often do not perceive patient information needs accurately and often overestimate how much information they provide patients (Beisecker, 1990). Cegala and McGee (1996) found that patients placed nearly three times as much weight on obtaining information about their medical status as doctors placed on providing such information. In a study by Beisecker (1990) which examined patients and decision making, they discovered that in order for patients to make a choice about their medical care, patients must realize they have a right to participate.

The effects of physician communication on patient outcomes show how physician behavior such as information giving, partnership building and good interpersonal skills relate to patient outcomes of satisfaction with medical care, compliance and recall of information (Roberts, Cox, Reintgen, Baili, and Gibertini, 1994). A study conducted by Lerman et al. (1993) described that patients with stage I or II breast cancer reported that although providers offered information and explanations, many patients had problems comprehending this information. Many patients also reported difficulties asking questions and expressing feelings to their health care providers. Roberts et al. (1994) discussed the importance of good physician-patient communication particularly when a diagnosis of breast cancer is made, because the patient must deal simultaneously with their mortality and an altered body image. In addition, the surgeon's role is to educate an emotionally distraught patient about her disease and available treatments so she can participate in making decisions about her care.

An important goal of patient education is to enable informed decision making and treatment choices. Roberts et al. reported that openness in communication encouraged patient decision making. Patient satisfaction with physician communication has been associated with interpersonal competence and information giving with suggestions that physicians tailor their communication to patient coping styles (Roberts et al., 1994).

Although many cancer patients prefer an active and collaborative role in decision making and desire information about the disease and its associated treatments, a large number of women with stage I or II breast cancer reported communication difficulties with the medical team (Stanton et al.,1998).

In a study conducted by Higgins (1993) it was suggested that medical practitioners aspire to promote patient participation in care but are seasoned not only by their beliefs regarding the concept, but also by the health care organization in which they practice. Cahill (1998) found that patients prefer to participate in their care while many health care providers prefer patients to be passive recipients of care. This study found that patient participation could not be assumed to be an approach to care that had been universally accepted by patients and clinicians. The literature reviewed describes that physicians play a substantial role in women's decision making and variability in surgeons' opinions are reflected in the surgeries they perform (Stanton et al., 1998). This study also concluded that older women were more likely to undergo MRM. Relative to the younger patients, older women perceived their surgeons as more supportive to MRM although they felt they had been offered a choice of procedures. This study queried whether physicians may less strongly recommend BCS to certain older women due to comorbidities associated with radiation therapies or because the surgeons held differential perceptions regarding the need of the older women. The question remains as to what degree of involvement surgeons wish their patients to have in decision making concerning treatment options.

The C. M.A.'s (1998) Clinical Practice Guidelines described the responsibility of the surgeon to include the patient in the decision making of their treatment. In the recent Canadian study by (Goel et al., 1997) they identified certain characteristics of the surgeon which were associated with the use of either MRM or BCS. These characteristics included their age, affiliation with a teaching facility, years since graduation from medical school and personal preferences. However, they did not consider the surgeons views on the role of patients in decision making. This study reviewed charts which identified demographics associated with type of surgery but did not actually question the surgeons. **There are no studies which have specifically asked surgeons why they choose particular forms of surgery and to what degree they involve women in decision making.**

(b). Patients' Perspective

Calls for an increase in patient participation in care are based upon the assumption that patients wish for and benefit from having a more active role in their health care (Cahill, 1998). Involving patients in the decision making process has shown to have possible advantages and disadvantages for the patients. Proponents for offering choice hope that involving patients in their own care may lead to higher levels of patient satisfaction with care and improve the acceptance of treatments.

There is also the hope that active involvement by patients in decision making may lesson psychological morbidity and improve patients quality of life. There is the worry, however, that offering choices may place an undue burden of responsibility on patients. Choice of a treatment which may subsequently prove unsuccessful might induce feelings of self blame and regret in the patient (Richards et al., 1993).

The degree of patient participation in care has been found to be associated with the patients age and education (Cahili, 1998). It may also vary according to a patient's condition. In a study completed by Blanchard, Labrecque, Ruckdeschel, and Blanchard (1988) which examined the interactions between hospitalized cancer patients and professional care givers they found that the more physically ill patients were less likely to want to participate in their care.

Cohen & Lazarus (1979) found that if patients needs for information are fulfilled, patients can assume an active role in treatment decision making and maintain some control over the stressful situation. Evidence suggests that patients with cancer in every age group want all relevant information associated with their illness, however, not all patients want to be involved in the treatment decision making to the same extent (Davidson et al., 1995).

Advocates for patients promote incorporating patients into decision making processes and empowering patients to become proactive in their care. It has been shown that when involved in decision making, their level of anxiety decreases and patient satisfaction increases (Bilodeau et al., 1996).

A study conducted by Beisecker (1990) examined patients and decision making, found that in order for patients to make a choice about their medical care, patients must first realize they have a right to participate. Other studies described by Beisecker, found that while 92% of cancer patients wished to have all the available information, only 69% actually preferred to participate in making the decision.

Women diagnosed with breast cancer may want a substantial degree of involvement in making decisions about their medical treatment. A study undertaken by Degner et al. (1997) found that 22% of breast cancer patients wanted to select their own medical treatment, 44% wished to select their treatment in collaboration with their physician, while 34% requested their physicians to make treatment decisions on their behalf. This study states that predictors such as age and education had a considerable impact on the degree of control the patients wished to exert. It found that younger, more highly educated women requested more control in their decision making.

Although women with breast cancer are being increasingly encouraged to make decisions about their treatment, all patients may not be comfortable doing so. Encouraging active participation in decision making when this is not a desired role may result in undue anxiety and distress. Alternatively, if an active role is desired, then some form of decisional support may be necessary to enable the decision making process to proceed (Beaver et al., 1996; Hughes, 1993).

The impact of a potential cancer diagnosis and the need to make timely decisions regarding treatments create enormous stressors that require the sensitivity and support of health care providers. The decision that is consistent with the patient's own value system is the least likely to cause regrets and negative psychological outcomes (Crawley, Kostic and Capello, 1990). **Although there has been a lot of research conducted in the arena of decision making and communication, there are little reported studies which have specifically asked women their view as it relates to decision making with respect to breast cancer surgery.**

1.3 Summary of Literature Review

Much research has been conducted surrounding many aspects of the breast cancer experience. A review of the literature indicates there is limited information as to why MRM is performed more often than BCS. Some studies found that the surgeon may be the most influential factor. Characteristics of the surgeon which may influence their practice preference for one surgery more than another include: their age, affiliation with a teaching facility, years since graduation from medical school and personal preferences. Those factors which appear to impact a woman's decision making and appear to play a significant role in her choosing a particular treatment include: her age, educational level, attitude and availability of services. Younger women who may have higher levels of education tend to choose BCS over MRM. It appears one of the most significant factors that induce women to choose MRM is the fear of recurrence. This fear tends to be a bigger foe to women than the actual cancer itself. The attitude of some women that the breast is diseased and should be completely removed and previous experience with persons who may have undergone MRM has been shown to strongly influence some women's decision toward MRM.

The literature review revealed extensive coverage on differing psychological aspects of breast cancer. Findings suggest that people with different life experiences view stressful events differently and therefore, tend to cope differently.

The literature describes the advantages of including patients in the decision making processes. It has been revealed by many studies that including patients in treatment options decreases anxiety levels, increases patient satisfaction and creates better coping abilities. However, the other side of including patients in decision making includes increased anxiety for some patients who do not wish to become active involved members of the team. Patients who make decisions when they are not prepared have been shown to suffer anxiety and depression stemming from uncertainty regarding their decision. Some patients suffer increased anxiety levels due to the increased levels of responsibility being placed upon them and consider it an added burden.

The psychological consequences of breast cancer and its treatments are well documented. Depression and anxiety related to adapting to an altered body image have been supported. Feelings of fear, worry and isolation are common among women diagnosed with breast cancer. Feelings of loss of femininity, independence and self esteem are also commonly expressed by patients with breast cancer who may be undergoing various therapies.

In conclusion, based upon the literature review, it is clear there have been studies conducted looking at regional variations in types of surgery for breast cancer in various parts of Canada. There are no studies regarding the numbers and types of surgeries being performed in Newfoundland. Also, there appears to be limited literature on the surgeons' view of the different types of surgery. Finally, there appears to be few Canadian or other studies which directly invite the women who have had a breast cancer surgery to give details of this experience.

1.4 Aims of the Study

The lack of literature previously described has lead to itemizing the primary aims of this study. The objectives of the study are:

1. To determine the rates and types of breast cancer surgery performed within the Health Care Corporation of St. John's, Newfoundland during the years 1994-1997.
2. To describe the views of surgeons regarding breast cancer surgery.
3. To describe the views of women in regard to their personal experience of having different types of breast cancer surgery.
4. To contrast the surgeons' view with that of the women.

Chapter 2: METHOD

2.1 Design

In order to address the previously described aims, the study was conducted in three separate but interrelated parts. The procedures and methodology of each part is detailed in the following sections after the general ethical considerations are reviewed.

2.2 Ethical Considerations

Permission to conduct this study was granted by the Human Investigation Committee of the Faculty of Medicine, Memorial University of Newfoundland following a review of the proposal (see Appendix A). Approval was also obtained from the Research Proposal Approval Committee (RPAC) of the Health Care Corporation of St. John's (HCCSJ) (see Appendix B).

A signed and witnessed consent form was obtained from each participant after a thorough explanation of the following information: rationale and purpose of the study, data collection, approximate time required from each participant and the ability to withdraw from the study at any time without incurring any repercussions. Included in each consent was permission to tape record the interviews and focus group sessions. Prior to note taking, verbal consent was also obtained. Before signing the consent forms, all participants were given the opportunity to read the consent and ask any questions (see Appendix C).

The participants were informed of measures which would be taken to assure their anonymity. These measures included the use of codes for identifying the tape recordings and questionnaires in place of names. Once each tape recording had been transcribed, the tapes were erased and all material was placed in a locked cabinet with only the researcher having access.

There were no identifiable physical risks as a result of this study. In anticipation of any of the participants of the focus groups becoming emotionally upset, arrangements for counseling with a psychologist employed by the HCCSJ were organized. Participants were also informed that even though they might not benefit directly from the study, it was anticipated that the information could enhance further research in this area.

2.3 The Statistics

2.3.1 Types of Data Extracted

The types of breast cancer surgeries being performed in St. John's and the frequencies of each type of surgery were reviewed. The types of breast cancer surgery being studied were Modified Radical Mastectomy and Breast Conserving Surgery. Data on all breast cancer surgeries were extracted for the period 1994-1997. In 1994 all hospitals within the St. John's region were amalgamated to form the Health Care Corporation of St. John's. After that time data coding of all surgical procedures was standardized across sites and stored on a single computer file.

2.3.2 Access

Access to this data was provided by the Health Records Departments of the three hospital where breast cancer surgery was performed. The data were extracted from the provincial medicare billing codes (MCP) as defined by the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures (CCDTSP see appendix D). Data were extracted from the computer files by certified health records technicians of the Health Care Corporation of St. John's.

2.3.3 Validity

It was noted that the surgeons performing the surgeries were using different terminologies to describe the same procedures. This led to different codes being placed into the computer system for the same procedure. In order to obtain consistent data, it was necessary to utilize textbook definitions of the two surgeries and compare these procedures with procedure codes identified according to the CCDTSP. This ensured that only the specified procedures were being included in the study. This list was reviewed by the certified health records technicians to ensure the codes being used were in fact those of modified radical mastectomy and breast conserving surgeries with axillary node dissections only.

To further validate the data, all charts with corresponding BCS codes were reviewed using the pathology and operative records as guides for ensuring correct coding of these procedures. This was felt to be necessary as there may be several different terminologies being used interchangeably for breast conserving surgeries. Also, randomized audits were conducted in those charts being coded for MRM to ensure validity. The randomization of the MRM charts was performed by simply picking an arbitrary number which was 10. Every corresponding chart belonging to the MRM computer code was reviewed in the same manner as described for the BCS group. When necessary, health records technicians assisted with deciphering the particular codes which did not appear to match either the operative record or the pathology report. If more than one procedure was performed on an individual at the same time, there were several codes being applied for this patient. In these cases it was necessary to complete chart audits to ascertain exactly what procedures had been performed. In addition some procedures have similar descriptions. This appeared to require the health records technicians to make judgement calls on the exact coding. By completing the chart audits it allowed the investigator the opportunity to on a case by case basis review the pathology and operative records to ensure the coding was correct.

2.3.4 Analysis

Each computer printout of surgical procedures was reviewed. The MCP billing codes were compared to the operative procedures to ensure they were the interventions actually being studied. If there was any question regarding the coding of a specific procedure, a chart audit was conducted for verification. After validation with health records staff and surgeons was received, the totals obtained for Modified Radical Mastectomy and Breast Conserving Surgeries were compiled and broken down by site. SPSS programing was used to analyze the data. Pearson Chi-Square was used to determine if any associations for specific data were present.

2.4 The Surgeons

2.4.1 Participants

All surgeons within the general surgery program of the HCCSJ who regularly did breast cancer surgery were approached to participate in the study. Once a general list of surgeons was obtained, the researcher reviewed the data obtained from each of the Health Records Departments on the types of breast cancer surgeries being performed and by which surgeons. There were a total of **8** surgeons approached for participation in the study. These surgeons regularly performed breast cancer surgery within their practice. A total of 7 of these surgeons consented to participate and completed the questionnaire and interview. There were a number of other surgeons who did perform these procedures on occasion. However, it was felt that their case loads were so limited in this area their input would not be constructive to the study. By agreeing to participate in this study, the surgeons also agreed to make the initial contact with their patients for possible entry into the study.

2.4.2 Questionnaire/Interview

The purpose of the questionnaire and interview was to elicit from the surgeons their general perceptions of breast cancer surgery within their practice. The questionnaire was reviewed by several of the surgical residents within the general surgery program and a practicing surgeon before the study began.

The questionnaire answered by each surgeon requested the following information:

- basic demographic information
- estimation of their surgical rates for breast cancer
- their practice as regards to offering second opinions and reappointments for discussion of options
- their practice regarding offers of choice between MRM and BCS
- their practice regarding provision of written material to the patient
- estimated time between diagnosis and surgery.

The questions for the questionnaire were developed from three sources:

1. The study by Goel et. al. (1997) on variations in breast cancer surgery.
2. The Canadian Clinical Practice Guidelines for the Care and Treatment of Breast Cancer (see Appendix E).
3. Comments made by surgical residents in pre-testing.

The interview attempted to gather more detailed information on:

- the amount and type of information each surgeon gave to each patient,
- their views on the role of women in surgical decision making,
- the factors they felt influenced patients' choices for surgical intervention of their breast cancer.

The questions pertaining to decision making were based upon work completed by Degner and Sloan (1992) which described the different roles women adopt when required to make medical decisions.

2.4.3 Procedure

All potential surgeons were contacted either in person or by telephone to introduce the study and initiate a further meeting. Once initial agreement was given, the researcher met with each physician at a pre-arranged time for review of the consent form. Each meeting took place in either the surgeon's clinic or the Pre-Admission Clinic at one of the hospitals. The surgeons were asked as part of their participation in the study if they would make the initial contact with their patients and give a prepared cover letter to each woman (See Appendix F). This cover letter described in summary the study, its purpose and what each participant's involvement would require.

The questionnaire was given to each surgeon at the initial meeting with the investigator when they provided consent. They were asked to complete the questionnaire and return it subsequently. The questionnaire was coded with a file number and did not include any names.

Prior to each interview the surgeon was again given information regarding the rationale of the study, confidentiality and their opportunity to withdraw from the study at any time. Each interview lasted approximately 20 minutes and was conducted in the surgeon's clinic area or office. All interviews were tape recorded and later transcribed. Only the principal investigator had access to each tape which was coded.

2.4.4 Analysis

The surgeons' replies to the questionnaire were tabulated. Immediately following the interview each surgeon's taped interview was transcribed verbatim by the researcher to ensure confidentiality. The tapes were reviewed several times to ensure the entire content of the conversation was collected. Re-listening to the tapes assisted the researcher to pick up cues within the conversation. Reading and rereading the verbatim transcriptions from the initial interview ensured that subtle nuances or innuendoes were not missed. This practice allowed the researcher to identify the salient themes which were analyzed using the constant comparative method of analysis allowing the subsequent interviews to develop.

2.5 The Women

2.5.1 Participants

The inclusion criteria for patient participation were: (1) any woman who had been diagnosed with stage I or stage II breast cancer and who had at the time of her diagnosis been given the option of a Modified Radical Mastectomy or Breast Conserving Surgery, and (2) was not presently receiving active treatment for her breast cancer. The surgeons who entered the study were responsible for choosing from their case files appropriate candidates and having their secretaries distribute the cover letter to each potential participant (see Appendix F). The women, if interested, were instructed to telephone their surgeons offices. Their names were then passed on to the principal investigator who then made contact. A total of four focus groups and one private interview were held with a total of 21 participants in all. Of the 21 participants, 12 women had received MRM while 9 had received BCS. The average length of each session was approximately 90 minutes.

2.5.2 Questionnaire

Each questionnaire requested the following information:

- basic demographic information,
- place of initial contact with their surgeon,
- length of time their diagnosis visit took;
- whether a second opinion was offered,
- if a particular treatment option was recommended for her,
- the estimated duration of time between their diagnosis and their surgery,
- whether they received any written information at the time of their diagnosis. (see Appendix G).

The questions for the questionnaire complimented those in the surgeon's questionnaire. The questionnaire was pre-tested with several employees working within a hospital setting at different levels of employment. Those involved in the pre-test were asked to time themselves to ascertain the length of time required to complete the questionnaire. Other than a minor grammatical change there were no problems noted with the wording of the questions. The general length of time for completion was established to be 10 to 15 minutes. The questionnaire was administered to the women after consent had been obtained for participation in the study. The questionnaire was returned either by mail or brought to the focus group in a sealed envelope.

2.5.3 Focus Groups

Focus groups, as a research methodology, are best suited for exploratory studies in which the investigator is interested in learning details regarding a specific phenomenon (Gray-Vickrey, 1993; Kitzinger, 1995; Stevens, 1996; & Wilkinson, 1998). Focus groups as we now know them were developed by sociologist Robert Merton and his colleagues Patricia Kendall and Marjorie Fiske. They developed the"focused group-interview" which was a group approach for studying audience responses to radio programs (Wilkinson, 1998). The use of focus groups began in the 1920s and was used primarily by proprietary companies for marketing research. Health researchers established the use of focus groups in social action research, notably family planning and preventive health education.

The women were asked to participate in a focus group discussion with a number of other women who had undergone the same procedure. All participants were given the option of a private interview rather than a focus group if so desired. Only one patient who had undergone a MRM asked for a personal interview.

There were ten main themes introduced for discussion for each focus group session. These themes consisted of:

- describing their initial diagnosis consultation,
- the information they were given,
- any concerns they remembered having at that particular time,
- the role of others such as family members or other health care providers in their decision making,
- their views of their surgeon,
- their prior experience with health care in general,
- experience with breast cancer,
- any advice for others,
- how they made decisions in general,
- more specifically how they made medical choices. (See Appendix H).

2.5.4 Procedure

Each focus group session was arranged at a time and location suitable to each participant. The focus group sessions were held at a small conference room at one of the hospitals. This setting was chosen as all participants knew the location of the hospital. In the evening, large signs displaying the room location were placed in the hospital foyer. Each woman was informed the sessions would be tape recorded and would last approximately one to one and a half hours . At the beginning of each session, the purpose of the study was again reviewed and assurances for confidentiality were given. It was reiterated at the beginning of each session that any participant wishing to leave could do so at any time. Also discussed was the availability for follow up counseling with the hospital psychologist if anyone so wished. The group sessions were casual in nature with introductions using first names starting each session.

2.5.5 Analysis

The women's replies to the questionnaire were tabulated. The tapes of the focus groups and the interviews were coded with a label and transcribed verbatim. The same process of analysis was used to explore the focus groups and interview was used to analyze the surgeons interviews. The transcribed tapes were again repeatedly reviewed by the researcher to gain a degree of comfort with the flow of the conversations and to ensure there were no missing pieces of information that may have been previously overlooked. Once all tapes had been transcribed, initials only were used to identify participants and all tapes were erased to ensure confidentiality. Each tape was reviewed repeatedly by the researcher who identified major themes for each group.

Chapter 3 : Results

3.1 Statistics on breast cancer surgery

There were a total of 363 breast surgeries conducted in the time period 1994 - 1997. Of these 71.9% were MRM, 26.1% BCS and 1.9% BCS/MRM.. The data were entered into the SPSS computer program and a series of Pearson chi-square tests were conducted to investigate the factors associated with type of surgery. These factors were investigated: hospital site, age of patient and residence of patient.

Table 2: Hospital by surgery type (1994/95, 1995/96 and 1996/97 are combined).

	Surgery Type						Total
	MRM		BCS		BCS/MRM		
Site A	n= 67	80.7%	n=13	15.7%	n=3	3.6%	83
B	n= 96	65.3%	n=49	33.3%	n=2	1.4%	147
C	n= 98	73.7%	n=33	24.8%	n=2	1.5%	133
Total	261		95		7		363

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	9.918	4	.042
Likelihood Ratio	10.061	4	.039
Linear-by-Linear Assoc.	.171	1	.679
N of Valid Cases	363		

Table 2 shows the types of surgery performed in the three hospital sites. There was a significant association between hospital site and type of surgery ((4)=9.92, p<.05). The rates for MRM were highest in Site A and lowest in Site B.

Table 3: Surgery type by year

		Year						Total
		1994-95		1995-96		1996/97		
Surgery Type	MRM	n=78	29.9%	n=86	33.0%	n= 97	37.2%	261
	BCS	n=28	29.5%	n=35	36.8%	n= 32	33.7%	95
	BCS/MRM	n=2	28.6%	n= 4	57.1%	n= 1	14.3%	7
Total		108		125		130		363

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided).
Pearson Chi-Square	2.542	4	.632
Likelihood Ratio	2.636	4	.620
Linear-by-Linear Assoc.	.359	1	.549
N of Valid Cases	363		

Table 3 shows the types of surgery performed in the different years of the study. There was no significant association between year and type of surgery suggesting a rather stable pattern in types of surgery during the period of the study.

Table 4: Womens' age by surgical procedure

	Procedure			
	MRM	BCS	BCS/MRM	Total
AGE <50 years	n= 66 60.6%	n=38 34.9%	n=5 4.6%	109
51-65 yrs	n= 86 71.1%	n=33 27.3%	n=2 1.7%	121
>66 years	n=109 82.0%	n=24 18.0%	n=0 —	133
Total	261	95	7	363

Pearson Chi-Square Tests

	Value	df	Asymp. Sig. (2sided)
Pearson Chi-Square	17.000_a	4	.002
Likelihood Ratio	18.585	4	.001
Linear-by-Linear Association	16.244	1	.000
N of Valid Cases	363		

Note. 3 cells (33.3%) have expected count less than 5. The minimum expected count is 2.10.

Table 4 shows the types of surgery obtained by women from different age groups. There was a significant association between age and types of surgery (= 17, p<0.01). The oldest women were most likely to receive MRM whereas the youngest women were most likely to receive BCS.

Table 5: Women's residence by hospital site

		Site						Total
		Site A		Site B		Site C		
Region	St. John's	n=32	16.6%	n=89	46.1%	n=72	37.3%	193
	Avalon	n=38	29.5%	n=44	34.1%	n=47	36.4%	129
	Other	n=13	31.7%	n=14	34.1%	n=14	34.1%	41
Total		83		147		133		363

Chi-Square Tests

	Value	df	Asymp. Sig. (2 sided).
Pearson Chi-Square	10.494a	4	033
Likelihood Ratio	10.525	4	.032
Linear-by-Linear Association	3.316	1	.069
N of valid cases	363		

Note. 0 cells (.0%) have expected count less than 5. The minimum expected count is 9.37.

Table 5 shows the area of residence of the women receiving breast cancer surgery in the three hospital sites. There was a significant association between area of residence and hospital site (= 10.49; $p<0.05$). Women in Site A, where most MRM's were conducted, were more likely to be from outside St. John's.

Table 6: Women's age by hospital site

	Site			
	Site A	Site B	Site C	Total
Age < 50 yrs.	n=22 20.2%	n=45 41.3%	n=42 38.5%	109
50-65 yrs.	n=27 22.3%	n=51 42.1%	n=43 35.5%	121
< 66 yrs.	n=34 25.6%	n=51 38.3%	n=48 36.1%	133
Total	83	147	133	363

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-square	1.190a	4	.880
Likelihood Ratio	1.189	4	.880
Linear-by-Linear Association	.624	1	
N of Valid Cases	363		

Note. 3 cells (33.3%) have expected count less than 5. The minimum expected count is 2.10

Table 6 shows the ages of the patients in the three hospital sites. There was no significant association between age of patient and hospital site. This would suggest that age of patient does not explain the variations in surgery between the three hospital sites.

3.2 Surgeons' views on breast cancer surgery

3.2.1 Demographic details

Table 7 shows that all surgeons were affiliated with a teaching hospital, all held academic appointments and that all but one was male. Five of the surgeons had Canadian training and the years of graduation from medical school ranged from two surgeons in the 1960s, three in the 1970s and two in the 1980s.

Table 7 . Demographic characteristics of the surgeons.

	N
1. Sex	
Male	6
Female	1
2. Years of graduation from medical school	
1960s	2
1970s	3
1980s	2
3. Country of medical training	
Canada	5
United States	1
Asia	1
4. Affiliated with teaching hospital	7
5. Holds academic appointment	7

3.2.2 Questionnaire findings

Table 8 summarizes the surgeons replies to the questionnaire about the diagnostic visit. The results show that according to the surgeons most diagnostic visits took place in the hospital clinic and lasted approximately 20 to 30 minutes. Only three surgeons replied they saw the women with another health care provider present. Again only three of the surgeons stated they always offered to reschedule another appointment for family members to be present. Six surgeons claimed they offered patients the opportunity to reschedule another visit to review their options. All surgeons stated they offered both Modified Radical Mastectomy or Breast Conserving Surgery to their patients. Also, all of the surgeons agreed that less than 10% of their patients requested a second opinion. Only one surgeon reported he provided written material to his patients. The average estimated time between diagnosis and actual date of surgery reported by all surgeons was one to two weeks.

Table 8: Surgeons' report of diagnostic visit

Visit	Option	N
Setting	Hospital Clinic	5
	Office	2
Length of visit	20 - 30 mins.	7
Presence of other health care provider	Yes	3
	Sometimes	1
	No	3
Offer of appointment for other family members	Yes	3
	Sometimes	1
	No	3
Offer of second opinion	Yes	2
	Sometimes	5
Requests by patients for second opinion.	< 10 %	7
Offer to reschedule visit	Yes	6
	Sometimes	1
Estimate time between diagnosis & surgery.	1 - 2 wks.	7
Offer MRM and BCS	Yes	7
Written material provided	Yes	1
	Sometimes	1
	No	5

3.2.3 Interview findings

(a). Reason to recommend MRM

The surgeons described three factors they considered when offering a patient an MRM. These were the pathology (size) of the tumor, the aggression of the tumor, and the patient herself. The pathology was described to include tumor size in relation to breast size with a breast mass greater than 4 to 5 cms. being a condition to preclude the option of BCS. A typical comment was:

> The tumor factors that are important are: size of the tumor, in general terms, tumors that are less than 5 cms. can be treated with lumpectomy according to the literature. However, you must recognize that to remove a tumor of 5 cms. with margin of surrounding breast tissue in a lot of women that's going to mean a lot of breast tissue. So basically, the larger the tumor, the more chance of a mastectomy.

All of the surgeons referred to the size of the tumor (e.g. "tumor greater than 5 cms.," " the breast mass that exceeds 4 - 5 cms. in size as being the point at which a mastectomy would need to be the treatment offered"). However, several of the surgeons modified this answer by saying it depended also on the size of the breast. For example:

> If there is a very large tumor in relation to the size of the breast I recommend mastectomy.

Another pathological feature that was taken into account was tumor aggression. It was felt that an aggressive tumor or one with vascular or lymphatic involvement would be best dealt with by MRM. A typical comment was:

> The histological features of the tumor are important. The more aggressive the tumor, the more likely you'd opt for a mastectomy.

Several of the surgeons emphasized it was not simply the physical characteristics of the tumor but also the perceived psychological profile of the woman. Two factors were important: so-called ignorance and patient ambivalence. With regard to ignorance, some surgeons felt that some women exaggerated the regional effects of radiation therapy and this made them reluctant to accept BCS. For example:

> The attitude of the patient is important. Probably of particular importance in Newfoundland is, there is a lot of residual ignorance for lack of a better word, for radiation therapy.

As regards to patient ambivalence, some surgeons felt that some women had their minds made up whereas others were not so confident. For example:

> I usually offer both, but if they often question you on what you think and you have to judge your patients. Some patients you

> can offer them the options and let them decide but others tend to sway one way or the other.

(b). Reason to recommend BCS

The surgeons emphasized that their decision to recommend BCS was similarly dependent upon the size of the tumor and of the breast. In this case, when the tumor was small and/or the breast was large they would offer BCS. The emphasis again was mainly on pathology. A typical response was:

> She would have reasonable size breasts and the lesion has to be less than 4 or 5 cms. in size and when the breasts have reasonable structure preferably in the peripheral part of the breast.

An additional factor was cosmetic concerns, e.g.

> You would offer the option with Stage 1 or 2. If you save the nipple you can save the breast.

Again, a minority of surgeons did make reference to patient attitude factors in particular, the surgeons felt that for most patients, MRM was the expected treatment and they were unaware of BCS. For example:

> I think almost with every patient I describe BCS, however, I think in Newfoundland it is difficult with some of the patients to under-

> stand the concept of BCS. Often that will be the only option I'll mention initially is BCS. The way I get around it is I say this is a breast cancer but it is one that isn't going to need or you don't have to have the breast removed.

3.2.4 Surgeons' views of women's participation in decision making

All surgeons described the importance of patient input in the decision making process. There was a noted complete agreement by all surgeons describing the importance of patients being completely comfortable with the final decision for their treatment and it was felt this could only be achieved if patients were active participants in the process. Every surgeon admitted offering patients participation in the decision making of their treatment options. For example:

> I think the area of cancer, in particularly breast cancer, to which is the topic that you and I are speaking about today, I think the greater degree of involvement of the patient, the greater chance for patient satisfaction.

However, another surgeon emphasized that ultimately their view should be the important one especially if a patient is making a choice that could be potentially harmful. His view was:

> I think patients need to be educated now such as you are able to and I think the surgeons always have a say as to what way things should go.

One also added that the surgeon should consider how the women will react after the surgery:

> They have to be comfortable with the treatment.
>
> There is no point in giving a partial mastectomy if she continues to worry about if it is going to come back later. So I think the patient, the woman has to be comfortable with the decision.

There was also agreement by all the surgeons that there has been a change in the way patients respond to these situations within the last several years. They felt that patients now want to become involved in their care and want to be completely informed of their options. They no longer sit and wait for their surgeons to tell them their options but now behave as consumers and ask informed questions regarding their care and their medical options. For example:

> Some patients come in now with an armload of papers they've gotten from the internet or libraries and such. Before I start to ask if they've got any questions they're already started with a list that are very relevant and you can tell they've researched the topic.

As to whether the patients wanted to make medical decisions, the surgeons felt that some patients wished to rely upon them to do so, some reached their decision entirely on their own, while others were comfortable collaborating with the surgeon. Some women preferred the surgeon to present all relevant information and then still wanted the surgeon to take the control for the decision. For example:

> My feeling is that most women want you to give them the answer and to make the decision for them. That's my honest opinion. You'll get some women who want to make the decision themselves and I think probably an increasing number of women who want to be not necessarily involved in the decision making but want to be informed as to what the choices are but when [they] ***are*** informed often ask what you think is best.

According to the surgeons some patients came to the diagnosis visit with their minds completely made up as to which surgery they intended to have should they have a positive diagnosis of breast cancer. These patients did not deviate from this decision regardless of any information their surgeon may have offered. These tended to be younger and possibly better educated. For example:

> Usually the younger patients tend to want to make their own decisions. I think the patients who have made decisions all of their life make decisions, and women who didn't make decisions all their life don't make decisions. Older women tend to rely heavily on my direction.

A typical response which indicated the surgeons felt the patients wanted more of a collaborative role consisted of:

> I think that the majority of patients right now do want to be

> involved. There is a very small percentage who will say go ahead and do what you want. I feel they want information and discussion.

Several of the surgeons felt that age was the key factor in deciding which patients wanted to be involved in decision making. For example:

> Very variable. It depends a lot on the age of the patient. I think a lot of younger patients come in with the literature so they know exactly what they want.

3.2.5 Dominant procedure

Five of the surgeons felt that MRM was being performed more often than BCS. The surgeons felt that it still came down to the patient's choice regardless of the information offered or what they, as the surgeon, said. There were several main reasons they felt patients chose this procedure more often. One reason was that other people such as family members or close friends who had breast cancer influenced their decision more than the surgeon. For example:

> Family history. Other people like what their neighbors have had and what other family members have had. People often listen to what their neighbors say more so than their doctors.

The surgeons felt another main reason the patients were choosing MRM instead of BCS was fear. There appeared to be the attitude of the patient that this is a diseased breast and it must go or the cancer will reoccur. For example:

> A segment of the population we see think that unless all the breast is gone, there is always the chance the cancer will come back and they won't take any chances.

One surgeon described the reason as fear and lack of education. He said:

> I think education and fear. Fear of radiation therapy and fear of recurrence. The concept that this breast is no good anymore. It has cancer, that's ignorance, that's lack of education and that will go on because that's what happened to the mother, the grandmother, the sister and that will be going on and on through time. Those are the people that come in with with mind made up.

There was general consensus that younger, and more highly educated women are the ones who choose BCS over MRM. For example:

> Certainly younger women often who attended post secondary school seem to prefer BCS more often then older women. Older women being I would say in the 50 to 60 year group. This is not

> old but we are talking the age group 30 to 40's vs. 50's to 60's. The 30-40 age range would seem by and large, my impression, to prefer the conservative breast route where ladies in their 50's and 60's seem to indicate a preference for mastectomy.

However, all surgeons agreed that family members and friends who had previously undergone a specific procedure for their breast cancer played an important role in women's decision making. For example:

> I suspect the younger age group of 30-40's may choose to research the topic. Patients who may be slightly older may tend to rely more on the advice of husbands or family or friends who may have had breast cancer in similar age groups.

The surgeons stated that patients looked at women they knew who may have had a mastectomy 20 or so years ago and see they are still alive and well and feel that losing a breast is a small price to pay to save your life. Several of the surgeons felt that to many patients MRM is a sure thing for survival. There was some discussion by some of the surgeons that because BCS is a relatively new procedure to the public it is only now being given credibility and it is therefore difficult for patients to relate anyone to this treatment. Accordingly, the surgeons felt that this tends to sway many women's minds to MRM because they feel it is the safer treatment and more reliable.

3.2.6 Surgeons' preference

The surgeons were asked how they would respond if asked how they would treat a family member who was diagnosed with breast cancer. All surgeons agreed this was a frequently asked question. It made most feel very awkward. Five of the surgeons said they explained to their patients that it is a very private decision and a very difficult question to answer. For example:

> Yes, I think that is a very unfair question from the patient's perspective and I try and stress it that it isn't my decision, it is their decision and I think I try to discourage that way of thinking because I think my wife would have BCS, I think. But if it ever comes up whether she would agree I don't know.

This is sometimes perceived by the patient as an attempt to evade the question. Several of the surgeons described explaining to the patients that by answering this question, if they truly felt there was a correct answer, this unfairly increases their role in the decision which they felt was not fair to them as a patient. For example:

> That's a common, fairly common question. It's never easy to answer because every situation is different. My answer is that you are not my sister or my wife and I can't indicate the choice I would make in that situation. There may be a perception of avoidance by the patient. I think the potential for the physician as the surgeon to influence the situation is too great in that scenario

> and to recommend a particular treatment is really taking away the choice from the patient so I tend not to go down that avenue.

Two surgeons stated they would, if asked, give a direct answer to the patient pertaining to which direction they would hope their family member would take. One surgeon responded by saying he would recommend BCS while the other maintained he would recommend a mastectomy. The surgeon who preferred BCS stated he felt this way as he was convinced by all previous studies that this option is as reliable as MRM and better in some way. He said:

> Patients ask me this occasionally. I basically tell them exactly what I have said before. I would tell them what I would do for my own wife and often do. I often say if you were my wife I would do this or that. I frankly have a harder time convincing patients to have a lumpectomy than I do a mastectomy. At least amongst our population of patients. I have to really convince them that a lumpectomy is a viable option.

However, the surgeon who preferred mastectomy stated he felt by removing the entire breast you are staying away from the tumor thereby decreasing the necessity of further resections to ensure you have all of the lesion plus the added fact there would not be any need for four to six weeks of radiation therapy. He replied:

> To me a mastectomy as a surgeon, you are going to remove

> the breast as opposed to removing around the lesion. You don't even go close to the lesion. So I would say that if it was a member of my family, I would suggest they go for a mastectomy.

3.3 The Women's Views

3.3.1 Sample Characteristics

There were a total of 21 patients who participated in this study. Twelve of the participants had MRM for their breast cancer while 9 had received BCS. In the MRM group, 58.3% (N=7) were in the 36-50 years age group while 41.6% (N=5) belonged to the 51-65 year age group. In the BCS patients, 55% (N=5) of the patients were in the 36-50 year age group and 44.4% (N=4) belonged in the 51-65 year group. There appeared to be little difference between the MRM and BCS group in regards to marital status or occupation. Twenty of the women lived in the greater St. John's region, while only one women lived outside the city. Table 9 summarizes the characteristics of the women in this study.

Table 9. Characteristics of the women participants

	MRM n = 12		BCS n = 9	
1. Age				
36-50	n = 7	58.3%	n = 5	55%
51-65	n = 5	41.6%	n = 4	44.4%
2. Martial Status				
Single	n = 0		n = 1	11.1%
Married/Cohabiting	n =10	83.3%	n = 8	88.9%
Divorced	n = 2	16.7%	n = 0	
3. Occupation				
Professional/Managerial	n = 3	25%	n = 2	22.2%
Secretarial	n = 5	41.7%	n = 3	33.3%
Homemaker	n = 2	16.7%	n = 4	44.4%
Other	n = 2	16.7%	n = 0	
4. Region				
City	n = 10	83.3%	n = 9	100%
Avalon	n = 2	16.7%		
Other	n = 0			

3.3.2 Questionnaire

Table 10 summarizes the women's replies to the questionnaire about the diagnostic visit. The results show that 73% of visits took place in the hospital clinic and lasted approximately 20 to 30 minutes. When asked if another health care provider was present during the visit, 54.5% of the women interviewed stated no. Less than 50% of women described being offered another appointment with other family members present, while 63.6% answered they were not offered a second opinion. Almost 60% claimed a particular treatment option had been suggested by the surgeon, and over 80% said they had not been offered any written material. Finally, 82% of the women reported waiting less than one week for their surgery.

Table 10: Women's report of the diagnostic visit.

Visit	Option	N
Setting	Hospital Clinic	16
	Office	5
Length of visit.	20 - 30 minutes	
Presence of other health care provider	Yes	10
	No	11
Offer of appointment for other family members	Yes	10
	No	10
	Unanswered	1
Offered second opinion	Yes	7
	No	13
	Unanswered	1
Particular treatment recommended	Yes	12
	No	9
Written material of options provided?	Yes	4
	No	17
Estimated time between diagnosis & surgery	Less than or equal to one week	13
	Between one and two weeks	4
	Longer than two weeks	3
	Unanswered	1

3.3.3 Focus Group

(a). Finding the lump

The members of the four focus groups and the one individual interviewed all began by recalling the event or events that led up to the actual diagnosis visit. Although asked by the interviewer to describe the actual visit when they received their diagnosis of breast cancer, only two of the women started at that point. The majority of the focus group participants gave extremely long detailed descriptions of the events leading up to the actual diagnosis visit. In many instances the account recalled events many years prior to the actual visit. Some examples are:

> When I had my first lump I was 16 and Dr. L. he's dead now and buried. He told me that I had a lump and that they were going to put me in and take the lump out.

> I went to my GP I was getting routine mammograms because I had a lump removed about 10 years previously in the same spot as where the cancer was.

> Well mine was really accidental. I had a hysterectomy in 1995 and the family doctor asked me if I had had a mammogram in the last year.

Without fail, each member of each group described in great detail the event of finding the breast lump or being called by physicians for repeat mammograms. In some instances, certain women were able to give specific details such as days of the week or times of the day and where they were when they found the breast lump. The events leading up to their biopsies whether surgical excision or needle aspirations were described in great detail. A typical example:

> I had this lump, I mean it was there for years, and I could feel it every time I went for breast examination and nothing. I had a mammogram done. I had it arranged that Dr. F. would be seeing me the same day, it was J's 16th birthday, September 2nd. The doctor said it was nothing. I gave him a slap on the back and said "I could kiss the jaws off you." Three years later I was doing my breast self exam and I just got in the mirror and flexed my muscles, I don't know what made me do it, so when I did it I saw this indentation, the lump hadn't changed in size. I saw my doctor and he sent me back to Dr. X.

The majority of the participants described how they felt while waiting for test results and the fear and anxiety they went through during this time. Typical terms used to describe their feelings were "feeling blank", "afraid", "constantly worried" "unable to be consoled".

This episode in the woman's life placed them in a type of limbo state where it was necessary to put their feelings and their lives on hold while they waited for test results. Many of the women described these periods as extremely stressful and difficult. A typical comment was:

> Then I had to wait for six weeks to have the needle biopsy done because it was before Christmas. I found that very difficult before Christmas and New Years. That to me was the worst thing, to have to wait for six weeks and thinking what will I be doing next Christmas.

Other women recounted getting the news from test results such as mammography and how they remembered their reactions. One such comment was:

> In July the doctor's secretary called and said that something had showed up on the mammogram. I was a few minutes before I answered him because I was so shocked

(b). Initial diagnosis visit

However, there was a distinct change in the women's accounts once they reached the diagnosis visit. When discussion of the visit began there was less description, less clarity on time lines and some descriptions became vague. Typical terms used to describe their emotions at this time were "hysterical", "numbed", "shocked", "unprepared" and "not truly hearing". The following are a few examples:

> At least I knew then, but I was hysterical at that point and I never heard half he told me.

> I was totally unprepared. I felt like he was telling this to someone else. It was like this is not me you're talking about.

> No matter what they tell you at the time of the diagnosis, I think there is only so much you are hearing.

> They sent me home. I'll tell you, they gave me a Valium before I left because I was out of it.

At this point several of the participants appeared to be thinking out loud and contradicting themselves as they continued with their account. At several points the interviewer needed to prod the women to elicit the information and this appeared to at times cause some of the participants to recollect something they had forgotten or it reminded them of a particular point they had forgotten. Some of the women described not remembering who was with them and what was actually heard. Others described knowing what the surgeon was going to say even before it was said. One woman described looking at her shoes, being unable to make eye contact with her doctor and recalling that all she could remember was that she had odd shoes on that day. There was a great deal of discussion from the participants describing their feelings and emotions they remembered experiencing once the diagnosis was given. Words used to describe emotions included "shock", "feeling faint", "quietly crying", "physically shaking" to "becoming hysterical". The following are some examples:

> Being speechless, I lost all sense of being.
>
> I was weak, shaking even. The poor doctor went pale.
>
> I went completely blank
>
> I just went blank. I don't think I spoke after he told me.
>
> I had to be sedated, all the time I kept seeing my mother's funeral.
>
> I was a little stunned.
>
> I remember being so cold.

(c). Decision making

When the women were asked to discuss how a decision was reached regarding the type of surgery, there were differences between the mastectomy groups and the breast conserving groups. Several of the women in the MRM (mastectomy) groups described having made up their minds regarding surgery even prior to receiving a final pathology report. Some described making the decision themselves prior to having had the biopsies, that if there was a positive cancer diagnosis they would have a mastectomy. This decision was made without discussion with the surgeon or discussing her options with family members or other health care providers. These participants recalled that even with the surgeons' suggestion of other options or being given information and time to consider other methods of treatment, they never faltered in their decisions.

For example, one woman said:

> I had already had my mind made up at that time that if it was malignant

> that I was going to go with the mastectomy and I had no doubts in my mind, absolutely.

Another woman emphasized that she persisted despite advice from the surgeon:

> I said I want a mastectomy. He said that it was an awful quick decision, are you sure? I said yes, I have thought about this and this is what I want.

Only one patient in the mastectomy group described seeking information from other sources and only when friends, family, and her family physician gave their input was the decision reached She described the time she took to reach her decision:

> I left and didn't go back for five weeks. I went back to my family doctor, to the Cancer Clinic, to a foreign doctor up in Grand Bank and to everyone I could possibly think of that I felt might me able to help.

When asked to describe their decision making skills in general, the majority of the women in the mastectomy group described themselves as being strong-willed, independent thinkers, who knew their own minds and usually liked to make decisions on their own. As one woman described:

> I knew in my heart that mastectomy was what I needed done and I made all my decisions.

The women who participated in the breast conserving surgery focus groups described going through the same emotions at their diagnostic visit, but tended to listen to the information supplied by their surgeons before reaching a decision. The women reported asking questions, taking time and thinking about their options. The majority of them felt they reached the decision in collaboration with their surgeons. They described waiting for the initial shock of the diagnosis to wear off, asked as many questions as they could think of and generally in collaboration with their surgeons decided on breast-conserving surgery. None of the women in this group described having their minds made up before receiving the diagnosis of breast cancer. It appeared the BCS group relied heavily on the information presented and collaborated with the surgeons to make their decisions. The majority of women in this group discussed trusting their surgeons that BCS was as successful as MRM and therefore chose BCS. Some of the thoughts expressed included:

> The doctor told me it was cancer and told me what my options were: a mastectomy, no treatment, or a lumpectomy and some radiation and possibly some chemotherapy. The doctor discussed the two surgeries and even drew them on the sheet on the bed. I realized that I could always go back to having the mastectomy if I wasn't happy but I couldn't really change the mastectomy and get my breast back. So, I chose lumpectomy.

> I weighed the pros and cons and tried to educate myself before I made my decision. He told me mastectomy and lumpectomy

had the same outcome so I chose lumpectomy.

(d). Post-surgical adjunctive therapy

With both of the surgical interventions there was still the possibility the patient would require chemotherapy and radiation therapy. The possibility of chemotherapy depended on the age of the patient, her menopausal status and whether the estrogen and progesterone receptors of the tumor were positive or negative.

Several women in each of the groups described the difficulties encountered with this phase of their treatment. Whether to leave work while receiving treatment was a major consideration. How people treated the women undergoing chemotherapy was discussed. Descriptions of close friends avoiding them or the strong bonds that were formed at this time was introduced by all. Other difficulties included the sickness, the fatigue and the loss of hair which was described by most as even harder to cope with than the loss of the breast to the mastectomy groups. All of the women who received chemotherapy described how difficult it was to pass a mirror or have their children see them bald. Some of the participants described building up the courage to actually make the decision to shave off their thinning hair and their families response to the final result.

The most common concerns associated with post-surgical adjunctive therapy , in particular chemotherapy, are summarized in Table 11.

Table 11 Common post-surgical adjunctive therapy themes.

Body image
Hair loss, weight loss, adjusting to scarring

Relationships with family, friends and co-workers
Support of family and friends, loss of friendships, attitudes of co-workers during chemotherapy positive and negative

Life-altering roles - dependent on others
Change of roles for family members & friends to provide physical and practical and emotional support. Curtailing social interactions due to altered body image and fatigue.

Side effects
Sickness (nausea and vomiting), fatigue, feeling of constant unwellness, fear.

Maintaining a positive attitude
Prayer, looking for small milestones (counting down the number of treatments left).

The event of chemotherapy to those women who required it was very anxiety provoking. The majority of the discussion at this point dealt with their altered body image. The change in their appearance from the chemotherapy caused some women to become reclusive. They missed family outings and attending parent night at their children's school or even avoided grocery shopping for fear of being seen in public. A typical response was:

> You hate to go to the bathroom because there are mirrors and your have to pass a mirror and look at yourself.

All participants described either the strength of support they received from partners, family, friends or co-workers or the loss of the support from these same people. One woman described the support she received from her husband:

> My husband used to love my hair long but when the chemo started to make it fall out I didn't know how he'd react. One night as I sat on my bed and watched my hair fall around me, he picked up my hair brush and brushed my hair out for me.

Another women described how her co-workers responded to her hair loss:

> I really wanted to try and stay working throughout my chemo. I couldn't afford a good wig and I didn't like how the cheap ones made my scalp feel. A lot of the girls at work like to sew and one day they each gave me a colored turban they had made for me. I was so touched.

However, there were those women who described the loss of life- long friends due to the illness.

> The woman who was my matron of honor at my wedding called one day and said how sorry she was to hear that I had breast cancer. I told her I was going to be all right and she said if I needed anything all I had to do was call her. Well, I did call her once shortly after that and I haven't

> heard from her in almost two years. Not one word.

For some women one of the worst parts of the treatment came when they were too sick or fatigued to do simple family tasks such as get groceries or do housework. Having to give up some of their independence and having to ask for help was very difficult for some women to accept. One woman described the loss of independence in this way:

> My radiation was booked for Wednesdays which was the same day I used to go to my son's school and volunteer in the mornings and get the groceries in the afternoon. I didn't think I would feel as badly as I did after each treatment and I had to give up going to school on Wednesdays and my husband or my sister used to get the groceries. That sounds pretty petty but it really bothered me that something that simple and I just couldn't do it.

All of the participants who required therapy after their surgery described the side effects of sickness, fatigue, fear and general feelings of malaise associated with their treatments. Some typical comments were:

> I was violently ill. I prayed to God that if he was going to take me, take me now.
>
> I died, I was some sick. I wondered what I had done in life or to who I had done it to that I was being punished now.

> It takes a chunk out of your life. You don't look at your little girl's pictures that they drew and stuff like that. You look at the time you went through the chemo because it is such a major event in life like the birth of a child, the death of a parent, it is your chemo time, isn't it?

One of the most important elements described for getting through the treatment phase of the disease was trying to maintaining a positive attitude. It was important to keep focused on the end result that with each treatment it was one less that they needed and one day closer to getting healthy and getting back to have some semblance of a normal life again. A typical comment was:

> I had a calendar on my kitchen wall and every day that I had to have a treatment was circled in red. After each one I'd put a big bold X over that date and when I could see more X's than circles I used to get really positive. It was my way of keeping a countdown to being normal.

(e). Most memorable event

The participants were asked to describe their most memorable event whether good or bad from the beginning to the end of their experience. Table 12 shows the most frequent responses:

Table 12 Most memorable event

Chemotherapy/Radiation Therapy
Sickness, altered body image, finally finishing

Fear
Afraid of not living through the treatment and fear of poor prognosis. Waiting for reports.

Waiting
Biopsy and investigational reports.

Support of family & friends.
Strength of some relationships & bonds with husbands, sisters, friends and co-workers.

Loss of relationships
Family and friends who could not be depended on for emotional or practical support.

Prayer
Dependence on and comfort received from prayer.

For all of the women who required chemotherapy and or radiation therapy as part of their treatment, it was described as by far the most memorable event of their experience. To each person there were different aspects of receiving this therapy that made it memorable, such as the hair loss, the terrible sickness and fatigue, or finally finishing and being told everything was over and they were fine.

The majority of women in all groups discussed the waiting associated with getting reports such as biopsy reports, CAT scan, and bone scan reports, and whether their lymph nodes were positive. The indescribable fear and the non-ending wait was likened to a "black hole in the center of my life" The waiting was described by the participants as the hardest thing for themselves and their families to deal with.

Many of the women described the strength of relationships that endured this time and the pain of having certain family members and friends avoid them because they did not know how to approach them.

Several of the women described relying on their religious faith and steadfast prayer to help get them through this time. There were those women who described themselves as not being religious before this time but now found themselves relying on their faith in God to keep them positive and focused. One woman's response was:

> What I found comfort in was prayer. I never knew what prayer was until I got this. It was just a lip service. I mean I always said my prayers and went to church but I tell you right now I have a direct line my dear and it gives you inner strength. I want to see my kids grow up.

(f). Common concerns

The common concerns that the mastectomy and lumpectomy groups shared was the prevailing fear of reoccurrence. Discussion in all groups described being very aware of the necessity for follow-up and some women mentioned being fanatical or paranoid about their health. The fear of reoccurrence was described as "constant," "obsessive," and, to one individual in the lumpectomy group, as "consuming".

For the women who were mothers, besides the fear of reoccurrence there was the fear of not living to see their children grow up or at least grow to an independent age where they felt their influence would not be missed as much.

(g). Information needs

When asked by the interviewer if, at the time of their diagnosis, there was anything they wanted to ask but were afraid to, the common response was their prognosis. The participants from both the mastectomy and lumpectomy groups described wanting to know how much longer they had and what the rest of their lives would be like. A comment was:

> I remember having a thought that I wanted to ask, I wanted to ask
> how much longer I had, that was my first thought.

All the women stated that it was the first thing that came to their minds but was not voiced. Many of the women described mentioning the fact that they had small children trying to illicit some positive response regarding their future. One woman stated:

> I didn't come out and say the words but I remember looking at him and saying, I have two little girls.

Other women sought information regarding what they should do to ensure they do not get reoccurrence or what the possibility of a reoccurrence was. A statement made from a woman in the mastectomy group included:

> I remember looking at him and saying well you can just get busy and take them both. I'm not living the rest of my life whatever that may be worried to death about it coming back into the other one.

While a woman from the lumpectomy group remembered her thoughts and described them in this way:

> I kept thinking, this is just great, I'm one of five girls in my family and each one of us have girls. What a legacy for our daughters.

(h). Life after breast cancer

At the time of the focus group interviews, most women had been cancer free for several years. At this time the women expressed a change in attitude towards their body and their lives. The women discussed having a major fear of reoccurrence which was the most prominent in their minds especially when the time for follow up testing got closer. The women described being more aware of their bodies and worrying more about any new lumps or bumps. The second issue women discussed was what they all described as the horrible waiting times for CAT scans and the annual visits to see the surgeon. Many described living their lives as one woman described it "just waiting for the other shoe to fall".

Third, there was great discussion around how they no longer worried about household chores such as a sink full of dishes. Instead they expressed a desire to savor every minute, to stop and "smell the roses" more often. Marking milestones was also a common point with the women. They marked off their lives by such measures as their children getting a year older and a little more independent or they themselves getting closer to a five year post cancer milestone or ten year post cancer milestone. One woman stated that "time is nothing anymore, it's all borrowed and it's precious." Another stated that each morning when she gets up to start her day she recites the Alcoholics Prayer. When asked what that was she began to recite "God Grant me the serenity ..." and three of the other group participants joined in.

Chapter 4: Discussion

Evidence suggests that there is no clinical advantage for modified radical mastectomy for women with stage I or II breast cancer over breast conserving surgery as a treatment method. In view of this, there is an ongoing need to review regional variations in these procedures and to determine the views of the surgeons and women with regards to these two forms of surgery.

This study provides some information with regards to issues concerning women who had breast cancer surgery in St. John's in the mid 1990s.

4.1 Statistics

This study reviewed the statistics of breast cancer surgery during the period 1994-1997. During this period only 26% of these surgeries were BCS. This compares to 44% in British Columbia and 68% in Ontario reported by Goel et al. (1997) and Iscoe et al. (1994). In those studies they excluded women with any lymph node involvement for which MRM is more likely. In the current study, cases with lymph node involvement were not excluded. However, since today the majority of cases of breast cancer are lymph node negative, it is unlikely that the proportions of BCS or MRM would change substantially. Further research should consider the pathology of all breast cancer surgeries to better clarify this report of high rates of MRM.

Several demographic factors were associated with type of surgery. First the rates for MRM were higher in that hospital where the majority of women came from outside St. John's. Iscoe et al. (1994) found that geography appeared to have been a considerable factor influencing BCS rates. They contend that when patients live long distances from radiation therapy centers it may be perceived by the patients as added inconvenience to their lives and therefore women opt for MRM which does not usually require radiation therapy. The participants of the focus groups and interview consisted mainly of women who lived in metropolitan St. John's. Only one woman resided in a rural region, however, she did state that travel distance was a major issue in deciding against breast conserving surgery which would require daily travel for radiation therapy.

The figures obtained for the numbers and types of surgeries performed for breast cancer included those women from outside metropolitan St. John's. The statistics, as indicated, show that many of the women were from outside the Avalon region of the province, (i.e. more than 100km. from the metropolitan hospitals). Some of the women were required to travel up to five hours to receive their surgery. It is possible that traveling long distances may encourage some women from outside St. John's to choose MRM to avoid the repeated visits to the hospital to receive radiation therapy as an adjunct to BCS. Further, more of the patients at the centre which had the highest proportion of MRM were drawn from outside St. John's. Future research should examine whether those patients from outside the city are being seen at a later stage in their disease therefore requiring MRM. It is possible rural hospitals refer cases of advanced breast cancer to one St. John's site which could partially explain the patterns of surgeries in the St. John's hospitals.

Age is another potential factor. Older women were more likely to have an MRM. Future research would need to consider whether these women are being diagnosed with a more advanced stage of breast cancer. In addition, further research of the elderly population is needed to establish whether because of the presence of co-morbidities, radiation therapy would not be considered, therefore, leading surgeons to limit potential options to this population.

4.2 The Surgeons

The results from the questionnaire displayed the surgeons as being co-operative and proactive in their delivery of care. It suggested the surgeons were aware of the objectives and guidelines set forth in the Canadian Medical Association's (1998) Clinical Practice Guidelines. They appeared keen to involve the women in decision making, to provide them with an opportunity to discuss their treatment options and to make their own choices regarding their surgery. However, the view of women was less enthusiastic. This would suggest that while the surgeons may wish to involve the women, they provide information during a time when admittedly the women are unable to understand the imparted information.

All of the surgeons who participated in this study were affiliated with teaching hospitals and all held academic appointments. Therefore, it would be expected they would be aware of the current recommendations and guidelines. It was not surprising to find that all of the participating surgeons were well versed in the C.M.A.'s clinical practice guidelines. It would be useful to examine the rural population of surgeons to assess their knowledge and use of these current C.M.A.'s recommendations.

(a). Reason to recommend MRM

According to the Clinical Practice Guidelines for the Care and Treatment of Breast Cancer presented by the C.M.A. (1998) MRM should be performed when the tumor size is large in proportion to breast size; and the patient's clear preference is for mastectomy. The statements made by the surgeons in the interviews correspond to the clinical guidelines on these issues. They appear to follow the guidelines set down by their peers for practice. There did not appear to be any deviation from the guidelines and all of those surgeons in this study clearly are aware of the guidelines which are in place.

Although all the surgeons described the pathology as the dominant factor, several described patient attitude as being of equal importance. None of the surgeons indicated they would favor one procedure over another for different age groups. There was no indication that older women were being offered MRM more often than their younger counterparts although evidence indicates that for some reason this age group appears to have this procedure more often than younger patients. When the surgeons described taking patient attitude into account they described assessing the patient's general attitude towards health and related matters.

(b). Surgeons' view of women's participation in decision making

A study by Beisecker (1990) describes that before patients can make a choice about their medical care, patients must first decide that they have a right to choose. It is also suggested that other studies have identified that 92% of cancer patients wanted all available information but only 69% preferred to participate in medical decisions It is the obligation of the primary surgeon to provide the information on which the patient may base her decision and to provide the guidance through the treatment options so that the patient may select what seems to her an appropriate action (Cady & Stone, 1990). Fallowfield (1997) advocates that given greater patient involvement in choice, that choice would lead to improved satisfaction with health care and acceptance of treatment. Other studies have verified patients receiving appropriate information report increased participation in treatment decision making, better preparation for medical procedures and increased satisfaction with treatment choices (Gray et al., 1998; Richards et al., 1995). Improved coping thereby decreases levels of anxiety and a greater ability to cope during and after treatment.

During the interview phase of this study, the surgeons were asked their views of women's participation in decision making. They were asked if they thought women should be involved and whether women in general wanted to become involved in decision making regarding their health care. All of the surgeons described they felt it extremely important to have patient input in the process of decision making. There was complete consensus by all surgeons who described the importance of patients being completely comfortable with the final decision for their treatments and it was felt this could only be achieved if patients were active participants in the process. Every surgeon claimed they offered patients participation in the decisions for their treatment options. The surgeons described observing three types of behaviors displayed by patients when deciding upon their treatment. Patients were described as (1) already having their minds made up about which procedure they wanted, (2) relying entirely on the surgeon to choose for them or (3) appearing to jointly reach the decision with their surgeons. Degner et al. (1997) describes three similar roles patients take on when faced with a life threatening illness which requires them to make major decisions regarding their treatment.

(c). Dominant procedure

Although the statistics show that MRM is by far the most frequently performed procedure in St. John's, it was necessary to ascertain if the surgeons acknowledged the same.

The surgeons were asked which of the two procedures, MRM or BCS they felt was being performed more often and to elaborate on their impression of why they felt it was. Five of the surgeons felt that MRM was still being performed more often than BCS. This confirms that even with offering treatments options they are aware of the propensity for MRM even outside their own practice. They felt there were three main reasons why this procedure remained the dominant procedure of choice for breast cancer surgery.

1. Family history: The influence of family members, close friends or even neighbors is strong and may be stronger than the physician's influence as patients may not have a long history with their surgeons. Findings from a study by Richards et al. (1993) also indicate patient's preferences may be influenced by their attitudes and beliefs based on previous experience, family, friends, the media and other health professionals.
2. Fear of reoccurrence: Patients may feel that their breast is entirely diseased and now life threatening. To leave any part of this breast would be to expect a reoccurrence and therefore if it is removed so is the chance the cancer will come back. This observation is consistent with other findings on breast cancer and psychological outcomes whereby fear of cancer and its possible reoccurrence seems to be a compelling factor in determining a woman's preference for treatment (Fallowfield, Hall, and Maguire 1990; Schain & Fetting1992).
3. Age: There was general consensus that younger and more highly educated women choose BCS over MRM. In the study conducted by Goel et al. (1997) and Iscoe et al. (1994) it was discovered that lower age was associated with greater likelihood of such surgery in British Columbia and Ontario. The women whose views are discussed subsequently, also agreed that family history and fear of reoccurrence were important in reaching their decisions.

4.3 The Women

The intent of the questionnaire was to assess whether the women's memories of their diagnosis visit was any different from what the surgeons stated they practiced. The questionnaire asked patients basic information as to matters surrounding their actual diagnosis visit such as where it took place, the length of time they remembered it being; whether they were offered a second opinion or another appointment to review the diagnosis. There were very few discrepancies noted between what the surgeons stated they do in actual practice and what the women remember. There was very little variation in any of the answers given by the women suggesting the surgeons were saying one thing but really doing another. However, there was one key difference. Approximately 60% of the women suggested their surgeons did recommend a particular form of treatment. All surgeons stated they offered both forms of treatment to the patients. There are several possible explanations for this difference. It is possible that the surgeons overstated the extent to which they offered both forms of treatment. Alternatively, the women did not "hear" the options. The evidence from the focus groups suggested that the latter explanation was the more likely conclusion.

It was not the intention in the focus groups or the interview to actually delve far back into the breast cancer experience with the patients. The starting point for discussion within the focus groups and interview post introductions and explanations was to be at the actual diagnosis visit. The patients were asked by the interviewer to describe the actual visit whereby they received their diagnosis of breast cancer. Only two of the women started their discussion at this point. The majority of the focus group participants gave extremely long, detailed descriptions of the events leading up to the actual diagnosis visit. In many instances the account recalled took place many years prior to this specific event. Some patients described their history of breast lumps that had been previously biopsied 35 years before. The amount of detail recalled was surprising as patients could still describe where they were on what day it was and how they felt when they found the lump or got news of an irregularity in their mammograms. The prominent themes expressed by all the respondents were the emotions they experienced while waiting to see their doctors, then awaiting consultations with surgeons or waiting for mammogram reports. Anxiety and fear built as the biopsy date approached and the longest and most difficult aspect of waiting was for the pathology report of the biopsy. Some patients described their heightened level of anxiety, fear and feelings of loneliness during this time. Feelings of isolation were described even when others surrounded them with support and genuine concern. These emotions are consistent with those described by patients in a study described by Shaw, Wilson and O'Brien (1994). They found that the time waiting for the actual biopsy to be completed and waiting for the results was extremely distressing. They also reported feelings such as shock, fear, anxiety and powerlessness. Isolation was another emotion described by those in that study.

Although most of the participants in this study described how difficult and distressing they found the waiting, others described looking for meanings in other events to symbolize their wellness. The women attempted to rationalize their symptoms. One woman described reminding herself that her two sisters had cysts removed from their breasts and therefore that was most likely all she had. Another patient took immense comfort from the way the surgeon kept eye contact and patted her hand as he told her not to worry. She felt certain at that time he would not be so assured if he was worried. This again is consistent with the findings by Shaw et al. (1994) who found that patients awaiting biopsies or results will look for clues that would predict the outcome of the biopsy findings.

When describing the actual diagnosis visit, it was evident this event was viewed by the patient differently than any of the events leading up to this point. The tone and cadence of voices changed, the amount of detail was less descriptive and time lines became vague. There was more detail surrounding what their feelings were than actual events of the situation. Some stated they did not remember what the surgeon said after he said the word "cancer". Some patients reported they became hysterical and had to be sedated or they just went blank. One patient remembered she felt very, very cold. Most of the patients admitted to not having a completely clear picture of the actual visit and have been told things that happened by whoever happened to be with them. Lazarus and Folkman (1984) described patients under duress as not coping through "information seeking" but rather using a process of "information management." This information management is used as a coping strategy which allows the patient to put limits on the amount and depth of information that they would accept at any one time. Another study conducted by Lavery and Clarke (1996) concluded that many women find the experience of breast cancer so overwhelming that they are unable to remember or completely understand the information that is presented to them. It would seem that this period of initial diagnosis of cancer is one of intense emotional upset for the women during which she cannot process any additional detail as regards to treatment options.

4.3.1 Decision making

The Clinical Practice Guidelines (C.M.A.,1998) clearly state in its objectives the need for patients with breast cancer to be empowered to make their own decisions as much as possible. The majority of oncology health care professionals believe that patients should be provided with the information to participate in treatment decision making (Northouse, & Worthman 1990). When patients are provided with information it fosters informed participation in decision making and may relieve emotional anxiety (Bilodeau & Degner 1996).

In recent years, health care providers have moved in the direction away from a paternalistic approach to one that actually encourages patients' autonomy and promotes their decision making for treatment. Still, there is strong evidence to support the notion that many people do not wish to be actively involved in deciding their course of treatment and would prefer that the decision making be left entirely to the physician (Beaver et al., 1996). The issue of giving patients all the needed information to help them with decision making is known to cause "decision dilemma" (Schain, 1990). The required imparting of information therefore needs to be individualized in light of the woman's level of education, her learning style, or her ability to comprehend confusing and anxiety provoking options. It also does not permit consideration of how her history or beliefs about breast cancer may color her interpretation, comprehension and assimilation of the information (Schain & Fetting, 1992).

In this study, the participants were asked to describe how they generally react when placed in a position whereby they must make medical decisions. Most of the patients stated they listened to all the information and generally followed the direction of the physician. These expressions were related to matters that were relatively non-invasive as in recommendations for blood work or consultations with other health care providers.

When each of the participants was asked to describe how she made the decision for her breast cancer treatment, there appeared to be differences between the MRM groups and the BCS groups. The general consensus of the patients in the MRM groups was that they had decided to have a mastectomy before their results were known and some as early as before their appointment with the consulting surgeon. This decision was made without discussion with the surgeon, family members, partners, or other health care providers. Several of these patients described knowing in their own minds what was best for them. The Canadian Breast Cancer Initiative's (1998) suggests that women take time to reach their decisions. It also suggests that women are the best judge of their feelings and body and this should not be discounted by anyone when decisions need to be made. These participants described being told by the surgeons what options they had available and were asked to take time to consider all the facts. Their decisions never changed. Only one patient in the MRM group stated she sought additional information from other sources and only when friends, family and her family physician gave their input did she choose a mastectomy. If we use Degner's (1997) model as a framework, the women would fall into one of these groups:

1. active: those women who actively chose MRM
2. collaborative: those women who chose BCS
3. passive: those women who either followed the surgeon's guidelines for MRM or BCS.

When the women were asked if they could describe why they felt it so necessary to insist on a MRM, they stated they would not be able to live with the fear of reoccurrence. This is a dominating theme noted by other researchers investigating why some women may prefer for mastectomy (Kotwall et al., 1996, Cady & Stone 1990, Shain & Fetting 1992). This would agree with the surgeons explanations as to why certain women favor mastectomy.

Those women in the MRM groups clearly stated that fear of reoccurrence defined their decision to undergo a mastectomy. A study by Fallowfield (1997) found that once diagnosed with breast cancer, the fear of reoccurrence was greater than the fear of cancer itself. This fear of reoccurrence was described as being heightened particularly surrounding recheck appointments, annual mammograms and routine doctor visits. Another prevailing theme particularly of those women who may have had young children, was the fear the illness would take their lives and they would not witness their children growing up.

The women who participated in this study were mainly urban with one exception and therefore, one would infer that travel distance should not be a major factor in their decision against breast conserving therapy. It was noticeable that only one participant mentioned radiation therapy as being her deterrent against choosing BCS. This was the one woman who resided approximately two hours outside St. John's.

The participants were asked to characterize their decision making skills in general. The majority of the women in the MRM groups portrayed themselves as being strong willed, independent thinkers. They were known by their families and friends as once having their minds set on something, there was no way to persuade them to change it.

Conversely, women in the BCS groups described listening to the information supplied by their surgeons, taking time and thinking thoroughly about their options, and often not deciding immediately. The consensus of the participants in the BCS groups felt they reached the decision in collaboration with their surgeon. There were those patients in both the MRM and BCS groups who felt they were not capable of making the decision and relied on the surgeon to do so. The findings of the current study appear to validate Degner's (1997) theory. In the present study it appears that for the most part, those patients who received MRM tended to adopt the active role, while the patients who received BCS appeared to adopt the collaborative role, while others adopted the passive role.

All women claimed they made the decision from their own anticipatory concern for their own post-operative feelings rather than what they thought their spouses felt. In a study by Margolis et al.(1989) similar findings were noted. It appears the breast cancer patient, when choosing her surgery, is not concerned how this will impact on anyone else. Other issues appear to dominate her thinking at this point.

4.3.2 Post-surgical adjunctive therapy

In certain instances there may be post-surgical treatments such as chemotherapy and/or radiation therapy. Women recalled the difficulties encountered with this phase of their treatment. Oftentimes they were faced with further dilemmas with respect to incorporating these therapies within their lifestyle and still sustaining some semblance of normality in their lives for themselves and their families. There were five main themes extracted from the vast amount of discourse in the focus groups and interview. These themes include trying to remain at work with altered body image and the side effects from the therapies which included illness and fatigue. The women described being so ill that family events such as children's birthdays, school outings etc. were looked upon as labor and difficult to get through. The loss of independence and having to rely heavily on others for daily maintenance of the family created a sense of loss and frustration.

For all of the women who required chemotherapy as part of their treatment, it was described as by far the most memorable event of their cancer experience. The sickness associated with the drugs or the altered body image, weight loss, hair loss or the feeling of relief of finally having finished their treatment were described. Several patients described wondering it they were being punished for something they had done.

Ashcroft, Leinster and Slade (1985) described several reports of psychological consequences of breast cancer treatment. The most prevalent were depression and anxiety which were often accompanied by psychosocial problems related to adapting to altered body image. Several of the experiences described by participants in the current study were similar to those described by Ashcroft et al. (1985).

Halldorsdottir and Hamrin (1996) describe the findings of several studies which indicate that the social context and social support from partners, family and friends are important for psychosocial adjustment and survival of cancer patients. Some women in the current study described either the increased support of family and friends or the loss of others

4.4 Surgeons/Women

Only one surgeon stated he did on a regular basis provide his patients with written material while over 80% of the women said they had not been offered any written material. This suggests that it was not a usual practice of most surgeons to offer written materials Jenny (1990) described the importance of giving patients current available material in a variety of forms. These materials will help to reinforce the information given to them during the diagnosis visit.

There was complete agreement between the surgeons and the women regarding the duration of time between diagnosis and actual surgery date being less than two weeks. The women voiced their feelings that this surgery should take place as quickly as possible and most surgeons stated they felt this was in the best interest of the patient emotionally and psychologically.

The surgeons also felt that other people such as family, friends or even neighbors influenced the patient more than the surgeon did. A large number of the MRM groups said they looked at their mothers or sisters etc who may have had a MRM and saw they were doing well after their mastectomies years before and were influenced strongly by this rather than what the surgeons were saying. Because they knew people who survived after MRM was performed, the women appeared to believe that MRM was preferable. Most women did not know anyone who had undergone BCS and were therefore afraid to chance the unknown.

Some surgeons felt that younger, better educated women tended to ask more questions, took more time to reach decisions and armed themselves with information from other sources before their decision was reached. This would agree with the statistics that showed that younger patients tended to have BCS.

The attitude of the patient was another reason presented by the surgeons as being a notable factor with women and decision making. There appears to be the attitude of some patients that this is a diseased breast and if any part of the breast remains the cancer will reoccur. This was a common theme expressed by the MRM groups participants.

The surgeons suggested they were frequently asked a very uncomfortable question pertaining to which treatment option they would wish their wives or daughter to undergo if they had breast cancer. Five of the surgeons stated they became evasive or explained that all situations are different. Two of the surgeons however, did state they actually answer this question if asked. One surgeon stated he told his patients he would suggest his family member have BCS as he was totally convinced it was the better procedure both physically and psychologically. The second surgeon stated if asked, he always advises an MRM. His rationale for this was that by removing the entire breast the actual tumor was not touched thereby decreasing the necessity of further resections to ensure you have all the cancer. The bonus of this procedure was there is usually no requirement for radiation therapy. When the women were asked if their surgeon recommended a particular treatment almost 60% responded they had.

It would appear that both surgeon influence and patient preference are the two most important factors for the high rate of modified radical mastectomies in St. John's Although approximately 60% of the respondents described they felt a particular treatment option was suggested by their surgeon, the actual details were vague. It was felt by many of the women that their memories of the diagnosis visit were unclear. However, many of those who had undergone MRM stated emphatically that they had made their own decisions with respect to type of surgery even before receiving a positive pathology report of malignancy. The fact that MRM was higher among the older women would suggest while these women may have different pathology. It appears they are opting for what could be described as the more traditional form of surgery which they may have heard about from their peers. Thus, efforts to reduce the overall rate of MRM should focus on education of this age group.

4.5 Limitations

In this study, data were retrieved in three ways in order to complete each of the aims. All procedures performed in a hospital setting are coded for record storage The Health Care Corporation of St. John's utilized the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures for computerized coding. Chart audits were completed on any chart that was coded as BCS as there are oftentimes problems with understanding the dictated procedures by the surgeons by the coding clerks. Human error with simple pressing wrong buttons could alter a particular code. In many instances more than one procedure was described and multiple coding was required. The pathology and operative reports of each chart coded for the breast conserving procedure were reviewed to corroborate the final diagnosis and code. To ensure the MRM procedures were correctly coded, a random chart audit was performed on these charts to verify the procedure. It should be noted that only one chart belonging to the BCS group was found to be coded incorrectly. This was coded as a BCS when in actuality it was a breast biopsy for a non-malignant fibroidadenoma.

The second limitation of the study has to do with the small number of surgeons who participated in this project. Those who did enter the study were the surgeons who did most of the breast cancer surgeries with in the Health Care Corporation of St. John's. Although other surgeons do perform these procedures, with one exception, their practices of breast cancer patients is relatively small. The surgeons who did participate in the current study had exemplary qualifications in that all maintained a practice within teaching facilities and all held academic appointments. This allowed the surgeons to have the ability to incorporate any clinical guidelines into their practice as many of the obstacles that rural surgeons would face were not present.

The third limitation of this study concerns the sample of women with breast cancer who entered the project. This study was conducted with a group of women who almost entirely resided in an urban area. This allowed this population to avail of larger facilities, additional equipment and easy access to a radiation therapy site. The results may have been different if the study had taken place in rural Newfoundland.

4.6 Recommendations

This study has focused on one issue within our health care environment which after years of painstaking research still needs to be addressed.

There are three main issues that need to be addressed for recommendations for practice. The first issue surrounds the high rate of modified radical mastectomy being performed which needs to be further investigated. Further research should include examining actual pathology of the breast cancer to assess the relationship between pathology and procedure. This investigation of pathology would show if this particular population is presenting with an advanced stage of carcinoma of the breast which would possibly preclude breast conserving surgery as an option. Thus, further examination and education into early detection would be required. If the study did not find that advanced pathology was the factor for higher rates of modified radical mastectomy other causes would have to be examined.

The second issue for recommendation is the subject of doctor patient communication. Although in this current study the surgeons suggested they gave women detailed information with regards to their diagnosis and treatment options, many of the women give vague recounts about their diagnosis visit and their encounter with the surgeon.

There is every indication that the most important element to patients who need to make decisions regarding their care is information. Patients need to have not only basic information but details that they, as individuals must have in order to be cognizant of the significance of the outcomes they are choosing. Information should be presented in such a manner as in not to exclude the individual but to incorporate them into the exchange. The major factor influencing successful adaptation after breast cancer therapy is participation by the patient in the treatment choice (Nattinger et al., 1998). Although most health care providers advocate that patients should be included in the treatment decision making, it has been shown that this can increase the stress on an already stressed patient. There are those patients who find it unbearable to be expected to make oftentimes life and death decisions. These patients are described by Degner (1997) as passive patients. Previous research indicated the three classes of physician behavior tend to improve patient adjustment to cancer diagnosis: (1) providing empathy, (2) attentive listening and conveying positive regard and (3) instilling hope (Roberts et al., 1994).

A related recommendation is for the surgeon to anticipate the level of anxiety and associated emotions the patient will experience when given a diagnosis of breast cancer. The patients involved in this study clearly reinforced the notion that this encounter is emotionally tense and oftentimes may leave the patient in a state of shock. This is not the time to continue with a detailed information session on stages of cancer or treatment options. Any information imparted at this time will be lost on the individual who is now in crisis.

The meaning of a particular surgical procedure may vary substantially for different individuals undergoing the same procedure (Kincey & Saltmore1990). Patients need to be viewed as individuals with breast cancer and not be looked upon as a breast cancer patient. One view looks at the individual's needs while the second view gives the impression that everyone with breast cancer has the same needs.

Patients should be encouraged to always have a support person with them when they will be attending the consultation visits and more especially for the final diagnosis visit.

An interdisciplinary team approach to treatment would be the best approach where disciplines other than the surgeon himself could take a role in treating the patient. Disciplines such as nursing, social work and psychology would be key players in the team approach. This gives the patient the opportunity to have more than one person involved in their care who is aware of where she is in the realm of the health care process. It also allows her to have other than her surgeon to contact should she require assistance. It fosters her belief that she is not isolated but can include her care givers as part of her social support. Social support has been viewed as a buffer against the effects of stress on both physical and psychological health (Kincey and Saltmore, 1990)

Another recommendation should be to encourage patients to take time to think about their situation and not to regard it as imminent death. Patients need to take themselves out of the unfamiliar environment of a hospital clinic or physician's office and have the ability to meet with health care providers who have an expertise in dealing with patients at this critical time. The time away from the crisis environment gives one the opportunity to put things into perspective and the opportunity to meet with other health care providers will allow for information to be reinforced.

The third recommendation of this study focuses on the findings that older women and those in the rural areas tend to undergo modified radical mastectomy more so than their younger and rural counterparts. Further study needs to examine surgeons' views as it pertains to the elderly population and whether they view this section of the population in a different light when describing breast cancer and its' associated treatment options. Also, this portion of the population appear to elect for the traditional method of breast cancer surgery. Further education aimed at these women may prompt a change in this pattern.

The issue of rural women choosing MRM over breast conserving surgery may be influenced by the distance they need to travel to access radiation therapy. It may also have to do with the lack of knowledge about radiation therapy. Many women appear to remember the stories of people who in previous decades received radiation therapy which induced side effects as in radiation sickness and severe burns. There needs to be an education program in place which clearly describes the radiation therapy process to enlighten people about the facts of radiation therapy as it is today.

In conclusion, it would be best to put it in the words of one of the women who participated in this study.

> When it came right down to it, I really needed to know that this was not the end of my life. I needed the doctor to understand that I wasn't dumb, I was terrified. I needed to feel that he was being honest with me and to know that he was treating me the same as he would if I were his own wife and that he cared about what happened to me.

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APPENDIX A: HUMAN INVESTIGATION COMMITTEE APPROVAL

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

1998 04 30

TO: Ms. Elizabeth Dicks

FROM: Dr. Verna M. Skanes, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: **Application to the Human Investigation Committee - #98.36**

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"Surgery for Breast Cancer in St. John's: The Statistics, The Surgeons' View, the Patients' View"**

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

Verna M. Skanes, PhD
Assistant Dean

cc: Dr. K.M.W. Keough, Vice-President (Research)
Dr. E. Parsons, Vice-President, Medical Services, HCC

St. John's, NF, Canada A1B 3V6 • Tel: (709) 737-6762 • Fax: (709) 737-5033 • email: rgs@morgan.ucs.mun.ca

APPENDIX B: RESEARCH APPROVAL COMMITTEE (HEALTH CARE CORPORATION ST. JOHN'S).

HealthCare
Corporation of St. John's

1998 04 20

TO: Dr. M. Murray/Dr. P. Gardiner

FROM: George Tilley, Senior VP-Corporate Affairs

SUBJECT: Research Proposal

Your research proposal **HIC # 98.36 - "Surgery for Breast Cancer In St. John's: the Statistics, the physicians' Views, the Patients Views"** has been considered by the Research Proposal Approval Committee (RPAC) of the Health Care Corporation of St. John's at their most recent meeting.

The committee has approved your proposal to be conducted at all sites (health records department) within the Health Care Corporation of St. John's. This approval is contingent on the appropriate funding being provided and continued throughout the project and on the provision of regular progress reports at least annually to the RPAC Committee.

GEORGE TILLEY
Senior Vice President, Corporate Affairs

GT/ls

c.c. Linda Purchase, Research Centre

General Hospital
Health Sciences Centre, 300 Prince Philip Drive, St. John's, Newfoundland, Canada A1B 3V6 Tel (709)737-6300 Fax (709)737-6400
SITES General Hospital • Janeway Child Health Centre/Children's Rehabilitation Centre • Leonard A. Miller Centre
St. Clare's Mercy Hospital • Salvation Army Grace General Hospital • Dr Walter Templeman Health Centre • Waterford Hospital

APPENDIX C: CONSENT FORMS

Surgeon's copy

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF NEWFOUNDLAND

and

Health Care Corporation of St. John's

Consent to Participate In Bio-medical Research

TITLE: Surgery for Breast Cancer in St. John's: The Statistics. The Surgeons' View. The Patients' View.

INVESTIGATOR: Elizabeth L. Dicks

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time.

Information obtained from you or about you during this study, which could identify you, will be kept confidential by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

1. Purpose of study:

This study proposes to look at the numbers of Modified Radical Mastectomy and of Breast Conserving Surgery performed within the Health Care Corporation over the last three years. The surgeons' views of the different types of surgical interventions for breast cancer will be examined. Also, the patient's perceptions of this event in their lives will be studied.

There are three main objectives to this project:

1. To determine the rates and types of breast cancer surgery performed in St. John's within the Health Care Corporation during the years 1994-1997.
2. To obtain the surgeons' views of breast cancer surgery.
3. To describe the patients' views in regards to their personal experience of having breast cancer surgery.

2. Description of Procedures:

You are asked to participate in a study that includes completing a short questionnaire and a brief interview which will be tape recorded.

3. Duration of participant's involvement:

Participation in the study will necessitate completion of a short questionnaire and a short interview. The duration of time is expected to be no longer than one half to one hour.

4. Benefits of Participation:

Although you may not benefit directly from this study, all health-care consumers, especially women newly diagnosed with breast cancer may benefit from an increased knowledge.

Liability: Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate. In no way does this waive your legal rights nor release investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I, ________________________, the undersigned, agree to participate in the research study described. Any questions have been answered and I fully understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been offered to me.

Signature of Participant: ________________________________
Date: ______________________

Signature of Witness: ___________________________
Date: ______________________

Patient's copy

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF NEWFOUNDLAND

and

Health Care Corporation of St. John's

Consent to Participate In Bio-medical Research

TITLE: Surgery for Breast Cancer in St. John's: The Statistics. The Surgeons' View. The Patients' View.

INVESTIGATOR: Elizabeth L. Dicks

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Information obtained from you or about you during this study, which could identify you, will be kept confidential by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

1. Purpose of study:

This study proposes to look at the numbers of Modified Radical Mastectomy and of Breast Conserving Surgery performed within the Health Care Corporation over the last three years. The surgeons' views of the different types of surgical interventions for breast cancer will be examined. Also, the patient's perceptions of this event in their lives will be studied.

There are three main objectives to this project:

1. To determine the rates and types of breast cancer surgery performed in St. John's within the Health Care Corporation during the years 1994-1997.
2. To obtain the surgeons' views of breast cancer surgery.
3. To describe the patients' views in regards to their personal experience of having breast cancer surgery.

2. Description of Procedures:

You are asked to participate in a study that includes completing a short questionnaire and attending a focus group which will be comprised of women all having undergone the same therapy for their breast cancer. These group sessions will be tape recorded.

3. Duration of participant's involvement:

Participation in the study will necessitate completion of a short questionnaire and a short interview. The duration of time is expected to be no longer than one half to one hour.

4. Benefits of Participation:

Although you may not benefit directly from this study, all health-care consumers, especially women newly diagnosed with breast cancer may benefit from an increased knowledge.

Liability: Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate. In no way does this waive your legal rights nor release investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I, ______________________, the undersigned, agree to participate in the research study described. Any questions have been answered and I fully understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been offered to me.

Signature of Participant:______________________________
Date:____________________

Signature of Witness:__________________________
Date:____________________

If you choose to participate in this study you need only to contact my office and state your willingness to enter the study. You will then be contacted by Mrs. Dicks, the Principal Investigator and an interview will be set at your convenience to discuss the study further. You may at any time choose to discontinue your participation.

If you choose not to participate in this study you need do nothing further. You will only be contacted by Mrs. Dicks if you notify my office of your desire to do so.

Thank you for your consideration.

Yours sincerely.

APPENDIX D: CLASSIFICATION CODES

✓"Neoplasm" is the term used to describe any abnormal growth of new tissue, benign or malignant. Neoplastic changes may occur in any body tissue at any age. Cells in the affected area multiply at a very rapid rate, disrespecting normal growth patterns and limits. There are two categories of neoplasms:

1. Malignant Neoplasms are tumours that behave in a life-threatening manner. What makes a tumour "malignant" is the ability to invade surrounding tissue and to metastasize. Malignant neoplasms include the following characteristics:

    - Tumour cells multiply rapidly.
    - The tumour usually has an irregular shape.
    - Tumour cells erode and infiltrate tissues surrounding the original focus.
    - Tumour cells may metastasize to distant sites via venous, arterial, and lymphatic channels.
    - Malignant tumours may be graded according to differentiation between tumour cells and normal tissue cells. Tumour cells be poorly differentiated or undifferentiated meaning that they resemble primitive or embryonic cells that do not have the capacity for mature cellular functions. On the other hand, they may be well differentiated, indicating that the tumour cells closely resemble normal cells from the tissue or organ in which the tumour arises.

2. Benign Neoplasms are generally not considered life-threatening. However, some benign tumours (such as brain tumours) impede or obstruct normal function and can cause death. Benign neoplasms exhibit the following characteristics:

    - There is limited potential for growth.
    - Tumours are usually encapsulated which prevents tumour cell invasion into surrounding tissue.
    - Tumour cells are usually well differentiated. That is, they are highly organized and specialized.
    - Tumours do not metastasize to distant sites

173 Other malignant neoplasm of skin (continued)

173.4 Scalp and skin of neck

173.5 Skin of trunk, except scrotum

Axillary fold
Skin of:
- Abdominal wall
- Anus
- Back
- Breast

Umbilicus
Perianal skin
- Buttock
- Chest wall
- Groin
- Perineum

Excludes: Anal canal (154.2)
Anus, NOS (154.3)
Skin of scrotum (187.7)

173.6 Skin of upper limb, including shoulder

Arm
Finger
Forearm
Hand

173.7 Skin of lower limb, including hip

Foot
Leg
Popliteal space
Thigh
Toe

173.8 Other specified sites of skin

ICD-9-CM — Malignant neoplasm of contiguous or overlapping sites of the skin whose point of origin cannot be determined
ICD-9 — See Note 4, page 101

173.9 Skin, site unspecified

Procedures commonly carried out for 172, 173 - ***Malignant neoplasm or melanoma of skin***

ICD-9	ICD-9-CM	Code Title and Notes
98.12	**86.3**	**Local excision or destruction of lesion or tissue of skin and subcutaneous tissue** See Excludes note
98.13	**86.4**	**Radical excision of skin lesion** Code also lymph node dissection (ICD-9 52.2-52.49) (ICD-9-CM 40.3-40.5).

174 Malignant neoplasm of female breast

Includes: Breast (female)
- Connective tissue
- Soft parts

Paget's disease of:
- Breast
- Nipple

Excludes: Skin of breast (172.5, 173.5)

174.0 Nipple and areola

174.1 Central portion

174.2 Upper-inner quadrant

174.3 Lower-inner quadrant

174.4 Upper-outer quadrant

174.5 Lower-outer quadrant

174.6 Axillary tail

174.8 Other specified sites of female breast

Ectopic sites
Inner breast
Lower breast
Midline of breast
Outer breast
Upper breast

ICD-9-CM	Malignant neoplasm of contiguous or overlapping sites of the skin whose point of origin cannot be determined
ICD-9	See Note 4, page 101

174.9 Breast (female), unspecified

Breast Cancer Surgical Procedures

As noted in the reference text Cancer of the Breast by W.L. Donegan and J.S. Spratt (W. B. Saunders Company, 1988),

> "Tumourectomy, segmental mastectomy, lumpectomy and tylectomy are all synonyms for a therapeutic procedure in which a primary tumour is removed from the breast with a margin of tissue, preferably with a margin histologically free of cancer, and with concern for producing an acceptable cosmetic result".

In general, these procedures involve removing just the tumour and some of the surrounding tissue should be coded to:

97.11 Local excision of lesion of breast in CCP
85.21 Local excision of lesion of breast in ICD-9-CM

In order to code lumpectomy and axillary node dissection, you would use codes:

CCP:

97.11 Local excision of lesion of the breast
52.2 Regional lymph node excision

ICD-9-CM:

85.21 Local excision of lesion of the breast
40.3 Regional lymph node excision

as a General Rule

The key to differentiating modified radical or radical mastectomy from lumpectomy with an axillary node dissection is that, the incision for the lumpectomy or tumourectomy is kept separate from the incision made for the axillary node dissection.

☐ **175 Malignant neoplasm of male breast [rest of 175 not in ICD-9]**

☐ **175.0 Nipple and areola**

☐ **175.9 Other and unspecified sites of male breast**

Procedures commonly carried out for 174 - *Malignant neoplasm of female breast*

ICD-9	ICD-9-CM	Code Title and Notes
52.13	40.23	Excision of axillary lymph node
52.2	40.3	Regional lymph node excision
97.11	85.21	Local excision of lesion of breast : lumpectomy
97.12	85.41	Unilateral simple mastectomy
97.14	85.43	Unilateral extended simple mastectomy
97.16	85.45	Unilateral radical mastectomy
97.27	85.22	Resection of quadrant of breast
97.28	85.23	Subtotal mastectomy
97.82	85.12	Open biopsy of breast
		Excludes note in ICD-9.

APPENDIX E: CANADIAN MEDICAL ASSOCIATION CLINICAL PRACTICE GUIDELINES AND SUPPLEMENT

CANADIAN MEDICAL ASSOCIATION JOURNAL • JOURNAL DE L'ASSOCIATION MÉDICALE CANADIENNE

CMAJ·JAMC

Clinical Practice Guidelines for the Care and Treatment of Breast Cancer

A Canadian consensus document

Supplement to CAN MED ASSOC J 1998;158(3 Suppl)

Health Canada Santé Canada

ASSOCIATION MÉDICALE CANADIENNE
CANADIAN MEDICAL ASSOCIATION

Canadian Breast Cancer Initiative

Questions and answers on breast cancer

A guide for women and their physicians

Based on The Canadian Clinical Practice Guidelines
for the Care and Treatment of Breast Cancer

Supplement to CAN MED ASSOC J 1998;158(3 suppl)

APPENDIX F: COVER LETTER TO PARTICIPANTS

Cover letter to surgeons.

Breast Cancer Surgery Study

I am a graduate student in the Faculty of Science: Community Medicine at Memorial University of Newfoundland, completing a thesis under the supervision of Dr. Michael Murray. I am obtaining a survey of physicians who have, as part of their practice, women requiring surgery for breast cancer. The intent of the questionnaire is to investigate your perceptions of this event in women's lives. I am requesting your permission to take part in this study by completing a short questionnaire and in assisting with the **initial** contact of patients to ascertain their interest in participating.

I am interested in determining from the physician's perspective topics such as roles women play when faced when required to make decisions regarding their treatment options, the amount of information imparted to women and what you feel these patients wish to know at this time. This survey will include a questionnaire that will include simple yes or no answers and several Likert Scale questions. You will also be given an opportunity to provide input in the form of comments on the questionnaire.

All information gathered in this study is strictly confidential and completely anonymous. You do not at any point need to disclose your name, all data will be coded by use of a computer number only. The questionnaire will be accompanied by a self-addressed envelope with no identifiable data.

Once initial contact with potential participants has been made, the Principal Investigator will by telephone make contact to set up a scheduled interview to explain all pertinent information regarding the study.

The results of my research will be made available to you on request. If you have any questions or concerns please do not hesitate to contact me at 778-3514.

I sincerely thank you for your participation in this study!

Yours sincerely,

Elizabeth L. Dicks
Graduate student, Memorial University.

BREAST CANCER SURGERY STUDY

Dear Madam:

Mrs. Elizabeth Dicks is a student currently registered in the Graduate Program: Community Health of the Faculty of Medicine at Memorial University of Newfoundland. As a partial requirement for the degree of Masters of Science she is required to conduct a research study. This study is under the direction and guidance of Dr. Michael Murray. This letter is to explain the purpose of her study, and to seek your cooperation and participation.

The purpose of this study is to describe the statistics in St. John's for both types of surgical interventions for breast cancer, to interview surgeons regarding their views of the different forms of treatment for breast cancer and thirdly, to study patient's perceptions of their breast cancer surgical experience. Participants in the third portion of the study will be asked to complete a short questionnaire and become involved in a focus group which will be tape recorded and analyzed by the researcher. (However, if an individual would prefer not to become a member of a focus group she will be given the opportunity for a personal interview). The focus groups will be designed to cover issues that the participants feel to be important in treatment decision-making processes. The themes for the focus groups will explore the patients prior experience of cancer and surgery, their perceptions of their initial consultation, perceptions of their surgeon and the role of others in their experience. The expected time frame of a focus group will be approximately one hour in length.

During collection and analysis of the data, and following its completion, all materials used for the study will be kept secure by the researcher. Complete anonymity is assured, and participants themselves will be invited to review the final report prior to submission to the review committee. There will be no names or distinguishing data in the report.

If you choose to participate in this study you need only to contact my office and state your willingness to enter the study. You will then be contacted by Mrs. Dicks, the Principal Investigator and an interview will be set at your convenience to discuss the study further. You may at any time choose to discontinue your participation.

If you choose not to participate in this study you need do nothing further. You will only be contacted by Mrs. Dicks if you notify my office of your desire to do so.

Thank you for your consideration.

Yours sincerely,

APPENDIX G: QUESTIONNAIRES

Record number___. ____.

Breast Cancer Surgery Study
Surgeon's Questionnaire

A great deal of literature has been written describing the surgical options available for those women diagnosed with Stage I or Stage II breast cancer. These two surgical options include Modified Radical Mastectomy (MRM) or Breast Conserving Surgery (Lumpectomy) with radiation therapy. This questionnaire is designed to collect some basic information on your surgical practices.

A. Estimation of Surgical Rates

1. Estimate the number of surgeries you have performed for Modified Radical Mastectomy (MRM) and the number of Breast Conserving Surgeries (BCS) in the last year.

#MRM_______ #BCS__________.

B. Patient Contact Information.

2. In which type of setting do you generally see your patients?

Office____ Hospital Clinic_____ Both_____ Other_____.

3. When giving patients their breast cancer diagnosis, in general how long is the visit?______mins.

4. Is there another health care provider present with you when you give the diagnosis of breast cancer to your patients?

Yes____ No____ Sometimes______.

5. Do you offer to reschedule another appointment with the patient so other family members may attend?

Yes____ No____ Sometimes______.

6. Do you offer your patients the option of a second opinion?

Yes____No____Sometimes______.

7. What percentage of patients would you estimate request a second opinion?________%.

8. Do you offer women with Stage I of II breast cancer surgical options of Modified Radical Mastectomy or Lumpectomy with radiation therapy?

Yes____ No____Sometimes_____.

Give reasons____

____

____

____

9. Do you offer to reschedule another visit to discuss the options before the patients makes a decision regarding their surgery?

Yes____ No_____Sometimes______.

10. How much time would you estimate elapses between the patient getting the diagnosis and actually having the surgery? __________days ________weeks.

11. Do you provide written material to your patients illustrating different surgical options?

Yes_____ No_____ Sometimes_____.

Reference number________

Breast Cancer Surgery Study
Patient Questionnaire

This questionnaire is designed to collect some basic background information on your experience of surgery for your breast cancer.

A. Demographics

Age: <35_____ 36-50_____ 51-65_______ >66__ ____.

B. Patient Contact Information

1. Where did you meet the breast cancer surgeon?

Office_____ Hospital Clinic_____ Both_____ Other_____.

2. When you received your breast cancer diagnosis, how long was the visit?________mins.

3. Was there another health care provider present with you when you received the diagnosis of breast cancer?

Yes____ No_____

4. Did the surgeon offer to reschedule another appointment so other family members could attend?

Yes_____ No_____

5. Did the surgeon offer you the option of a second opinion?

Yes_____ No_____

6. Did your surgeon recommend a particular treatment option for you?

Yes_____ No_____

7. How much time elapsed between you getting the diagnosis and actually having the surgery?

Days_____ Weeks_____.

8. Were you provided with any written information illustrating the different surgical options?

Yes____ No_____.

Thank you for your participation in this study!

APPENDIX H: FOCUS GROUP/INTERVIEW THEMES

Breast Cancer Surgery Study

Focus Group Themes

1. Initial diagnosis consultation.
2. Information presented: What they wanted and were afraid to ask.
3. Concerns.
4. Role of others (e.g. family members, other health care providers, etc.).
5. Surgeon.
6. Prior experience with health care.
7. Prior surgical experience.
8. Prior experience of breast cancer.
9. Advice for others.

APPENDIX I: SURGEON INTERVIEW QUESTIONS

Surgeons Interview Questions

1. What factors would lead you to recommend Modified Radical Mastectomy?
2. What factors would lead you to recommend Breast Conserving Surgery?
3. Do you think women should be involved in decision making regarding their surgical treatments? If so how?
4. Do you think women want to be involved in decision making regarding their surgical treatments? If so, to what extent?
5. How would you respond if asked: "If I were your wife/daughter etc which procedure would you recommend I undergo for breast cancer?
6. Which of the two procedures for breast cancer surgery (MRM, BCS) do you feel women, when given the option choose most often?
7. Which factors do you feel influence their decision?