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## Factors which influence women's decisions for choice of primary surgery for Stage I and Stage II breast cancer

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**FACTORS WHICH INFLUENCE WOMEN'S DECISIONS FOR CHOICE OF  
PRIMARY SURGERY FOR STAGE I AND STAGE II BREAST CANCER**

**by**

**Barbara Mastaglia RN, RM**

**A Thesis Submitted in Partial Fulfillment of the  
Requirement for the Award of**

**Bachelor of Nursing (Honours)  
at the Faculty of Health and Human Sciences  
School of Nursing, Edith Cowan University**

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## ABSTRACT

A descriptive correlational study was conducted to describe the factors that Western Australian women with either Stage I or Stage II Breast Cancer, perceived to be important considerations when deciding upon either Modified Radical Mastectomy (MRM) or Breast Conserving Treatment (BCT) for surgical treatment.

The Conflict Theory of Decision Making (Janis & Mann, 1977) was used as the theoretical framework to guide this study. Ward, Heidrich and Wolberg's (1989) Factor List, the Multidimensional Health Locus of Control (MHLC) Scale (Wallston, Wallston & DeVellis, 1978) and a demographic questionnaire were used to measure variables.

Questionnaires were mailed to a consecutive sample of 370 women diagnosed with breast cancer during a six-month period and selected from the Cancer Registry at the Health Department of Western Australia.

Results revealed that women who had undergone BCT rated the surgeon's preference as a more important factor and influence on decision-making than the MRM group,  $t(101.10) = -2.30, p = .02$ . These women also rated the factor concerning no difference in long term survival between the two surgeries as a more important influence than the MRM group,  $t(106) = -3.33, p = .00$ .

Area of residence was also significantly associated with surgical choice. Women in rural areas tended to choose MRM rather than BCT,  $\chi^2(1, N = 160) = 12.75, p = .00$ .

Important sources of information that women used to assist them in decision-making were the surgeon, their family and General Practitioner (GP). There was a significant association between women's involvement in decision-making and use of GP as an information source,  $\chi^2(3, N = 164) = 9.94, p = .02$ .

The majority of women (54.30%) wanted the decision for surgery to be fully their own with women in the BCT group preferring a more active role in decision-making compared to the MRM group,  $u = 2368.00$ ,  $p = .01$ .

Most women had participated in making their decisions as much as they desired, had enough time in which to make their decisions and had received enough information. A moderate correlation between adequacy of information and enough time for decision making was found,  $r(158) = .58$ ,  $p = .00$ . Correlations were also found between the subscales of MHLC and age, information adequacy, enough time for decision-making, and level of emotional distress.

These results will assist health professionals to focus on ways of providing valid information and support to women and their families at the time of decision-making. In particular, findings will assist nurses to better understand the process of decision-making for breast cancer surgery and the main issues of importance to women. Furthermore, nurses will be better able to assist women with their treatment decisions according to their preferred level of involvement.

## DECLARATION

"I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text".

Signature.

Date.....25/3/98<sup>U</sup>.....

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## CHAPTER 1

### Introduction

This chapter will present background information pertinent to this study followed by documentation to support the significance of the research. The overall purpose of the study and major research questions will also be presented. A definition of all terms used in this study is found in Appendix A.

### Background to the Study

Breast cancer is a major health concern for women. This disease is reported as the most frequent cancer in women throughout the world apart from non-melanocytic skin cancer and is a leading cause of their death (Kricker & Jelfs, 1996). Despite modern advances in medical science, the cause of breast cancer remains elusive and unknown. Many women are confronted annually with a diagnosis of breast cancer and as well as coming to terms with a life threatening disease, they are required to make decisions about treatment in an extremely short period of time.

### Incidence and Screening of Breast Cancer

In Western Australia (WA) approximately one in eleven women are at risk of developing breast cancer (Cancer Registry, 1997). This rate is expected to increase with the aging population with women over fifty years of age forming the largest risk group. Statistics from the Cancer Registry at the Health Department of Western Australia (HDWA) also indicate that breast cancer was the leading type of cancer diagnosis for women in WA in 1995 with 939 new cases notified (Cancer Registry, 1997). Moreover, many women are likely to be diagnosed with breast cancer at a much earlier stage of the disease due to the current National Mammography Screening Program for the Early Detection of Breast Cancer which commenced in 1989 in WA and became formally

implemented in 1992 (Lefler, 1995). This program provides free mammography screening and targets women between 50 and 69 years of age. Because of this screening program, earlier diagnosis of breast cancer occurs and smaller breast tumours are also found.

### Surgical Treatment

Whilst there is no known cure for breast cancer, primary treatment involves surgical intervention. Randomised clinical trials (Fisher et al., 1985, 1989, 1993; Jacobson et al., 1995) have shown no significant differences in survival rates between women who have been diagnosed with early stage breast cancer and who have had either a Modified Radical Mastectomy (MRM) or Breast Conserving Treatment (BCT) (commonly referred to as Lumpectomy), with wide axillary node excision followed by a course of adjuvant radiotherapy for treatment. The National Health and Medical Research Council (NHMRC) in Australia endorses the fact of no difference between the two surgeries on long term survival (NHMRC, 1995). Consequently, it is now generally accepted that women diagnosed with either Stage I or Stage II Breast Cancer (see Appendix A for definitions) are able to choose between two surgical options for primary surgery. In some cases however, contraindications to radiation may preclude a surgical option for some women and therefore they may be restricted to only Mastectomy as a choice for surgery. Absolute contraindications to receiving radiation therapy include a pregnant women in her first or second trimester of pregnancy, presence of multicentric disease, previous radiotherapy treatment to the chest wall or the breast and a history of collagen vascular disease (Knobf, 1994b). Kinne (1990) also includes relative contraindications such as, the size of the tumour and its location in comparison to the remainder of the breast, those women who present with two or more palpable carcinomas and cases where diffuse microcalcifications are present on mammogram.

### Surgical Choice

Treatment selection is a very difficult and stressful process for women, and internal and external factors influence the individual's initial decision-making for either a MRM or BCT (Valanis & Rumpler, 1985; Ward, Heidrich & Wolberg, 1989). Individual choice of surgery ultimately determines subsequent treatment regimens and can affect psychosocial adjustment to the disease (Fallowfield, Hall, Maguire & Baum, 1990). Whilst a choice of treatment for early stage breast cancer implies selection of one or another pathway for surgery, it is often forgotten that a choice for an individual may also include the option of not having surgical treatment.

A woman's area of residence also has some influence on her choice of surgery. Available data from HDWA indicates that out of a total of 563 metropolitan breast cancer cases in WA in 1992, 361 (64.12%) women underwent Mastectomy (Simple and Radical) and 202 (35.87%) elected BCT (Dobson & Penman, 1994, p. 18). Of 180 breast cancer cases reported in rural Western Australian women in 1992, 142 (78.88%) selected Mastectomy and 38 (21.11%) chose BCT (Dobson & Penman, 1994, p. 18). As radiotherapy treatment is only available in Perth, the availability or convenience of these treatment centres for many woman may influence overall choice of treatment (Byrne et. al., 1993).

### Significance of the Study

Deciding between two choices of surgical treatment for breast cancer is a difficult and stressful time for women, due in part to fear of the diagnosis of "cancer", connotations of dying and consequently a sense of urgency for decision-making regarding treatment (Knobf, 1994a). Decisions for surgery which are made at or just after the diagnosis of breast cancer determine subsequent adjuvant treatments and have implications that can

affect psychosocial adjustment and long term quality of life (Fallowfield, Hall, Maguire & Baum, 1990; Fallowfield, Hall, Maguire, Baum & A'Hern, 1994; Maguire, 1989; Stefanek, 1992). Offering a choice of surgery for breast cancer treatment has some effect in reducing levels of anxiety and depression in women and their husbands (Morris & Royle, 1988).

Holland and Rowland (1987) suggest that because women have an increased input in the decision-making process for primary surgery, their fears and anxieties become increased regarding having made the "right decision". In particular, it has been found that women who chose Lumpectomy, were concerned with having made the correct decision (Cawley, Kostic & Cappello, 1990). This uncertainty regarding the correct choice for surgery can impact on long term adjustment to the disease not only for the women themselves, but also for their partners and families as well. Negative beliefs about cancer have continued to promote uncertainty in women four years after their initial surgical treatment for breast cancer (Hilton, 1988). According to Cawley, Kostic and Cappello (1990), the informational and psychosocial needs of women selecting Lumpectomy as an alternative treatment to Mastectomy deserved a closer attention and could be better addressed by health professionals. Furthermore, the researchers suggested that the health team could better assist women by providing increased preoperative information to assist and enhance women's decision-making, provide increased information to women to help them understand potential adverse effects of surgery (e.g. lymphoedema), and in general provide more sensitive support.

Provision of information and support from health professionals such as nurses, has been found to be less than optimal by women undergoing Mastectomy and other surgery for breast cancer (Northouse, 1989; Suomenen, Leino-Kelpi & Laippala, 1995). Maguire (1989) suggests that inadequate information and support to women at the time of surgery



for Mastectomy is a causative factor in psychological and psychiatric morbidity. Consequently a need exists for nurses to better understand the factors women consider when they make their decisions for surgery. For nurses to gain a better understanding of the issues and factors surrounding decision-making and which factors ultimately influence choice for primary surgery by women with breast cancer, empirically based information about these topics is needed. Nurses can then use this knowledge to support and assist women in their process of decision-making. Such support will help women to clarify issues of concern, identify and mobilise coping strategies and start the process of adaptation to living with breast cancer (Kalinowski, 1991). Data about the extent to which women wish to participate in the decision-making process and the sources of information they use to facilitate their decisions will also help nurses implement individual nursing care plans during various stages of the disease trajectory.

#### Purpose of the Study

Before women can make a choice about surgical treatment, they require sufficient and valid information upon which to base their decision. Such information plays an important part in treatment selection (Hughes, 1993b; Pierce, 1993) and regardless of adjuvant protocols, is needed to assist women cope with their disease (Graydon et al., 1997). Information needs of women following surgery for breast cancer, are a reflection of priority needs present at the time of decision-making for surgery (Luker et al., 1995).

Internal and external factors that influence decision-making for surgical treatment by women with breast cancer have been identified in North America (Valanis & Runpler, 1985). Factors that influence decision-making for either a MRM or BCT have also been reported (Ward, Heidrich & Wolberg, 1989). A study of published research identified through the literature, did not reveal any studies relating to the factors that influence

decision-making by Australian or West Australian women for surgical treatment of early stage breast cancer.

The purpose of this study was to identify and describe the factors which women with Stage I and Stage II Breast Cancer in WA perceive to be important considerations when choosing between either a MRM or BCT. When looking at the factors which women consider and those which ultimately influence their decision-making process, the extent to which they desire to make their own choice or retain control of the decision-making process and the environment surrounding them as individuals needs to be considered (Ward, Heidrich & Wolberg, 1989). Environmental factors or independent variables that may impact on the decision-making process include: sources of information used in decision-making, the amount of time given to make a decision, the influence of other people on decision-making, demographic factors such as age, level of education and area of residence and health locus of control beliefs.

### Research Questions

The main research questions of interest in this study were:

1. What factors influence decision-making by women when choosing between either MRM or BCT for treatment of Stage I and Stage II Breast Cancer?
2. What sources of information do women consult to assist them in making their choices for primary surgery?
3. To what extent do women wish to participate in or retain control of the decision-making process for their breast cancer surgery?
4. (A) Is there a relationship between the extent of desired participation for decision-making and sources of information used?

(B) Is there a relationship between the extent of desired participation for decision-making and choice of MRM or BCT?

5. What is the relationship between the multidimensional health locus of control beliefs of women and the following variables: preference for involvement in decision-making, enough time for decision-making, adequacy of information for decision-making, level of emotional distress at the time of decision-making and age of the woman?

#### Summary

Relevant background information to this study has been presented in this chapter with a focus on the incidence and screening of breast cancer and the surgical treatment of this disease. The significance and main purpose of this study has also been explained along with the major research questions of interest in this study.

## CHAPTER 2

### Literature Review

Many aspects of breast cancer treatment for women have been the focus of study and research in nursing and other health related disciplines. This review will cover factors that influence women's decisions for surgical treatment options for early stage breast cancer and individual control over decision-making for breast cancer surgery or illness treatment. Although past studies can be grouped under these headings, issues are identified through each individual study that could easily apply to either grouping and vice versa. Health Locus of Control as an independent factor in decision-making and methodological issues will also be discussed. Specific literature relating to theoretical issues will be presented in Chapter Three.

#### Factors Influencing Decision-Making

Previous researchers have reported a number of variables that influence women's decisions when they select between either a MRM or BCT for breast cancer surgery. These studies have been conducted with convenience samples from breast clinics or through retrospective reviews of medical histories and report that internal and external factors have been influential determinants for women during the decision-making process.

In a small descriptive study of 22 American women with either Stage I or Stage II Breast Cancer and who had a mean age of 55 years, Ward, Heidrich and Wolberg (1989), identified factors which women considered and perceived to be important when choosing primary surgery for their breast cancer. Women in the sample were one to two weeks post surgery and had been selected from a Breast Problem Clinic. Whilst eleven women had

chosen BCT and 11 women had chosen MRM, three of those women who selected BCT were required to undergo Mastectomy due to intraoperative findings.

To determine their knowledge about breast cancer and its treatment, the women were interviewed and given a Breast Cancer Information Test. A Factor List was also used to determine women's reasons for their choice of a particular surgery.

Results revealed that those women who chose BCT were significantly younger (mean of 50.40 years) than those who chose MRM (mean of 59.50 years). Concerns regarding radiotherapy that included side effects, inconvenience, efficacy and fear of cancer recurrence, were major influences for women deciding on MRM. Similar importance ratings of losing a breast or concerns with body integrity and fear of radiotherapy were deciding factors for those who chose Lumpectomy. The three important factors which influenced decision-making for the group as a whole were fear of cancer recurrence, a desire to avoid a second surgery in the future and the preference of the surgeon. Important sources of information and external influences on decision-making by women in this study came from their surgeon, family, friends and information from the clinic.

Eleven women in this study wanted the decision for surgery to be fully their own whilst the remainder wished to share their decision with either the surgeon, their spouse or a family member. The researchers reported a trend whereby women who chose MRM wanted the decision to be fully their own compared with those who chose BCT who wanted to share the decision.

Hughes (1993b) explored the relationship between treatment decisions of a convenience sample of 71 women (mean age of 48.71 years) diagnosed with either Stage I or Stage II Breast Cancer and the type and amount of information presented at their initial

clinic visit. The women who were in the process of deciding on type of surgery for their breast cancer were selected from a Chicago Breast Clinic. Lumpectomy was the surgical choice for 46 women in this study and 25 women chose Mastectomy.

The amount of information presented and the nature with which information was presented to each woman during her initial clinic visit was determined by using a 26-item observer checklist. Information recall was assessed two months after surgery by a telephone interview.

Results suggested that treatment choice was related to income and age of participants. Women with lower incomes chose Mastectomy. Moreover, those who chose Lumpectomy were in a slightly older age group (51.23 years) whilst the Mastectomy group had a mean of 47.39 years. Other results revealed that surgical treatment choice was unrelated to the amount of information that women had received at the time of the clinic visit. Women who had undergone Mastectomy received significantly more information prior to their clinic visit in comparison to those who chose Lumpectomy. The Mastectomy group reported an average of four sources of information whereas the Lumpectomy group reported fewer than three. Choice of surgery was also unrelated to the manner with which information was presented. Recall of information presented was found to be poor for both groups of women. Those who chose BCT recalled from zero to four items and for those who chose Mastectomy, 66% could not recall a single item.

Demographic variables that influenced treatment choice by women with Stage I Breast Cancer were identified by Graling and Grant (1995). The retrospective review of 58 charts of women registered with a tumour registrar in a Northern Virginia hospital found that the majority of women (38 or 65.60%) had undergone BCT and the remainder MRM.

The mean age of the sample was 56.50 years, 63.80% were married, 56 women had health insurance and 43 women had attained a high school level of education.

Further results revealed that level of education was a significant factor in patients' choice of treatment. Women with higher levels of education chose BCT, indicating perhaps that these women may have consulted or requested more information about their choice of surgery. Women who were older than forty years of age also chose BCT as primary surgery twice as often than those who were younger than forty. This was similar to the findings of Hughes (1993b), although the researchers in this study suggested that their findings may have reflected a surgical trend in the geographic area at the time.

Another retrospective review of medical records of 251 consecutive cases of breast cancer surgery performed during a two-year period at a North Carolina hospital was carried out by Kotwall et al. (1996). Hospital charts were firstly reviewed for eligibility for choice of surgery and 77 cases were found to be ineligible for Breast Conserving Surgery (BCS) due to clinicopathological reasons. The remaining 174 cases were considered eligible for BCS and were subsequently examined for demographic factors such as age, marital status, ethnicity, medical insurance coverage and proximity to the medical centre.

Clinicopathologic factors such as family history of breast cancer, tumour size and noninvasive histology were also determined.

Seven focus group interviews (six groups were women who had Mastectomies and one group comprised women who had BCS) consisting of six or seven women in each group were then carried out among 44 of the women. The purpose of the interviews was to determine the factors that women perceived to be important in the decision-making process. This occurred approximately one to two years following surgery and from the information obtained from the focus groups, an instrument was developed and subsequently

used to conduct telephone interviews with 118 women in the original sample. The individual interviews were then conducted two to three years following the woman's surgery and in view of this time lapse, recall of past decisions by the women could have been biased.

Findings revealed that 31 women had BCS and the remainder had MRM (also included total Mastectomy). There was no significant difference between the two groups according to demographic variables. Using a multivariate logistic model, the only variable found to be a significant predictor of surgical procedure was tumour size.

Data from the focus group revealed that the physician's advice and survival concerns or fear of additional cancer were two major areas that influenced decision-making for a particular surgery. Women who had undergone a Mastectomy did so on advice from their surgeon "and often were not presented with options" (Kotwall et al., 1996, p. 171). Women in the BCS group also followed the surgeon's recommendation but options were presented and they were given a choice about surgery. For this reason, women were more inclined to request a second opinion or seek advice from family or friends. Other results indicated that Mastectomy was considered a definitive means of removing the cancer. Mastectomy meant that one was not always thinking about cancer and having this surgery removed the fear associated with radiotherapy. For the BCS group, having a conservative procedure meant that they could always have further surgery at a later date if necessary. The most important source of information for women in this study was their surgeon.

### Summary

These studies reveal that demographic factors such as the age of the woman, her level of education and income are factors that influence decision-making for either BCT or MRM. Specific individual concerns regarding body integrity, survival concerns, fear of



cancer recurrence, wanting to avoid further surgery, concerns regarding radiotherapy, surgeon's advice and tumour size influence personal choice of surgical procedure.

Information sources used by women to assist decision-making about surgery included their surgeon, family and friends; with those women selecting MRM using more information sources than those selecting BCT. Treatment choice was unrelated to the amount of information obtained from clinic sources or the manner in which it was presented.

### Control Over Decision-Making

The notion of control over decision-making in the health area has received increasing attention in the literature, partly in response to an age of consumerism and in part as a requirement for informed consent. Therefore, individuals are encouraged to be autonomous and participate in decisions that influence their survival and quality of life. As a result, decisional control over treatment choices by patients has been studied in various health care settings.

In a Canadian study of 60 patients with cancer (16 men and 44 women), 33 of whom were women with breast cancer, Degner and Russell (1988), found that a preference existed for the individual to be included in decision-making about treatment. Treatment as such was not defined and the types of surgical procedures that the patients had received were also not reported.

The sample consisted of 30 individuals younger than 39 years of age and 30 who were older than forty years of age. They were purposively selected from oncology clinics at various stages of their disease, to fit a theoretical sample of three groups of decision-makers; "keepers", "sharers" and "givers" of control. Patients completed two sets of vignettes to determine degree of control in treatment decision-making. One set of

alternatives focused on control between patient/physician whilst the other set concerned control between patient/family.

Findings revealed that in the scale concerning patient and physician control, 39 patients ( $n = 59$ ) “fell toward the keeper end of the dimension rather than the giver away end”. A pattern of joint control in decision-making between patient and physician was also preferred over keeping control or giving control away.

Larson, Svardsudd, Wedel and Saljo (1989) investigated the involvement of 666 Swedish patients of both sexes with a mean age of 56.60 years, in decision-making for general and orthopaedic surgery. The sample were selected from a large hospital pre operative list and individuals completed questionnaires after their decisions for surgery had been made and one week prior to their elective surgery.

Results revealed that 73% of participants ( $n = 459$ ) felt that they had been involved in the decision-making regarding surgery to the extent that they desired. The exact numbers of male and female participants were not recorded, but 77% of the men desired to be fully involved in their decision-making compared with 68% of the women. The group of patients with cancer; the types of which was not recorded, regarded their decisions for surgery as being harder in comparison to those patients without cancer. The reasons for this were not revealed in this study. In addition, women and immigrants reported being less satisfied with the decision-making process. The authors concluded that this may have reflected a tradition in surgery which was less sensitive to the information needs experienced by women. A lack of knowledge of the Swedish health care system was also proffered as a reason for the dissatisfaction of the immigrants.

It is evident that patients with or without cancer desire to be involved in decision-making for surgical treatment or other treatment decisions regarding their health. Other

researchers have studied control over decision-making by women for treatment at varying time intervals following surgery for breast cancer.

A Canadian study of 35 women diagnosed with either Stage I ( $n = 17$ ) or Stage II ( $n = 18$ ) Breast Cancer, examined the relationship between patients' preferences for decisional control and illness information using a card sort technique (Hack, Degner & Dyck, 1994). The patients were between two and six months post surgery and were selected consecutively from two cancer treatment centres.

Participants were receiving either chemotherapy ( $n = 17$ ) or radiotherapy ( $n = 16$ ) treatment and were aged between 32 and 83 years of age. The type of surgery that the women had undergone for their breast cancer was not reported.

In examining role preference ordering for decision-making between "passive" and "active", results indicated that 15 women wished to play an active role in treatment decisions whilst 20 women wished to play a passive role. Further examination of relationships between six combinations of active, collaborative and passive role preference orderings also indicated that 13 women preferred a collaborative/passive role for decision-making. This was the most common role preference ordering selected. Those women who desired an active role in choosing their treatment required more detailed information about their medical care. This was in contrast to those who preferred a more passive role where less information was requested.

Similar findings regarding preferences for participation in treatment decision-making were also reported from a British study of 150 women newly diagnosed with breast cancer and 200 women diagnosed with benign breast disease (Beaver, Luker, Owens, Leinster & Degner, 1996). Women with breast cancer were selected consecutively from a physician's practice at a large university teaching hospital and interviewed in the hospital

ward following their admission and prior to surgery. They were an average of 2.50 weeks from diagnosis and had a mean age of 54.80 years. Their stage of breast disease was not reported and 99 women (66%) were expected to undergo Lumpectomy while 50 women (34%) had planned to undergo Mastectomy.

The comparison group with benign breast diseases had a mean age of 39.20 years and had a higher education level than the women with breast cancer. These women were selected from a breast clinic in an out patient department and were interviewed in the clinic at the same hospital. All women in both groups appeared to have been treated by the same surgeon.

A number of variables were correlated with decision-making preferences for treatment. A weak positive correlation was found between decision-making and age (older women preferred a more passive role), a weak negative correlation was found between decision-making and level of education (women with lower levels of education preferred passives roles in decision-making) and a weak positive correlation was found between decision-making and social class (women who had a lower social class preferred a passive decision-making role) for the newly diagnosed group with breast cancer. Weak positive correlations were also reported for the benign group between decision-making and age and decision-making and social class.

A scaling model was used to analyse the decision-making preferences of the women that involved preferential choice data being converted to a rank ordering of preferences. The rank ordering of the decision-making roles therefore represented the degree of control that the individual wished to have over decision-making (Beaver, Luker, Owens, Leinster & Degner, 1996, p. 13). Results revealed that the majority of women with breast cancer wished to play a passive role and leave treatment decisions to their doctor. In contrast, the

women with benign breast disease wished to play a collaborative role or share the decision-making with their doctor. The authors proposed that lack of information may have contributed to the women with breast cancer feeling uncomfortable in active decision-making.

A study to determine the roles of breast cancer patients and their doctors in choosing their treatment plan, whether age was a predictor of patient preferences in decision-making and the fears of breast cancer patients and their coping styles was carried out by Johnson, et al. (1996).

The sample of 76 women with a mean age of 54.60 years was selected from a Cancer Centre and Research Institute in Florida. Forty-five women were interviewed at a postoperative follow-up visit which occurred within one month from surgery whilst the remaining 31 women were contacted via telephone interview and through mailing out questionnaires. Lumpectomy had been the choice of surgery for 36 women and 40 had chosen Mastectomy. Stage of breast disease was not reported.

Results revealed that 79.70% women wanted a role in decision-making and 73.60% wanted their physician to make a recommendation for treatment. Many women (76.30%) had specific fears about their breast cancer, but did not disclose these to either their doctor or other health professionals, such as nurses. Fears included anxiety about losing a breast, chemotherapy and fear of dying before their children had grown.

An assessment of the women's coping style by using the Miller Behavioral Style Scale, revealed that 15 were classified as "monitors" (information seekers who benefited psychologically from the information given) and 23 were classified as "blunters" (information avoiders who preferred not to know all about their diagnosis, care and

treatment). The remaining 38 women used a combination of both coping responses.

Coping style therefore did not affect decision-making.

Age however, was seen as a predictor of decision-making. Women younger than 52 were likely to want their doctor to make a treatment recommendation and all women under 40 ( $n = 14$ ) wanted a physician's recommendation. It was also reported that older women were less likely to have specific fears about coming to terms with breast cancer.

Researchers have also used samples with participants diagnosed at various stages of their breast disease in order to determine their decisional roles for treatment and their information needs.

Bilodeau and Degner (1996) investigated the information needs, sources of information and decisional roles of women with breast cancer. A cross-sectional survey was carried out with a convenience sample of 74 women who had a mean age of 57.50 years. These women were within six months of their diagnosis and had been selected from an oncology clinic in Canada. Twenty-three women had undergone Mastectomy and 46 women had elected BCT. All four stages of breast disease were represented in this sample; 60% had Stage I disease and 30% had Stage II disease.

Findings revealed that the majority of women (43%) preferred a passive role in treatment decision-making and 20% preferred an active role. Decision-making roles were not compared according to either stage of disease or type of surgery. Also, it was difficult to ascertain whether the decision role related to a particular area of treatment decision-making (such as chemotherapy and/or treatment for side effects) or whether the reference was to the idea of "treatment" in general. Similar to the findings of Johnson et al. (1996), age was also found to be a predictor of decision-making role, as women aged between 65

and 83 assumed a passive role in decision-making. However, in the study conducted by Johnson et al. (1996) women had a mean age of 54.60 years.

Desiring a passive role in decision-making may well be part of a generation belief in that what the doctor says or recommends is best. Alternatively, as all stages of breast disease were represented in this study, advanced disease, rather than age as such, may also have contributed to women wanting a passive role.

Information resources used by the women and ranked from most to least importance were cited as physicians, nurses, friends or relatives, brochures, medical journals (or textbooks), videotapes, television or radio programs, women's journals and newspapers. The physician was the most frequent actual source of information for the women, as was reported by Kotwall, et al. (1996). Information needs focused on stage of disease, likelihood of cure and available treatment options.

A recent Canadian study was carried out to determine the role women with breast cancer wished to play in medical decision-making, the extent to which they believed that they had achieved their preferred level of involvement and the types of information which were most important for them (Degner et al., 1997).

Over a two-year period, a consecutive sample of women was selected from two oncology clinics in Manitoba and a comparable group of women was selected from two hospital oncology clinics during a four-month period. A total of 1,012 women participated in the study and the mean age of the group was 58.25 years. The majority of women (42.80%) had less than high school education, were married (66.80%) and retired (35.10%).

Similar to the study of Bilodeau and Degner (1996), women at various stages of their breast disease were also represented in this study, with the majority of women

(53.60%) having Stage II breast disease at the time of diagnosis. Diagnosis of Stage I breast disease was reported for 33.20%. The majority of women (55.20%) were more than two years since diagnosis and type of surgery was noted for the entire group; Mastectomy had been the treatment for 60.80% and 37.00% of women had undergone Lumpectomy.

Interviews were conducted during which a card sort technique was used to determine decision role. This technique had been used in previous studies (Beaver, Luker, Owens, Leinster & Degner, 1996; Bilodeau & Degner, 1996; Degner & Russell, 1988; Hack, Degner & Dyck, 1994) and it was found that only 22% of the women preferred to select their own medical treatment. Forty-four per cent of the women wished to share their treatment selection with their physician and 34% of women wished the physician to make treatment decisions on their behalf.

Age, education level, having chemotherapy treatment and time since diagnosis were reported to be predictors of preference for treatment decision-making. Women younger than 50 years and those who had more than high school education were more likely to prefer an active or collaborative role in treatment decision-making. A trend was evident where women with an earlier stage of breast disease were also more likely to prefer an active role. Women who were interviewed closer to the time of diagnosis or who had chemotherapy were less likely to prefer active roles in decision-making.

Only 42% of women in the entire sample reported achieving their preferred role in decision-making. Of this group, women closer to the time of diagnosis reported achievement of a preferred role more so than others. At the other end of the scale, a small group of women (14%) who were further from diagnosis, believed that they had been pushed into taking more control of decisions than they would have wished. For those



women who wished to have an active role, only 18 (or 21%) out of a total of 86 believed that they had actually achieved this preference.

Priority information needs of the women newly diagnosed with breast cancer ( $n = 278$ ) in this study were not unlike those reported by Bilodeau and Degner (1996) and included concerns regarding cancer, treatment options and adverse effects. Other information needs concerned family risk of acquiring cancer and impact on family, self care at home and sexuality. Whilst information about sexuality and femininity were important for women younger than 50 years, overall the entire group judged information about sexuality to be least important. Women older than 70 years wanted information about how to look after themselves at home.

### Summary

The studies reviewed in this section relating to women with breast cancer, were concerned with control over decision-making for follow up treatment after breast cancer surgery and were not related to the actual time of decision-making for choosing initial surgery. Nevertheless, it is apparent that overall, individuals desire to participate in treatment decisions concerning their health and well being. Women who had surgery for breast cancer, or who were about to undergo surgery for breast cancer, or who were having adjuvant treatment for breast cancer, preferred either a passive or collaborative role in treatment decision-making. Women who wished to share decision-making for treatment preferred to do this with their surgeon.

The age and education levels of women have some influence over their preferred decision-making roles. Conflicting results regarding younger woman and their decision roles are apparent in comparison to older women who prefer a more passive role. Individual coping-style was not indicative of desiring more or less control over decision-

making. Those women with higher levels of education preferred an active role in decision-making. Desiring an active role in the decision-making process also meant that the individual required more information.

### Locus of Control

There is some evidence to suggest that the concept, “locus of control”, has an influence on the health beliefs and subsequent health outcomes of individuals. Therefore, locus of control indirectly has some influence on the decision-making of patients for their treatment for different health conditions.

The concept of locus of control describes the extent to which individuals perceive that life events which occur to them are as a result of their own behaviour (internal control) or as a result of outside events such as luck, fate or chance (external control) (Strickland, 1978). This internal-external locus of control concept stems from Social Learning Theory (Rotter, 1954) and it was from this theory that Levenson (1981) developed her work on generalised locus of control beliefs as had been the case with Rotter.

### Multidimensional Health Locus of Control

Based on the work of Levenson (1981) and an earlier unidimensional Health Locus of Control (HLC) Scale developed by Wallston, Wallston, Kaplan and Maides (1976), a Multidimensional Health Locus of Control (MHLC) Scale was developed (Wallston, Wallston & De Vellis, 1978). This instrument has two parallel forms and these are for use in situations where repeated measures are needed over a short period of time (Wallston & Wallston, 1981).

The multidimensional nature of “health locus of control” considers three dimensions of this concept and the MHLC Scale consists of three subscales. Internal Health Locus of Control (IHLC) categorizes whether individuals believe that their health

outcomes or health behaviours are directly within their own control. An external health locus of control orientation is used to describe those individuals who believe that what happens to their health is not under their control. Consequently health outcomes are believed or perceived to be due to chance, fate or luck and this is termed Chance Health Locus of Control (CHLC). Alternatively, health outcomes are viewed as being externally controlled by the actions of powerful others and this dimension is termed Powerful Others Health Locus of Control (PHLC) and can include persons such as doctors, nurses, family or friends.

The three dimensions of the MHLC scale are statistically independent (Wallston & Wallston, 1982, p. 69). Wallston and Wallston, (1981, p. 207) further state that the three subscales cannot be used to obtain a single overall score because significant but negative correlations exist between IHLC and CHLC. However, IHLC and CHLC can be combined to produce a combined scale; often termed, Internal-External or I-E. This is not unlike the original HLC Scale (Wallston, Wallston, Kaplan & Maides, 1976).

The next section of this review will focus on literature related to MHLC. Whilst many researchers have used the MHLC construct in their research, not all have documented which form they used in the particular study. Therefore, the reader has no way of knowing which form was used. Furthermore, literature relating to MHLC beliefs and decision-making by women for breast cancer surgery is sparse. In view of this fact, literature is reviewed regarding studies which have used the MHLC construct on patients prior to surgery, with patients following surgery, patients who have another type of cancer and a laboratory study regarding treatment decisions by women for breast cancer surgery.

Smith and Draper (1994) compared the beliefs of a group of 21 nurses and 32 patients (18 men and 14 women) regarding control of health and perceptions of the amount

of patient control that existed. The sample of patients who had a mean age of 39.70 years were selected from a mixed surgical ward in a large hospital in the north of England, following admission for elective surgery. Eighteen patients had oral or facial surgery, eight had spinal or neurosurgery and six had general surgery. A previous hospital admission was reported by 83.30% of the patients.

The majority of nurses who were female (90.50%) had a mean age of 36.50 years and had spent a mean of 12.62 years in nursing. All categories of nurses were represented in the sample with the majority being staff nurses.

Questionnaires were used to gather data and were completed by the patients between day one and day three following operation and included the Perceived Control Scale, The Krantz Health Opinion Survey and MHLC Scale, form B.

In relationship to the MHLC, there was a significant difference between nurses and patients on the PHLC subscale. Patients scored higher on this scale suggesting a greater belief in the control of others over their health. Negative correlations were also reported between the patient's level of education and their perceptions of control. More educated patients perceived their control to be less. Significant negative correlations were also found between PHLC and CHLC and education level. The authors concluded that patients who had fewer years of education had a less desire for control over their health but had a greater belief in external control of chance happenings or control of powerful others. There was no significant difference found between nurses' perceptions or patients' perceptions of patient control.

Meyer, Russo and Talbot (1995), conducted two studies. The first was a laboratory study to examine the decision-making and prose comprehension of women with an authentic case study on breast cancer. The variable "age" was investigated as a predictor of

five hypotheses which guided the laboratory study. The second survey study focused on treatment decisions made by women following diagnosis of breast cancer.

In the first study, 94 women were recruited from women's groups in rural central Pennsylvania and through other methods such as advertisements in newspapers, from a university campus and from a retirement centre. Ages ranged between 18 and 88 years and the women were grouped as young ( $n = 27$ ), middle-aged ( $n = 35$ ) and older women ( $n = 32$ ). The young group of women had a higher education level than the other two groups and six women had personal experiences with benign breast conditions or breast cancer.

The women completed the following instruments: the Quick Word test to determine reading comprehension, Reading Habits Questionnaire (to determine whether the individual debates information when they read it and whether they prefer a debate or a solo speaker when getting information about a topic), MHLC Scale form A, a demographic questionnaire and The Current Knowledge about Breast Cancer Questionnaire. A two-page transcript on information about breast cancer from a telephone health information service, together with the recommended solutions were also given to the women and they had to recall in writing the information and advice given. In addition, a free recall passage on breast cancer was given. Finally, an unfolding health scenario with three problem statements was also given to the women and they were required to select solutions and give reasons for each selection.

The first problem related to whether women would make a decision immediately or later between three options regarding a course of action to further investigate a breast lump not shown to be cancerous on x-ray. The second problem related to whether women would make an immediate or later decision and what extra information they might need regarding a scenario where an intra ductal breast cancer (not diagnosed by mammogram or

ultrasound) had not been completely removed. In this case the surgeon did not make a recommendation and he was also going away in two weeks time. The third health problem was the same as problem two, but six solutions were provided, as was advice from eight sources. One solution had to be chosen and a reason given for the choice.

For problem one, 79% participants selected Lumpectomy as the solution to the problem and there was no difference between the three age groups regarding this choice. Thirty-seven women stated that they would have made an immediate decision in situation two that involved carcinoma in situ and 55 would have delayed their decisions. There was no difference between the three age groups and their final decisions. Another Lumpectomy or reexcision was selected by 38% participants as the course of action to take.

Treatment decisions were found to be related to the type of information women had selected as important whilst reading (through underlining and recall) and the type of information recalled after reading about various treatment options. The influence of prior knowledge appeared to be an important influence or factor in decision-making. In scenario two, 60% women stated that they required further information before they could make a decision. Prior knowledge of radiation was the only prior knowledge variable related to later decision-making.

Whilst the researchers discussed the various scoring methods employed in this study for many of the measures, the scoring of the MHLC scale was not mentioned. It was therefore assumed from reported results of only IHLC and PHLC, that IHLC and CHLC scores had been combined to form a composite score and was thus reported as IHLC. As a result, an internal dimension or IHLC and an external dimension, PHLC were reported. IHLC was one of a number of variables not found to influence immediate versus delayed decision-making. Older women were found to make decisions about treatment for breast

cancer much more quickly in comparison to younger women and they valued powerful others (PHLC) more so than the other two groups. However, no significant difference in scores was found between those women making an immediate treatment decision and those delaying their decisions regarding PHLC. Younger women also showed a greater internal locus of control but this was not statistically significant,  $p < .06$ . The researchers concluded that health beliefs did not appear to be related to decision time.

Explanations for an immediate decision by older women focused on the need for a decision before the cancer had time to spread. In contrast, reasons for delaying a decision by the younger age group of women focused on the need to obtain a second opinion and learn more about disease and treatment options. Older women were also less likely to seek information when making decisions and did not recall as much information compared with younger women.

The second study was conducted to determine whether in reality, older women with breast cancer had taken less time to make a treatment decision in comparison to younger women. The sample consisted of 75 women selected from a Breast Clinic in central Pennsylvania who had a diagnosis of breast cancer within the previous ten years. At the time of the study most of the participants were 2.9 years from the time of decision-making. The majority ( $n = 46$ ) were middle-aged, 15 were young women and 14 were older women. Education level was slightly higher for the middle-aged group in comparison to the other two groups. Questionnaires were mailed to the women and covered a range of questions relating to the decision-making time but the MHLC scale did not appear to have been included.

Results revealed that the women who made a decision for surgery on the same day were older (mean age of 55.61 years) whilst the women who took longer (weeks) were ten

years younger (mean age of 46.11 years). Further results suggested that women who were older, women who worked in the medical profession with knowledge about breast cancer treatment and less educated women, made their decisions faster. Nevertheless, time spent in decision-making was not related to the type of treatment selected for breast cancer.

Those women who requested a second opinion were younger and had completed more education. Twenty-six women also stated that they had either not made a decision (the doctor or their husband made the decision) or that there really was not much of a decision; “they just got the cancer out”. Finally, older women and less educated women also felt that they had not made a decision for surgery, but they did not view the whole situation as one that needed much effort for decision-making.

A study of 38 men and 31 women who had a primary diagnosis of leukaemia was conducted, to examine the moderating effect of disease severity and the patient’s treatment history, upon the relationship between health locus of control and psychological distress (Andrykowski & Brady, 1994).

The participants had a mean age of 35.90 years and were recruited over a three and a half-year period during their hospitalisation for evaluation for a bone marrow transplant. It was assumed that the study was located in Kentucky (USA) as the researchers did not record from what area they had chosen their sample. The majority of participants were married and 32% had an education level greater than high school.

Of the sample, 29 patients had acute leukaemia, 36 had chronic leukaemia and four had a preleukaemic condition. Depending on how they had responded to normal treatment protocols for their cancer in the past, patients were categorised into two groups. The first group was comprised of 42 patients who had either chronic or acute leukaemia and were named, “Treatment Failure” group. The second group was called “No Treatment Failure”



group and consisted of 27 patients with either chronic leukaemia in their first stable phase, or those who had acute leukaemia and were in their first remission or those with a preleukaemic disease.

Patients completed five instruments. These included: Profile of Mood State (measures recent affective state), the "Distress" subscale of the Psychological Adjustment to Illness Scale (measure of recent psychological and social adjustment to illness), Sickness Impact Profile (a measure of illness related dysfunction), Perceived Health Questionnaire (used to measure current health status of respondent and health status prior to diagnosis of cancer) and MHLC Scale (specific form not reported).

The researchers calculated a composite score of psychological distress for each person and a score for disease severity that indicated their current health status. Correlations were then calculated with demographic variables and psychological distress but no associations were found. Women however, indicated a greater amount of distress in comparison to men.

A hierarchical multiple regression analysis was then calculated to determine whether the relationship between health locus of control and psychological distress was moderated by the variables of disease severity and the patient's treatment history. As was the case with Meyer, Russo and Talbot (1995), the researchers in this study appeared also to have calculated a composite score for IHLC by combining IHLC and CHLC, (although this was not documented) as only IHLC and PHLC results were reported. The interaction between gender and the Internal-External health locus of control by severity of illness was a significant predictor of the psychological distress scores. PHLC, severity of disease and treatment history interaction were also predictive of psychological distress scores. Those individuals in the "No Treatment Failure" group with a low PHLC score had rapidly

increasing psychological distress scores with increasing severity of illness scores. Those individuals in the “Treatment Failure” group with high PHLC were associated with least distress when severity of illness was low and the greatest distress when severity of illness was high. In contrast, low PHLC beliefs were associated with greater distress when severity of illness scores were low and least distress when these scores were high. The authors concluded that health locus of control beliefs and psychological adjustment to illness is moderated by contextual variables.

A final study reviewed was one conducted by Mitchell (1997), who compared the health locus of control beliefs of a sample of 155 women undergoing day surgery for minor gynaecological health problems, with their required level of preparatory information. The sample of women were randomly selected from allocations to five consultants from a hospital in Manchester (United Kingdom) and information regarding type of surgery undertaken was not reported. The majority of the women (74%) were aged between 18 and 35 years and 26% were aged between 36 and 65 years.

Participants were interviewed and completed two questionnaires once formal admission procedures had been completed. Questionnaires included MHLC Scale (specific form not reported) and a Patient Information Questionnaire (PIQ) designed to determine the amount of information patients wished to have prior to surgery.

Results revealed that no correlation was established between the three dimensions of the MHLC and the level of selected preparatory information. Five levels of health locus of control were identified with the eight typologies as described by Wallston and Wallston (1978). However, only 29.10% participants had a matched coping style with high or low PIQ scores which were comparable with Internal, External or Chance scores (MHLC). The author suggested that a number of methodological issues may have influenced these results.

One point raised was the validity of the patient information questionnaire (developed by the author of the study) and another was the fact that patients exhibited signs of anxiety whilst completing the questionnaires (prior to surgery) and therefore the validity of patient's responses was questioned. Besides these methodological issues, the author presented ways in which future pre-operative psycho-educational programs could be developed. Main recommendations included education programs for patients should take place from a few days up to one week prior to admission, family or friends to be involved in the decision-making process, patients should be given the choice about the level of information they want and following hospital discharge, a telephone hot line service should be available at the hospital for patients.

### Summary

This literature review focused on three main aspects that influence decision-making for surgical treatment by women with early stage breast cancer; factors that influence decision-making, control over decision-making and MHLC beliefs.

Women considered many factors as important when they make their decisions for surgery. These ranged from surgeon's recommendation or advice, survival concerns and fear of cancer, concerns regarding efficacy of the specific surgical treatment and/or radiotherapy and concerns regarding body integrity to the actual tumour size. Information sources, notably information obtained prior to clinic visits, prior knowledge of breast cancer and its treatment and information obtained from family, friends and their surgeons, had a great deal of influence on decision-making for the women.

On the whole, the literature supported preference for control over decision-making by women with breast cancer for treatment decisions following their surgery. Age and level of education were seen as predictors of the amount of control individuals preferred

over their decision-making but there were reported differences in the amount of control younger women wished to have, whilst older women wished to have less control. On the other hand, younger women took longer to make a decision. A preference for an active role in decision-making was associated with women's needs for more information.

From the literature reviewed, it would be difficult to ascertain whether health locus of control beliefs influence treatment decision-making for health problems by individuals with or without cancer. Nevertheless, there was an association between patients with low education levels in a hospital ward situation and higher scores for PHLC and CHLC beliefs. An association between older aged women making decisions for treatment of breast cancer in a laboratory situation and PHLC was also evident. Finally, MHLC and psychological adjustment to illness appears to be moderated by contextual variables such as disease severity and patients' treatment history.

Based on this literature review, the following sets of variables were considered appropriate for investigation and inclusion in this study: demographic variables such as age and level of education; external factors such as surgeon's preference, adequacy of information for decision-making and sufficient time for decision-making; internal factors such as fear of cancer recurrence, fear of radiotherapy and concerns regarding breast loss; preferred decision role and MHLC beliefs.

## CHAPTER 3

### Theoretical Framework

This chapter presents a discussion of the theoretical assumptions used to guide this study. Variables of interest in this study and their relationships are also identified within the framework.

#### Conflict Theory of Decision Making

The Conflict Theory of Decision Making (Janis & Mann, 1977) was used as the theoretical framework to guide this study. This theory was influenced in its development by the work of Kurt Lewin and Leon Festinger and describes how individuals, when confronted with a situation that entails serious consequences, make their decisions. In situations that involve serious outcomes, intense conflict often arises because of a need to make an immediate decision. The conflict becomes acute because there is an awareness of a risk of suffering losses regardless of the eventual course of action chosen. According to Janis and Mann (1977, p. 46), “simultaneous opposing tendencies within the individual to accept and reject a given course of action” leads to decisional conflict. Individuals are often in a quandary about which course to follow in order to achieve a reasonable outcome. This creates conflict and the individual experiences symptoms of stress. These symptoms include hesitation, vacillation, feelings of uncertainty and emotional stress. The magnitude of the individual’s perception of the losses that may eventuate from whatever choice is chosen, will determine the intensity of the symptoms of stress (Janis & Mann, 1977, p. 49).

The authors present five basic patterns of coping behaviour that affect quality decision-making by individuals and consequently their final decision and subsequent adjustment to the solution to the problem. Patterns of behaviour include unconflicted

inertia, unconflicted change to a new course of action, defensive avoidance, hypervigilance and vigilance (Janis & Mann, 1977, p. 52).

Unconflicted inertia refers to the cognitive process of a decision-maker being confronted with an impending warning in a situation and the necessity to make an immediate decision depending on the risks associated with each course of action. If the risks are perceived to be a small threat if they materialise, the person will continue as is, or avoid any further search, such as looking for information to help solve the problem. If the person believes that there is a threat of harm eventuating they will try and find a way of escaping from the problem or situation. This is called unconflicted change to a new course of action. This type of decision behaviour is characterised by individuals looking to their past experiences of decision-making with difficult problems or consulting the opinions of others and selecting the “salient” point.

Alternatively, if individuals perceive that serious risks are inherent and depending whether they have a high level of hope for a satisfactory outcome, they will continue searching and may adopt strategies that they perceive will protect them. Such a strategy is termed “defensive avoidance” decision behaviour. This involves either avoiding cues that would trigger the need to think about the problem (such as not reading any information), getting another person to make the decision (family member, friend or doctor) or using bolstering techniques. Bolstering techniques include ignoring known and available information on the problem and rationalising the aspects that are considered unsafe (Janis & Mann, 1977, p. 58). If individuals perceive that they still have enough time and adequate information, they can make a careful search and consider all alternatives; vigilant or effective decision-making then occurs. On the other hand, if there is a perceived lack of time for finding a solution to the problem by the individual, mounting feelings of

helplessness occur leading to hypervigilance; defective judgement and subsequently inadequate decision-making (Janis & Mann, 1977, p. 62).

### Supporting Literature

Using the descriptive Conflict Theory Model that has also been proposed as a model for aeronautical decision-making (O'Hare, 1992), Pierce (1993), identified five empirical indicators of decision behaviour by women making a decision for surgical treatment for their breast cancer. She conducted a qualitative study with 48 women (mean age 49.60 years) who had early stage breast cancer and who were interviewed after they had decided on a choice for surgery, but prior to the actual surgery.

Indicators of decision behaviour included perceived salience of alternatives, conflict, information seeking, risk awareness and deliberation. Perceived salience referred to the extent to which the individual was geared toward one option depending on the amount of information she had received. Conflict was reported and occurred when the women either had preferences for treatment but these were discouraged, they were unable to discriminate between the options given to them but had to make a decision, or when a particular alternative was strongly recommended but this was not the preference of the individual. The views of family members regarding treatment decisions also contributed to the conflict.

Information seeking occurred when women could not discern differences between the alternative treatment and they needed consistent information to help them make a decision. Defensive avoidance was used by a number of women who did not require much information and "risk awareness" was not defined as such by the women. Instead, safety and uncertainty were their concerns regarding each surgical option. A variation in the

amount of deliberation and consequently information seeking by the women was also reported.

### Application of Theoretical Framework to the Study

In view of Pierce's application of the Conflict Theory in a breast cancer population and the useful results reported, use of this theory was deemed appropriate to guide the present study. Furthermore, Ward, Heidrich and Wolberg (1989) reported variables that empirically guided their work within the conflict theory framework as proposed by Janis and Mann (1977).

### Contributing Factors that Impinge on Decision-Making

Although the Conflict Theory of Decision Making provided a useful theoretical framework to guide the study, additional empirical findings contributed knowledge about specific factors that might influence decision-making by women for their breast cancer surgery.

Variables that have some influence over decision-making and those that have been identified through the literature include internal and external factors and preferred decision-making role of the woman. Internal factors focus on personal fears such as fear of dying from cancer, fear of radiotherapy and concerns regarding body integrity. External factors include adequacy of information, sufficient time to make a decision, level of emotional distress at decision time, the influence of preferences of other individuals for a particular surgery, demographic factors such as age, level of education and area of residence and type of breast cancer with ensuing pathology status of the tumour.

Individual control over decision-making and preferred decision roles are further variables that impact on individual decision-making for health treatment in general and adjuvant treatment for breast cancer. Health locus of control and in particular, MHLC



beliefs were also hypothesised as other variables that could have an influence on individuals' decisions for a particular type of surgical treatment for breast cancer.

#### Decision-Making Process for Breast Cancer Surgery

A synthesis of Janis and Mann's theory augmented by the contributing factors relevant to decision-making by women for surgical treatment of early stage breast cancer was applied as the theoretical framework to guide the study. This application is presented in Figure 1.

When women are confronted with having to make a choice between two options for surgery for treatment of breast cancer, conflict can arise (Pierce, 1993). Intense conflict can be generated because of the notion of urgency for surgery for "cancer", that is often conveyed, together with unfamiliarity of medical terminology, issues of delayed versus immediate breast reconstruction and the various adjuvant treatment options (such as radiotherapy) that follow each surgical procedure. An awareness of suffering losses is depicted in the framework and focuses on connotations of dying from cancer (fear of cancer) and the impending breast loss. Ward, Heidrich and Wolberg, (1989) found that women selecting MRM were influenced in their decision-making by concerns of radiotherapy (which is required following Lumpectomy) and fear of cancer recurrence. Similar importance ratings of losing a breast and fear of radiotherapy were deciding factors for those women in their study who chose Lumpectomy. Therefore, the decision-making process involved decisional conflict for a number of women; avoiding one set of concerns meant facing the second set.

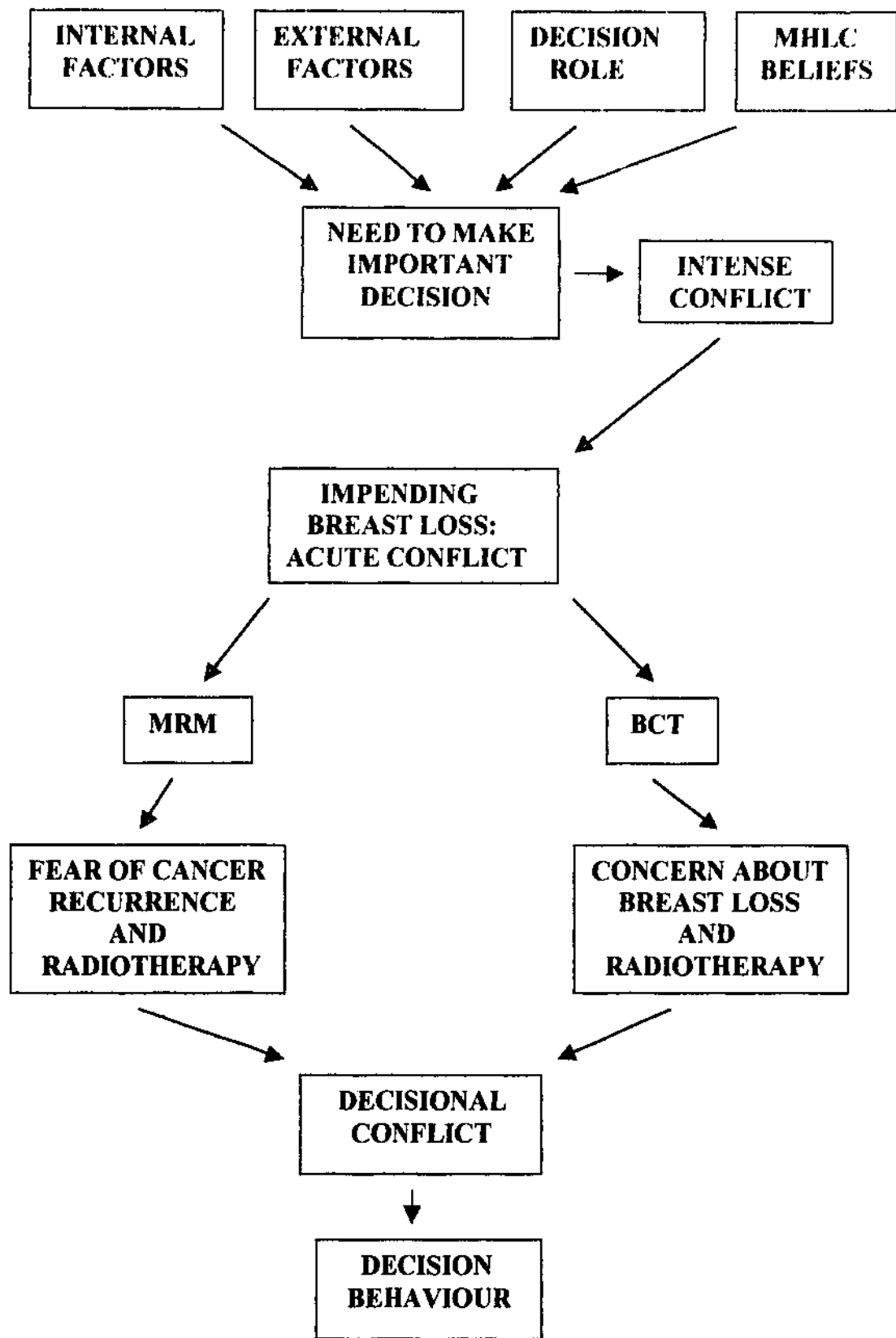


Figure 1. Theoretical framework of decision-making for breast cancer surgery based on Conflict Theory of Decision Making (Janis & Mann, 1977).

## CHAPTER 4

### Method

This chapter will describe and outline the method used to carry out this study. The following sections will be presented: research design, sample, instruments, procedure for implementing study, data collection and data analysis. Ethical considerations that were pertinent to this study will also be presented.

#### Research Design

A descriptive correlational design was used for this study. Descriptive designs are useful to "observe, describe and explore aspects of a situation" (Polit & Hungler, 1989, p. 129). Furthermore, descriptive designs allow the phenomena of interest to be viewed as they naturally occur without manipulation of variables (Burns & Grove, 1993).

In this study the primary variables of interest were the factors which influenced decision-making for either a MRM or BCT. These factors included demographics such as age and completed level of education, sources of information used by women to assist decision-making, factors that influenced personal choice of surgery, individual control over decision-making and MHLC beliefs. By using this design, relationships between variables were also identified, as were differences between those women choosing MRM and those choosing BCT.

#### Sample

A consecutive sample of women ( $N = 379$ ) diagnosed with breast cancer during the six month period, 1st October 1996 to 31st March 1997, were identified through the Cancer Registry at the HDWA. The Cancer Registry receives notifications of diagnoses of all major cancers in individuals (males and females) from pathology reports from all

hospitals throughout the state.

A six month period was chosen in order to obtain an adequate sample size based on past annual rates of newly diagnosed breast cancer cases in WA and to ensure some representation of rural women in the study. A further consideration was limiting the period to six months to reduce possibility of participants' inability to recall past events.

Whilst every effort was made to ensure accuracy of diagnoses of breast cancer cases during the designated time, due to the notification procedures at the Cancer Registry, some women were diagnosed with their disease outside of the time frame. On return of completed questionnaires it was found that one woman had stated her date of diagnosis as August 1996, ten women stated that they were diagnosed with their disease in September 1996 and a few women ( $n = 3$ ) completed date of diagnosis as April 1997. Given the fact that these women had received letters of invitation and were interested in participating, it was decided that they could be included in the sample.

The sample of women identified with breast cancer were then cross matched with the Death Register at HDWA on 30th April 1997 and nine women were found to be deceased at this time. As a result, 370 letters were mailed inviting participation.

As all women diagnosed with breast cancer were expected to be over eighteen years of age no limits were set regarding age. Likewise, other eligibility criteria for inclusion in this study, such as the individual's ability to understand or write English or their mental status, were not set for this study. Women only had to have been diagnosed with either Stage I or Stage II Breast Cancer.

### Instruments

Three instruments were used to gather information from participants concerning the variables under investigation. A demographic questionnaire (see Appendix B)

included items necessary to gather relevant background information from participants such as their age, marital status, occupation, level of education attained and area of residence. Other items helped to determine stage of breast disease and what type of surgery and treatment the women had received for their breast cancer.

#### Factor List

Permission was received from Ms Ward to use the Factor List in this study (see Appendix E). The Factor List (Ward, Heidrich & Wolberg, 1989) evaluates reasons for choosing one versus the other type of surgery (see Appendix C). It consists of 18 items in a rating scale format to determine how particular factors influence choice of surgery. Responses to questions range from "not at all important" to "not applicable to my situation". Another item determines the sources of information women used to assist them with decision-making and how important these sources were in helping them make their decisions. Eighteen other questions assess women's perceptions of involvement in decision-making, extent of desired participation in decision-making and whether other individuals indicated a preference for a particular surgery. Space was provided following open-ended questions for participants to add their written comments.

#### Amendments.

Some minor revisions to the questions in the Factor List were carried out following institutional review and prior to use, as the questionnaire had previously been used in an interview format. As a result, the wording of questions 11 and 13 in the Factor List were changed to reflect a more sensitive approach. Questions 17 and 18 were added by the author and question 19 was altered to include "Cancer Foundation, Breast Assessment Clinic and information from elsewhere" as two items in this section

were related to the Breast Problem Clinic in a university hospital in America. Question 19 was also changed to rank the sources of information rather than select only three items which was the case in the original format. The term “physician” was also changed to reflect Australian terminology of “doctor” or “medical specialist” where appropriate.

“Cannot recall” was added as an extra response item in questions 1 to 17 in the Factor List and also to all the other questions so women were not forced to answer the particular question if they could not remember. Questions 25 to 30 were added to determine whether women consulted other medical specialists or alternate therapists prior to making a decision for surgery. Finally, question 32 was included to ascertain whether women experienced any conflict during their decision-making experiences.

#### Reliability and validity.

Content validity for the Factor List was determined by two clinical specialists in Oncology (Ward, Heidrich & Wolberg, 1989). For the present study reported here, a pilot test of the demographic questionnaire, HLC Scale and the modified Factor List was conducted. Participants included in the pilot test were ten women from various backgrounds (one of whom had surgical treatment for breast cancer twelve months prior to the pilot study) and a General Practitioner (GP) with considerable experience in treating women with breast cancer. They were asked to answer a number of specified demographic questions, complete the HLC Scale and comment on the remaining questions. Further comments were invited on any aspect of the questionnaires regarding legibility, sensitivity of questions and general format. As a result of this scrutiny some words were simplified and some items in the Factor List were reworded.

### Multidimensional Health Locus of Control Scale

The MHLC Scale (Wallston, Wallston & De Vellis, 1978) was used to determine whether the individual's health locus of control was either internal or external and also whether health locus of control could feature as an independent variable influencing decision-making. This Likert-type scale of 18 items was developed from an earlier general unidimensional HLC Scale (Wallston, Wallston, Kaplan & Maides, 1976) which was based on Rotter's (1954) Social Learning Theory (Rotter, 1954; Rotter, 1982). Development of the MHLC scale was also influenced by the work of Levenson (1981) on generalised locus of control beliefs.

The MHLC scales are comprised of two parallel forms, "A" and "B". These two equivalent forms can be used in research designs where repeated measures over brief periods of time are required (Wallston & Wallston, 1981). As the literature supports the use of either parallel form, Form "B" was arbitrarily selected for use in the present study (see Appendix D).

Form B of the MHLC is comprised of six items related to Internal Health Locus of Control (IHLC), six items related to Chance Health Locus of Control (CHLC) and a further six items related to Powerful Others Health Locus of Control (PHLC). Individuals with an IHLC believe that they can control health outcomes whilst individuals with an external health locus of control believe that their health outcomes are due to chance happenings or fate (CHLC) or are under the control of powerful other people such as friends, family or doctors (PHLC).

The 18 items in the questionnaire are not grouped according to the individual locus of control dimension but are mixed. Questions range from "strongly disagree" (scored as one) to "strongly agree" (scored as six). Therefore each subscale has a

potential range of scores from 6 to 36 with a median of 21. A score above the median indicates a high internal locus of control while a score at or below the median indicates a low internal locus of control. Eight locus of control typologies can be classified according to whether the individual scores above or below the median on the three dimensions (Wallston & Wallston, 1982). Published reliability estimates as measured by Cronbach's alpha coefficient for the MHLC scales range from .67 to .77 (Wallston, Wallston & De Vellis, 1978).

Two small typographical errors were discovered in question seven and question 12 of the MHLC scale after the mail out. A later review of findings indicated no evidence of response error for these questions. These errors have subsequently been corrected for this paper.

#### Procedure for Implementing Study

Once permission was obtained from the Confidentiality of Health Information Committee (at HDWA) to access confidential data from the Cancer Registry (see Appendix F), the number of newly diagnosed breast cancer cases were identified. To make allowances for any late notifications of breast cancer cases from hospitals to the registry, an extra month was allowed to pass before the study was implemented. The initial mail out thus occurred on the 30th April 1997.

Questionnaires were sent from the Health Information Centre (HDWA) in envelopes that endorsed the HDWA. All envelopes were marked "confidential" to ensure that the recipient opened the letter. A letter of introduction (see Appendix G) from the manager of the Health Information Centre introducing the researcher plus a cover letter (see Appendix H) from the researcher detailing the purpose of the study was included with the questionnaires. The letter of introduction, cover letter and



questionnaires also included the telephone numbers of the researcher, a contact person at the Health Information Centre and the researcher's supervisor should the women have any queries or concerns about the study. The researcher, her supervisor and Dr Threlfall at HDWA received a number of telephone calls regarding the study. These are summarised in Appendix J.

A Free Post envelope was also included for participants to return information to the researcher at her home address. A follow up reminder letter (see Appendix I) was sent from the HDWA to all of the 369 women two weeks after the initial mail out. One letter from the initial mail out was returned to HDWA as address unknown and attempts to locate this person by staff at HDWA were unsuccessful.

#### Data Collection and Data Analysis

All questionnaires were numbered on return to assist data management and items were coded for data analysis. Data in nominal, interval and ratio form were analysed using the Statistical Package for the Social Science (SPSS) 6.1.2 for Windows (1995) software. Descriptive statistics were used to summarise the data and frequency tables were created to compare distributions of the variables.

Prior to computing inferential statistical analysis the variables were assessed for normality by using a combination of probability plots, Histograms, Stem and Leaf Plots, skewness and kurtosis, depending on the level of the data (Coakes & Stead, 1996). All of the variables in the Factor List, a number of demographic variables and the three MHLC scales were assessed in this way. Whilst not all variables were normally distributed, a decision was made to use a combination of parametric and non-parametric tests for statistical analysis in view of the sample size. Experimenting with non-parametric tests on all data produced the same results as parametric tests.

### Quantitative Analysis

The main statistical tests used in this study included Chi-Square, Independent Sample T-Test and Pearson Product Moment-Correlation Coefficient. Chi-Square analysis was used to calculate the differences of observed and expected frequencies of nominal variables such as type of surgery and area of residence and therefore determine whether an association existed between the variables.

Scholars Glanz (1987), Hopkins, Hopkins, and Glass (1996) and Kuzma (1992), provide various rationale for use of the statistical tests ANOVA or T-Test. Therefore, Independent Sample T-Test was used to analyse significant differences between those groups of women choosing MRM versus BCT on demographic variables such as age and months since surgery, factors that influenced choice of surgery and MHLC beliefs.

Pearson Product Moment-Correlation Coefficient was used to analyse relationships between MHLC beliefs of women and a number of variables. These variables included age, preference for involvement in decision-making, enough time for decision-making, level of emotional distress at the time of decision-making, adequacy of information for decision-making and extent of desired participation in decision-making.

### Qualitative Analysis

A content analysis of written responses to open-ended questions was undertaken using latent content analysis as described by Field and Morse (1985). Individual written comments were firstly read in the context of their responses to all of the chosen answers. The comments were then transcribed and grouped under headings such as other factors that influenced decision-making, conflicting advice; yes or no and the reasons why, choice for surgery; yes or no and the reasons why. The surgical choice of

the respondent which included either MRM, BCT, both surgical procedures, no surgery or missing surgical type, was also noted next to each written response. All responses were then grouped according to choice of surgery and specific answer, whether it was in the affirmative or the negative. Following this procedure, codes were produced for similar or like responses and a taxonomy was thus produced for all responses. This method of grouping and the subsequent taxonomy of descriptors was validated by a nurse researcher with considerable experience in qualitative research studies. Summaries were then provided in a group form so as not to identify individual respondents.

### Ethical Considerations

This study was approved by the ethics committee at the Edith Cowan University (see Appendix K) and also reviewed and approved by the Confidentiality of Health Information Committee (HDWA) for permission to access confidential information from the Cancer Registry (see Appendix F). The committee proposed that no names were to be released to the researcher so all participants remained anonymous and no code numbers were used.

As mentioned earlier, the initial and follow up mail out were conducted from the HDWA. A letter of introduction from HDWA forwarded with the questionnaire explained to participants that their names had not been released to the researcher or to any other person. A cover letter from the researcher also explained the purpose of the study and the risks and benefits of participating.

Participation in the study was voluntary and consent to participate was implied on return of completed questionnaires. Refusal to participate incurred no penalty. Individuals who did not wish to participate were requested to tick a box at the bottom

of the cover letter. This was required to differentiate between those respondents who were Stage III and Stage IV Breast Cancer and those who did not wish to participate.

Women were assured that they would not be identified by their written responses to open questions. A request was made for respondents not to identify their names or any other names such as doctors, hospitals or clinics on the questionnaires. All returned questionnaires and computer disk data when not in use were locked in a cupboard in the researcher's home.

The telephone numbers of the researcher and her supervisor were included in the cover letter for any individuals wishing to question any aspect of the study or discuss other relevant issues. A number of women took advantage of this invitation and a summary of telephone calls received is provided in Appendix J.

Because of the sensitivity of the study, it was felt that some women or their families could experience some discomfort in recalling their time of decision-making for breast cancer surgery whilst participating in the study. Permission was received from the Cancer Foundation, to include their help line telephone number in the cover letter so that women had access to support if required (see Appendix L).

It was also necessary to consider the "timing" for this study as the potential existed for influencing participant's decisions if the study was conducted prior to a decision being made for surgery. Therefore the study was conducted after decisions for surgical treatment had been made.

## CHAPTER 5

### Results

The results of this study will be presented in this chapter firstly focusing on the demographic characteristics of the sample and then on the breast cancer and treatment related variables. This will be followed by the results of descriptive statistics for the entire group and separately for the two groups; those who chose BCT and those who chose MRM. Inferential statistical analyses as they relate to the research questions are lastly reported.

An alpha level of .05 significance was set for all data analysis. Computed results were rounded to two decimal points and these are reported as exact  $p$ ,  $t$ ,  $r$ ,  $u$  and  $\chi^2$  where appropriate. As not all questionnaires were answered in full, there is a variation in  $N$  values due to missing scores. Results from respondents who answered “cannot recall” for a particular item, or who did not answer a question, were not recorded as frequencies in tables.

Four questionnaires were completed on behalf of the women by their carers or family due to disability, illiteracy or frailty. These questionnaires were included in the study as each one mentioned the reasons why the questions had not been answered by the woman herself. The carers in each instance had either been involved in the decision making for surgery or were fully conversant with the circumstances.

Open responses to questions were analysed by using latent content analysis as described by Field and Morse (1985) and as outlined in Chapter Four.

#### Characteristics of the Sample

Three hundred and seventy letters of invitation were mailed to women who had a diagnosis of breast cancer. Two hundred and forty women responded to the invitation to take part in the study. Of these, thirteen women identified themselves as having either

Stage III ( $n = 11$ ) or Stage IV ( $n = 2$ ) Breast Cancer and were ineligible to participate.

Another 62 did not wish to take part resulting in a sample of 175 participants for a response rate of 49.16%. Nine women volunteered reasons for their refusal to take part and these are outlined in Table 5.1.

Table 5.1

Reasons for Non Participation

<b>Reason</b>	<b><u>n</u></b>
Already involved in a research study	1
Returning to an overseas country	1
Never had a choice; doctor made decision	1
Elderly; did not have surgery, questions not applicable	1
Health and literacy problems	2
Elderly; unwell	1
Questions irrelevant	1
Diagnosed with breast cancer in 1992	1
( <u>N</u> = 9)	

Age and Marital Status

The ages of the women ( $n = 174$ ) ranged from 31 to 89 years with a mean of 57.95 years ( $SD$  13.63) and a median of 57.00 years. The majority ( $n = 120$ ) were married/de facto and the remaining 54 were either, single, divorced or widowed. Table 5.2 provides a summary of the marital status of the sample.

Table 5.2

Frequency Distribution of Marital Status

<b>Marital Status</b>	<b><u>n</u></b>	<b>%</b>
Married/De Facto	120	69.00
Widowed	33	19.00
Divorced	11	6.30
Never Married	10	5.70
<b>(<u>N</u> = 174)</b>		

Dependant Children

A minority of 37 women (22.00%) had dependant children (also included grandchildren) in their care and 131 (78.00%) reported no dependants. Ages of the children ranged between 1 and 53 years. Table 5.3 shows the number of dependant children.

Table 5.3

Frequency Distribution of Dependant Children

<b>Number of Children</b>	<b><u>n</u></b>	<b>%</b>
No Children	131	78.00
One Child	8	4.80
Two Children	18	10.70
Three to Five Children	11	6.60
<b>(<u>N</u> = 168)</b>		

### Education Level of Respondent

According to the number of women who provided their completed level of education ( $N = 162$ ), the majority (56.80%) reported this to have been high school. Thus “high school” may have included from one to five years of schooling. Fifty-six women (34.60%) indicated that they had completed some form of tertiary education including TAFE or university studies. Fourteen women (8.60%) reported completing an education level less than high school that included either a primary school level or no schooling.

### Country of Birth

The majority of women (63.80%) were born in Australia (includes WA) followed by the British Isles, Europe and Asia. A small group of “other” countries included India, New Zealand, South Africa and the United States of America. A summary of country of birth is provided in Table 5.4.

Table 5.4

#### Frequency Distribution of Country of Birth

Country	<u>n</u>	%
Western Australia/Australia	104	63.80
British Isles	38	23.30
Europe	8	4.90
Asia	6	3.70
Other	7	4.30
$(N = 163)$		



### Language

English was the first language spoken at home for 94.50% ( $n = 156$ ) of the sample ( $N = 165$ ). Languages other than English were spoken by a minority of 5.50% ( $n = 9$ ). Alternative languages included Italian, Greek, German, French, Ukrainian, Yugoslav, Tagalong and an indigenous language.

### Area of Residence

Of the sample ( $N = 163$ ), 132 women (81.00%) were urban dwellers and 31 (19.00%) lived in a rural community.

### Occupation

The occupations of respondents were grouped into seven categories and reported as work status prior to surgery and work status following surgery i.e., at the time of completing the questionnaire. Both paid and unpaid work, were considered within this grouping. As Table 5.5 shows, prior to surgery the majority of women (37.00%) were homemakers ( $n = 60$ ) and no women considered themselves unemployed.

Table 5.5

Frequency Distribution of Occupations Prior to Surgery

<b>Occupation</b>	<b><u>n</u></b>	<b>%</b>
Clerical/Computing	28	17.30
Skilled Trade/Farming	15	9.30
Professional/Management	25	15.40
Labourer/Unskilled	11	6.80
Retired	16	9.90
Homemaker/Voluntary	60	37.00
None	7	4.30

(N = 162)

Note. As reported by respondents, "None" includes pensioner, no work, nothing and invalid.

Following their surgery and at the time of the study, 116 (70.30%) women (N = 165) were doing the same work as they did prior to surgery whilst 49 (29.60%) were doing different work. Work changes included not working, retired, on leave, sick leave, leave without pay and unemployed. Occupation changes that occurred for the women following their surgery are provided in Table 5.6.

Table 5.6

Frequency Distribution of Occupation Changes Following Surgery

<b>Occupation</b>	<b><u>n</u></b>	<b>%</b>
Same Work	116	70.30
Same Work but Part Time/Casual	2	1.20
Different Work	14	8.50
Unemployed	16	9.70
Retired	7	4.20
Sick Leave/Leave	5	3.00
Leave Without Pay	5	3.00
(N = 165)		

Religious Affiliation

The women reported a wide range of religious denominations and these were grouped into five categories. The majority of respondents (n = 83) were Protestant. The “other” group represents Hebrew, Jewish, United Parish, Astara and Tribal Aboriginal. A summary of the religious affiliations of the respondents is provided in Table 5.7.

Table 5.7  
Frequency Distribution of Religious Affiliation of Respondents

Religion	<u>n</u>	%
Protestant	83	51.90
Catholic	32	20.00
None	31	19.40
Christian	9	5.60
Other	5	3.10
(N = 160)		

Summary

The typical respondent in this sample with a diagnosis of breast cancer was aged 57.95 years. She was in a married/de facto relationship with no dependants and lived in an urban community. She had more often completed high school education, was born in Australia, spoke English at home and had a Protestant religious affiliation. Prior to surgery she was a homemaker and following surgery retained the same work status.

Breast Cancer and Treatment Variables

The following section will report results of the disease characteristics of the sample and treatment related variables.

Stage of Breast Cancer

Of the women who responded to the question related to stage of breast cancer (N = 160), 48.80% (n = 78) had Stage I Breast Cancer and 46.30% (n = 74) had Stage II Breast Cancer. Eight women (5.00%) did not know their stage of breast disease.

### Surgical Treatment

The surgery elected for treating their breast cancer was specified by 168 women. BCT (Lumpectomy) was the choice of surgical treatment for 96 women (57.10%) and 58 women (34.50%) had undergone MRM. Twelve women (7.10%) had two surgical procedures; Lumpectomy followed by MRM. Therefore, a total of 70 women had received a MRM. Two women (7.10%) did not have surgery for their breast cancer.

### Months since Surgery

The number of months since surgery for breast cancer was calculated from the nominated month of surgery, to the month of May 1997 as the mail out occurred on 30th April 1997. For those cases where women did not nominate their date of surgery, but only the date of diagnosis of breast cancer, this was used to calculate the number of months since surgery, as for the majority of respondents, surgery occurred within approximately one week of diagnosis. The date of diagnosis was also used to determine months since surgery for the two women who did not have surgery. Therefore, the number of months since surgery ( $N = 167$ ) ranged from zero (surgery in May, 1997) to eight months (surgery in September, 1996) with a mean of 4.38 months ( $SD$  1.79).

### Doctor Consultations

Of the sample who responded to the question related to how many doctors they had consulted prior to surgery ( $N = 169$ ), the number of doctor consultations for opinions regarding breast cancer treatment ranged from zero; where women stated that they did not consult any doctors, to six. A total of 77 women (45.60%) consulted two doctors. This was the most common number of consultations and usually included a GP and Surgeon.

### Other Health Professionals

Results of consultations to other health professionals (such as seeing another surgeon for a second opinion, Radiation Oncologist or Medical Oncologist) for opinions regarding treatment for breast cancer prior to surgery are not provided here due to inaccuracies in respondents' answers. In general however, women commented that consultations to a Radiation Oncologist or Medical Oncologist occurred after surgery. A number of the women's comments also suggested that if they had a specific medical condition that warranted an opinion prior to surgery or they were having a breast reconstruction procedure, they were then seen by the oncologists before surgery.

### Alternate Therapists

At the time of the study and following their surgery ( $N = 164$ ) a minority of seven women (4.20%) reported consulting an opinion from an alternate therapist regarding breast cancer treatment. Advice was obtained from alternate therapists including Naturopath, Homeopath, Chinese medical person, through general reading sources and praying. Only one respondent had enquired about an alternate therapy prior to surgery.

From the written comments provided by six women who had received either BCT or MRM, the general advice from all alternate therapists was to continue with orthodox medical treatment and use alternate therapy to help support the body and to maintain the immune system. Whilst the majority of experiences with alternate therapists were positive, one woman reported an unfavourable experience.

### Adjuvant Treatment

Chemotherapy, Radiotherapy and Tamoxifen were all adjuvant treatments, which the women had just begun, were going to start at a later date, or had completed. Forty three women would have had a course of Chemotherapy whilst 82 would have had Radiotherapy

treatment. Over half of the sample ( $n = 87$ ) were taking Tamoxifen tablets. Adjuvant treatments of the sample are documented in Table 5.8.

Table 5.8  
Frequency Distribution of Adjuvant Treatments

Treatment	Receiving/ Completed		Later Date		Unsure		N
	n	%	n	%	n	%	
Radiotherapy	73	43.70	9	5.40			167
Chemotherapy	41	24.80	2	1.20			165
Tamoxifen	87	51.80			2	1.20	168

Familial History of Breast Cancer

Only 47, or 27.80% women ( $N = 169$ ) indicated a family history of breast cancer. Of this group, the most common family member who had breast cancer was their mother ( $n = 18$ ) followed by their by sister ( $n = 15$ ). Other family members with a history of the disease included aunt, cousin, grandmother, daughter and niece. One hundred and thirteen women (66.90%) reported no history of first degree relatives with breast cancer.

Breast Assessment Clinic

Only 63 women (38.20%) reported attending a Breast Assessment Clinic ( $N = 165$ ). The majority, 58.80% ( $n = 97$ ) had not attended a clinic and comments made by a number of women suggested that they did not know about assessment clinics. Five women (3.00%) were uncertain about whether they had attended an assessment clinic or not.

### Private Health Insurance

It was of interest to note, that at a time when private health insurance was on the decline in the community and before the government incentives to encourage individuals to take out private health insurance had commenced (1st July, 1997), 92 women ( $N = 164$ ), or 56.10% documented having private health insurance.

### Group Comparison

Women were next grouped according to type of surgery chosen for breast cancer treatment; whether they had BCT ( $n = 96$ ) or MRM ( $n = 70$ ). The two women (in their eighties) who had no surgery for their breast cancer were included as missing values. The two groups were then compared on the following demographic variables: age, marital status, completed level of education, occupation before and after surgery, number of dependant children and area of residence. Disease characteristics were also compared and included stage of breast disease, months since surgery, adjuvant treatments, family history of breast cancer and attendance at Breast Assessment Clinic.

### Comparisons of Demographic Variables

The MRM group ( $n = 70$ ) were slightly older than the BCT group ( $n = 95$ ) with a mean age of 59.39 years ( $SD\ 13.11$ ) in comparison to the BCT group who had a mean age of 56.12 years ( $SD\ 13.88$ ). However, this difference was not statistically significant,  $p > .05$ .

The two groups were homogeneous with regard to the number of months since time of surgery. The MRM group ( $n = 69$ ) recorded a mean of 4.52 months from surgery ( $SD\ 1.79$ ) whilst the BCT group ( $n = 93$ ) recorded a mean of 4.31 months ( $SD\ 1.77$ ) since surgical treatment.



A significant association between where the women lived and their choice of surgery was found. Women in rural areas tended to choose MRM rather than BCT,  $\chi^2 (1, N = 160) = 12.75, p = .00$ . Table 5.9 provides a comparison between women living in urban and rural areas and their choices of surgery.

Table 5.9  
Frequency Distribution of Type of Surgery According to Area of Residence

Area of Residence	MRM		BCT	
	<u>n</u>	%	<u>n</u>	%
Urban	46	54.80	83	74.20
Rural	22	13.20	9	17.80

(N = 160)

Note. MRM denotes Modified Radical Mastectomy and BCT denotes Breast Conserving Treatment.

No other significant differences between the two groups of women according to demographic characteristics or disease and treatment variables were found,  $p > .05$ .

### Factors Which Influence Decision-Making

To determine what factors influenced decision-making for surgery, women were asked to rate 18 items (see Factor List in Appendix C) ranging from not at all important (scored as zero) to extremely important (scored as four). The scale also allowed women to indicate if a factor was not applicable or if they were unable to recall the influence of this factor on decision-making. Results reported here are based on the complete data responses from women who rated the factor on the zero to four scale and who had either a MRM ( $n = 70$ ) or BCT ( $n = 96$ ). High mean scores indicate that the particular factor rated as more important than low mean scores.

#### Decision-Making Factors

According to the women who provided complete data, all of the factors rated varying levels of importance. Nevertheless, two factors from the Factor List emerged as more important influences on decision-making for the women in comparison to the others. These were firstly, knowing the surgeon's preference for the type of surgery they should have, and secondly, the fact that there was no difference between either a Modified Radical Mastectomy or Lumpectomy followed by Radiotherapy in long-term survival.

Factor three; "knowing my surgeon's preference for the type of surgery I should have" was rated as important, very important or extremely important by 88.20% ( $n = 143$ ) regardless of type of surgery. There was a significant difference between the BCT group ( $n = 85$ ) and the MRM group ( $n = 58$ ) regarding this factor,  $t(101.10) = -2.30$ ,  $p = .02$ . Women who had undergone BCT rated this factor as significantly more important than women who were treated with MRM.

Factor 11 which concerned no difference between the two surgeries in long term survival was also reported as an important, very important or extremely important factor by

63.90% of the women ( $n = 108$ ) regardless of type of surgery. Once again a significant difference was found between the two groups (BCT,  $n = 65$  and MRM,  $n = 43$ ) regarding this factor,  $t(106) = -3.33$ ,  $p = .00$ . Women who had selected BCT rated this factor as more important than women who had undergone MRM. Mean scores for all of the factors according to surgical groups are provided in Table 5.10.

Table 5.10

Mean Scores of Factor List According to Surgical Groups

Factor	MRM			BCT		
	<u>M</u>	<u>SD</u>	<u>n</u>	<u>M</u>	<u>SD</u>	<u>n</u>
M.R.M. experiences of others	1.56	1.51	46	1.53	1.39	68
B.C.T. experiences of others	1.17	1.26	40	1.14	1.18	55
Surgeon's preference	2.64*	1.37	58	3.13*	1.05	85
Preference of close person	1.85	1.47	53	1.90	1.57	71
Fear of cancer recurrence	3.26	1.19	61	2.96	1.35	78
Return visits for radiotherapy	1.25	1.43	44	1.00	1.39	75
Fear of radiotherapy	1.35	1.48	49	1.12	1.35	77
Side effects of radiotherapy	1.49	1.53	49	1.72	1.50	79
Losing a breast	1.82	1.49	60	2.24	1.56	80
Partner's feelings	1.71	1.34	48	1.61	1.44	72
No difference in survival	1.53*	1.24	42	2.43*	1.45	65
Future breast reconstruction	1.28	1.32	63	1.39	1.50	76
Extra surgery in the future	3.13	1.06	61	2.92	1.38	81
Dying from cancer	3.06	1.30	65	2.94	1.42	81
Loss of arm mobility	2.03	1.34	63	2.19	1.48	83
Amount of pain involved	1.38	1.30	60	1.41	1.30	85
Financial cost	.97	1.35	61	1.15	1.41	80
	(N = 70)			(N = 96)		

\*  $p < .05$ .

### Supplementary Factors

Other factors that influenced decision-making were determined from the open responses. Following content analysis additional factors emerged as having an influential role on decision-making.

The following factors influenced women's decision-making and were reported by women who had received BCT:

1. Surgeon's recommendation or advice was followed, as he/she would know what was best. Options were either not given or were fully presented.
2. The age of the woman, where family and doctor made the decision.
3. Size of the breast tumour had been reduced by chemotherapy or the tumour was detected very early and decision-making did not occur. Having a particular type of breast cancer such as Ductal Carcinoma in Situ only warranted B.C.T.
4. Concern regarding body image and the fact that mastectomy was emotionally distressing.
5. No difference in survival rates between the two types of surgery.
6. Common sense.

Approximately 33 women who chose MRM recorded that the following factors influenced their decisions for surgery:

1. Surgeon and/or GP's recommendation was followed due to having trust in the surgeon or alternatively the recommendation was followed because no other options were discussed and no choice was given.
2. The size of the tumour, the pathology result of the biopsy or frozen section, the particular type of cancer and having a second instance of breast cancer.
3. Past and present medical history.

4. Fear of cancer and wanting to eradicate the disease. Mastectomy was seen as a safer option.
5. In the face of a life threatening disease there was no choice if you wanted to live.

Women who had two surgical procedures; BCT followed by MRM, and who provided written comments documented the following factors that influenced their decision:

1. Being given support from either partner, family or surgeon regarding the breast loss.
2. Previous experience with cancer and disbelief that both surgical outcomes were the same. Family history of breast cancer and other types of cancer.
3. The pathology of the tumour.
4. Age of the woman (middle forties).
5. The seriousness of the situation ("cancer") or a resignation of the fact that the breast had to be removed.
6. Surgeon's decision.

#### Information Sources

To determine the sources of information that women consulted to assist in decision-making, a list of ten sources was provided and women were requested to rank these from one to ten in order of their importance and use. However, women found it difficult to comply with this direction. Following consultation with a Research Consultant, a decision was made to analyse responses next to an item indicating a "yes equals one" response and a blank space indicating a "no equals two" response. Individual scores for each of the ten sources were summed and means obtained. A mean of 1.00 for the ten sources represented using all sources of information while a mean of 2.00 meant that the woman had not used any sources.

The two groups of women were then compared according to their choice of surgery (MRM or BCT) and use of each ten individual sources of information.

#### Significant Sources

Chi-Square analysis revealed no significant association between the type of surgery the women had received and their use of the ten information sources for decision-making,  $p > .05$ . However three information sources emerged as important for both groups. These sources included Surgeon, family and GP. Their Surgeon was an important source of information for both groups. For the MRM group, family was nominated as a more frequent source of information than information from their GP. In comparison, the BCT group indicated their GP as a more frequent resource than their family. These findings are recorded in Table 5.11.

Table 5.11

Rank Order of Mean Information Sources According to Surgical Groups

Source	MRM			Source	BCT		
	<u>M</u>	%	<u>n</u>		<u>M</u>	%	<u>n</u>
Surgeon	1.09	91.40	64	Surgeon	1.10	89.60	86
Family	1.26	74.30	52	General Practitioner	1.25	75.00	72
General Practitioner	1.29	71.40	50	Family	1.31	68.80	66
Friends	1.36	64.30	45	Friends	1.38	61.50	59
Cancer Foundation	1.41	58.60	41	Cancer Foundation	1.45	55.20	53
Scientific Journals	1.44	55.70	39	Scientific Journals	1.47	53.10	51
Nurse	1.46	54.30	38	Media	1.48	52.10	50
Breast Assessment	1.50	50.00	35	Breast Assessment	1.50	50.00	48
Centre				Centre			
Media	1.50	50.00	35	Nurse	1.52	47.90	46
Other Information	1.87	12.50	9	Other Information	1.87	12.50	12
	( <u>N</u> = 70)				( <u>N</u> = 96)		

Further analysis revealed that there was a significant association between two variables; the extent of ones' own involvement in decision-making; (the woman's preferred decision-making role) and use of an information source which was GP;  $\chi^2$ , (3, N = 164) = 9.94,  $p$  = .02. Those women (regardless of type of surgery) who preferred to keep control of the decision-making process reported more use of their GP as an information resource.



### Additional Resources

Twenty-six women (who had either recorded or not recorded their surgical treatment) described other sources of information that they had used to assist in their decision-making. A content analysis of the open responses revealed four categories of information. These were:

1. Electronic media sources including use of computer and the Internet. Television advertising also featured.
2. Literature sources accessed through local library, Cancer Foundation or given to the woman by her GP and/or Surgeon.
3. Influence of prior experiences that included firstly; influence of past personal experiences with family or friends with breast cancer or other types of cancer and secondly, the influence of other peoples' experiences which was obtained through work experiences in health areas related to breast cancer or advice from other related specialists in the field.
4. No sources of information influenced decision-making, where the main influence documented was "self".

### Decision-Making Control

Women were asked a number of questions to determine the extent of their personal involvement or control in decision-making for surgery. Of the sample ( $N = 164$ , which also included the two women who did not have surgery), the majority ( $n = 89$ ) or 54.30% wanted the decision to be fully their own. Fifty-nine women (36.00%) wished to share the decision with someone else and 13 (7.90%) wanted to delegate the decision to another person. Three respondents (1.80%) could not recall the extent of their involvement in decision-making. For those women who wanted to share their decision, the person most

commonly nominated was surgeon followed by spouse or partner. These results are presented in Table 5.12.

Table 5.12  
Frequency Distribution of Decision Roles for Total Sample and Surgical Groups

Decision Role	Total Sample		MRM		BCT	
	<u>n</u>	%	<u>n</u>	%	<u>n</u>	%
Keep Decision	89	54.30	43	35.20	39	46.80
Share Decision	59	36.00	19	24.90	39	33.10
Delegate Decision	13	7.90	4	5.60	9	7.40
	(N = 164)		(N = 67)		(N = 89)	

Note. Those women who could not recall their preference for decision-making are not included in this table.

Comparison of Decision-Making Roles

Further analysis was carried out to determine significant differences between the women when grouped according to type of surgery undertaken and their preference for a particular decision-making role. Past research has reported a psychological dimension of preference for control over decision-making by individuals with cancer and/or breast cancer which has a rank order (Beaver, Luker, Owens, Leinster & Degner, 1996; Bilodeau & Degner, 1996; Davison, Degner & Morgan, 1995; Degner & Russell, 1988; Degner & Sloan, 1992; Degner et al., 1997; Hack, Degner & Dyck, 1994). In view of this fact, the variable related to preference for decision-making was treated as ordinal data. The

women's responses regarding their preference for involvement in decision-making were rank ordered and compared according to their choice of surgery by calculating Mann-Whitney U Test. A significant difference was found between the mean ranks of scores of the MRM group ( $n = 67$ ) and the BCT group ( $n = 89$ ),  $u = 2368.00$ ,  $p = .01$ . The individuals in the BCT group were ranked higher in terms of their preferred decision-making roles indicating that they preferred a more active role.

#### Factors Affecting Actual Participation in Decision-Making

A majority of the women or 82.30% ( $N = 164$ ) strongly agreed that they had participated in the decision for surgery as much as they preferred. There was no significant difference between those women who chose MRM or BCT and their participation in decision-making. Likewise, 67.10% of the women ( $N = 164$ ) strongly agreed that they had sufficient time within which to make their decisions. Furthermore, most (63.50%) strongly agreed that they had received enough information upon which to make their decisions.

A moderate correlation was found between the two variables, enough information on which to make a decision and enough time in which to make a decision,  $r(158) = .58$ ,  $p = .00$ . The Coefficient of Determination,  $r^2$  was used to determine the "meaningfulness" of  $r$  (Hazard Munro, Visintainer & Page, 1986). The independent variable, enough information for decision-making, accounted for 33.64% of the variance of the dependent variable, enough time.

The majority of women or 68.00% ( $N = 169$ ) also stated that there had not been any preference expressed for a particular type of surgery by other individuals considered to be important in their lives. For the 31.40% of women ( $n = 53$ ) who indicated that an important person had expressed a preference for either MRM or BCT, this person usually was a partner and/or family member.

### Cognitive Status

Women in the sample ( $N = 154$ ) were asked about their capacity to think clearly at the time of decision-making and 77 (50.00%) strongly disagreed or somewhat disagreed with the statement that they were upset at this time. Approximately 54 women (35.00%) strongly agreed or somewhat agreed that they had experienced a difficult time thinking clearly about their decisions. Of the remaining women, 20 (13.00%) were neutral in their responses and three (1.70%) recorded “cannot recall”.

### Conflicting Advice and Surgical Choice

An overwhelming 94.50% women ( $N = 164$ ) felt that they had not received any conflicting advice regarding their decision for surgery. Of those women who provided data ( $N = 160$ ), 89 women (55.60%) felt that they had been given a choice for their surgery. On the other hand, 68 women (42.50%) felt that they did not have a choice regarding their surgery.

Of those women who chose MRM ( $N = 70$ ) and who answered the question on “choice” ( $n = 66$ ), 31 or 47% felt that they had been given a choice for surgery, whilst 34 or 51.50% felt that they did not have a choice for their surgery. Likewise, of the BCT group ( $N = 96$ ) and who answered the question on “choice” ( $n = 88$ ), 55 or 62.50% women, felt that they had been given a choice for surgery, whilst 31 or 35.20% felt that they did not have a choice regarding their surgery.

### Content analysis of written responses.

Women who had selected BCT felt that they had been given a choice regarding their surgery because of the following reasons. Firstly, all options had been given to them by the surgeon and these had been fully discussed. Secondly, the women had chosen a different surgery to the one recommended or their choice represented “the fastest treatment

with least after treatment". Finally, information sources that the women accessed through literature, the Internet or Cancer Foundation validated their personal choice.

Those women who chose MRM felt that they had been given a choice regarding their surgery because all procedures (such as breast reconstruction) and alternatives were explained. Other reasons which women cited for having had a choice included, choosing a different surgery to the one recommended, there was no other option and they had support from their family and doctor, as they did not trust Lumpectomy and Radiotherapy.

According to the women who had received two surgical procedures, BCT followed by MRM, choice regarding surgery occurred because they felt MRM was the best course of action to take. Their choice was also positive within the range of information and knowledge given. Furthermore, these women were able to cite (in writing) the options given to them and therefore they had a choice.

For those women who had BCT and felt that they did not have a choice regarding their surgery, the following reasons were given. Firstly, women had total confidence in their surgeon and felt that he/she would know what was best for them and therefore followed his/her advice. Consequently the surgeon made the decision. Secondly, the surgeon favoured Lumpectomy for surgical treatment, Mastectomy was not warranted, the size of the lump did not indicate a need for Mastectomy and the only option explained was Lumpectomy followed by Radiotherapy. Thirdly, women expressed a sense of resignation concerning their surgery due to the fact of having cancer and also because no other alternatives were available apart from surgery. Having cancer also suggested that one really did not have much choice.

The women who had undergone MRM and documented not having a choice felt this was due to the following reasons. Firstly, nothing else was offered in terms of treatment

except whether or not to have a breast reconstruction. Secondly, the type of cancer such as Paget's disease of the nipple or the position and size of the lump in relation to the size of the breast, warranted Mastectomy. Thirdly, this type of surgery (MRM) was perceived to be the best way or only way to remove the cancer. Again the sentiment expressed was; "if you have cancer, one really does not have a choice". Finally, age was documented as the reason for not having a choice because the woman was elderly (in her seventies) and in another instance, Mastectomy was "the best decision in the circumstances".

Comments by women who had two surgical procedures (BCT and MRM) and who said that they did not have a choice regarding surgery, felt that this was due to the fact that they were either in shock or they did not have enough time to make a decision. These women also reported that the surgeon made the choice or suggested the surgery.

#### Multidimensional Health Locus of Control

The fifth research question directed the researcher to examine the extent to which the MHLC beliefs of women might be an additional factor influencing the decision-making process.

#### Reliability Analysis

Prior to determining whether any relationships existed between the MHLC beliefs of women and selected variables, a reliability analysis of the three subscales (six items for each scale) of the MHLC was conducted. Results were obtained by computing Cronbach Coefficient Alpha, a measure of internal consistency of a scale (Jacobson, 1988). Internal consistency ratings for the three subscales were IHLC ( $N = 157$ ) .65, PHLC ( $N = 154$ ) .64 and CHLC ( $N = 153$ ) .73.

Locus of Control

Following the reliability analysis, individual MHLC scores for all three subscales were grouped, summed and means calculated for the BCT group and the MRM group. The mean scores of the three subscales of the MHLC were similar for both surgical groups; both were more internally oriented in their health locus of control rather than externally oriented. Low scores on the IHLC scale, do not imply that the individual believes their health is controlled by external events, but rather only indicates that their scores are not reflective of the internal dimension (Wallston & Wallston, 1982). The mean scores of IHLC, PHLC and CHLC for the MRM group were found to be higher than those of the BCT group, but these differences were not statistically significant as computed by Independent Sample T-Test,  $p > .05$ . Results of the mean scores for the three dimensions of the MHLC scale are provided in Table 5.13.

Table 5.13

Mean Scores of Multidimensional Health Locus of Control Scale

Locus of Control	MRM			BCT		
	<u>M</u>	<u>SD</u>	<u>n</u>	<u>M</u>	<u>SD</u>	<u>n</u>
IHLC	24.84	4.58	64	23.80	4.64	87
PHLC	20.54	4.70	63	19.86	4.96	85
CHLC	18.25	5.75	64	17.52	5.49	83
	(N = 70)			(N = 96)		

Note. IHLC indicates Internal Locus of Control, PHLC (Powerful Others Health Locus of Control) and CHLC (Chance Health Locus of Control) comprise two components of External Locus of Control.

### Relationship between Multidimensional Health Locus of Control and Selected Variables

Pearson Product-Moment Correlation Coefficient was calculated to determine relationships between the MHLC beliefs of women and the following variables: actual preference for involvement in decision-making, enough time for decision-making, enough information for decision-making, level of emotional distress at the time of decision-making and age of respondent.

Pearson's correlation coefficient "is a numerical statement of a linear relationship between two variables" (Sprinthall, 1994, p. 206). The value of  $r$  was used to determine the direction of the association between two variables. Values range between  $-1.00$  (perfect negative relationship) through zero (no relationship) to  $+1.00$  (perfect positive linear relationship). A value closer to  $1.00$  indicates a strong positive correlation between the two variables (Argyrous, 1996, Burns & Grove, 1993, Sprinthall, 1994). A two-tail test was used.

To assist in determining the strength of any associations, the categories as described by Burns and Grove (1993), Caulcott (1992) and Hazard Munro, Visintainer and Page (1986) were used.

Results revealed statistically significant relationships between locus of control and a number of variables. Firstly a low negative correlation between IHLC and age,  $r(157) = -.17, p = .03$  and a low positive correlation between PHLC and age,  $r(154) = .26, p = .00$  were found. In addition, a low negative correlation between IHLC and enough time for decision-making was found,  $r(157) = -.16, p = .04$  and a low positive correlation between CHLC and enough time for decision-making,  $r(153) = .20, p = .01$ . Furthermore, a low negative correlation between CHLC and level of emotional distress at the time of decision-making was established,  $r(153) = -.23, p = .00$ . No significant statistical relationships were



found between the MHLC beliefs of women and their preferences for involvement in decision-making,  $p > .05$ . Finally, a low positive correlation was found between CHLC and adequacy of information for decision-making,  $r(153) = .18, p = .03$ . Results of all correlations are provided in Table 5.14.

Table 5.14

Pearson's Correlation Coefficients of Multidimensional Health Locus of Control and Selected Variables

Variable of Interest	IHLC		CHLC		PHLC	
	<u>r</u>	<u>n</u>	<u>r</u>	<u>n</u>	<u>r</u>	<u>n</u>
Age	-.17*	157	.04	153	.26*	154
Time	-.16*	157	.20*	153	.48	154
Information	-.02	157	.18*	153	-.05	154
Involvement in Decision-Making	-.07	157	.14	153	.04	154
Level of Distress	.01	157	-.23*	153	-.13	154
	(N = 171)		(N = 171)		(N = 170)	

Note. IHLC indicates Internal Health Locus of Control, CHLC indicates Chance Health Locus of Control and PHLC indicates Powerful Others Health Locus of Control.

\*  $p < .05$ .

Summary

The demographic characteristics of the 175 participants in this study and the differences between the two groups of women; those who chose BCT and those who chose MRM have been reported.

Many factors were considered to influence decision-making for either BCT or MRM. However, the main influences on choice of surgery were firstly knowing the surgeon's preference for a particular surgery and secondly, the women's knowledge of the fact that there is no difference between either MRM or BCT in long-term survival.

Information sources used by the women to assist in the process of decision-making mainly included people as a resource. These included their surgeons, family members and GPs. Even though women used a variety of information sources to assist them with decision-making, the majority wished to be involved in making the decision for surgery and maintain control of the process themselves. A significant association between the woman's preferred decision-making role and GP as an information source was found. A significant difference was also found between the BCT and MRM groups and their preferred decision-making roles with those women choosing BCT preferring to keep control of the decision-making process.

Furthermore, a significant association between where women lived and their choice of surgery was found. There was a tendency for rural women to choose MRM rather than BCT. Of the 31 rural women in the sample, only nine selected BCT.

The MHLC beliefs of women also had some influence over their reported decision-making. Whilst both surgical groups were found to be more internally oriented in their MHLC beliefs, no statistically significant association was found between the IHLC, CHLC and PHLC and preference for involvement in decision-making. However, low correlations were found between MHLC and a number of variables including age, enough time for decision-making, level of emotional distress at the time of decision-making and adequacy of information for decision-making.

## CHAPTER 6

### Discussion

The major findings of this study which were presented in Chapter Five will be interpreted and discussed in this chapter. Limitations of the study are also considered including theoretical and methodological issues. Implications for clinical nursing practice and recommendations for future research are also presented.

#### Interpretation of Major Findings

The main purpose of the study was to identify and describe the factors which women with Stage I and Stage II Breast Cancer in WA perceived to be important considerations when choosing between either a MRM or BCT.

#### Important Factors that Influence Decision-Making

A number of important factors were found to influence the decision-making process of women. The 18 items in the Factor List were all rated at varying levels of importance by the women and had some influence over personal decision-making. For the MRM group, fear of cancer recurrence, wanting to avoid further surgery in the future and fear of dying from cancer were important considerations in decision-making. For women selecting BCT, the surgeon's preference, fear of cancer recurrence and fear of dying from cancer were important factors.

These findings are not unlike those of Ward, Heidrich and Wolberg (1989) where the three main influences on decision-making for women in their study were found to be fear of cancer recurrence, wishing to avoid a second surgery in the future and the surgeon's preference. In addition, similarities are seen with results from other researchers where the physician's advice, survival concerns and fear of additional cancer influenced decision-making (Kotwall et al., 1995).

Unlike the study of Ward, Heidrich and Wolberg (1989), where concerns regarding radiotherapy and fear of cancer recurrence influenced women who chose MRM and concerns regarding body integrity and radiotherapy influenced women selecting BCT, concerns with radiotherapy side effects or inconvenience were not significant issues for women in this study. Likewise, whilst the possibility of losing a breast was an important factor for many women, it was not viewed as a significant influence on decision-making.

In considering decisional conflict where fear or concerns of radiotherapy were seen to oppose fear of cancer and breast loss within the theoretical framework, this was not readily apparent. The opposing conflict was more in relation to the fear and connotations of cancer and the potential threat of breast loss. Women may well have played down their concerns about radiotherapy.

In assessing functional status of women with breast cancer, prior to surgery and at eight weeks following surgery, Hughes (1993a) reported a decline for all women regardless of type of surgical intervention. She felt this was due to the possibility of a combination of side effects of radiotherapy and a lack of social support for the women who had Lumpectomy. Whether these factors regarding radiotherapy or breast loss would still attract the same rating of importance for women at more than eight months from surgery, which was the maximum time from surgery for women in this study remains unknown.

In comparing the BCT and the MRM group; knowing their surgeon's preference for a particular surgery was a significant influencing factor for those selecting BCT more so than those selecting MRM. The open responses of women validated this factor in many instances; they felt that the surgeon would know what was best for them. For those 42.50% of women regardless of surgical procedure, who felt that they did not have a choice

regarding their surgery, the two main reasons focused on the influence of the surgeon and the connotations of having cancer where one really did not have much choice.

Regarding the surgeon's influence, content analysis of written responses revealed that this was due to either the surgeon favouring one or the other type of surgery, the surgeon made the decision because of the particular type of cancer or the alternate surgery was not discussed. According to findings reported by Pierce (1993), one cause of conflict for women occurred when one particular surgery was strongly advocated which was not the preference of the individual. Comments by women in the present study indicated that they had in fact experienced some conflict, although in many instances the terminology of "conflict" was not mentioned. Overall, 94.50% women felt that they had not received any conflicting advice.

There was also a significant difference between the two groups of women and how they rated their level of importance regarding the equivalence of both surgeries on long-term survival. Those women who chose BCT considered this to be a more important factor in their decision-making compared to the MRM group. However, only 42 women who had MRM and who provided complete data out of an eligible 70 responded to this question. A number of women, regardless of surgical procedure, left the question unanswered or inserted a question mark as their response. This suggests that they may not have had adequate knowledge about this factor, therefore clouding interpretations about the significance of this finding.

Women's knowledge about treatment of breast cancer and their interpretation of information presented by their surgeons appears to contribute greatly to the actual choice of surgery. Hughes (1993b) also states that individual perceptions of the surgeon's preference

may influence treatment choice. Individuals may hear or interpret a recommendation when in fact it was never given.

#### Supplementary Factors that Influence Decision-Making

Supplementary factors that influenced decision-making by women were similar for all regardless of type of surgery chosen. Some factors that the women documented were the same as those in the Factor List but for unknown reasons, women felt a need to write their personal version of the factor. Once again the surgeon's choice or recommendation featured. In many instances women documented not having an option due to the pathology of the tumour, particular type of breast cancer (Paget's disease of the nipple or Ductal Carcinoma in Situ) or breast size and relationship of tumour. Kotwall et al (1996) reported that tumour size was a predictor of surgical procedure in their study. They also reported how the BCT group were given choices which encouraged women to seek further information or advice in comparison to the MRM group where choice was not given.

Analysis of other factors that influenced decision-making by women in the current study focused on concern regarding body image, fear of cancer, age of the woman, previous experience with cancer, seriousness of the situation being "cancer" and having support from partner, family and/or surgeon.

From their comments, a number of women in the present study still viewed Mastectomy as a safer option compared to Lumpectomy followed by radiotherapy and consequently it was seen as a procedure that would eradicate the disease. Therefore, previous beliefs or knowledge of cancer/breast cancer had some bearing on decision-making. This was similar to findings reported by Myer, Russo and Talbot (1995) where women's prior knowledge was a factor in decision-making with prior knowledge of radiotherapy related to later decision-making by the women.

Unlike the findings of Graling and Grant (1995), no demographic variables such as age, level of education of respondent or income were found to be important factors influencing decision-making for either types of surgery. However, some women did document that their age was a reason why they had selected a particular surgery. In addition, some older women stated that their age precluded them from having radiotherapy and so they underwent MRM.

Income as an external factor influencing decision-making was not tested in this study as all women would have been covered by Medicare for their surgery and adjuvant treatment, unlike other countries where health insurance coverage is not universal. Furthermore, 56.10% of the sample were covered by private health insurance at the time of the study. The financial cost of surgery was included as a factor in the Factor List, but this was not rated as a very important factor for the women. However, time off work or time away from family commitments may not have been considered as a financial cost, as a number of women documented a variety of work changes following their surgery. Those women who documented home duties as their main occupation prior to surgery retained this status following surgery.

Whilst no women documented that their area of residence or inconvenience of treatment centre was a consideration when selecting their surgical treatment, a significant association was found between area of residence and choice of surgery. Rural women tended to select MRM instead of BCT in comparison to urban women. This corresponds to recent findings where a review of Medicare statistics in Australia found that considerable variation existed in the surgical treatment of women for breast cancer depending on geographic location (Craft, Primrose, Lindner & McManus, 1997). From their study the authors concluded that women in rural or remote areas were likely to undergo MRM due to

lack of radiotherapy treatment centres which may have influenced their decision-making for surgery. Researchers in Italy (Grilli, & Repetto, 1995) and Canada (Hislop, et al., 1996) have found a similar trend where women residing close to a radiation treatment centre or having treatment in the main city centres underwent BCT, whilst those women outside these areas had MRM.

Apart from the availability of radiotherapy treatment, ethnicity, cultural factors or lifestyle and access to information resources need to be considered as other reasons why rural women in general tend to select MRM. Many aboriginal women live in rural and remote areas and they were under represented in this study. The exact reason or reasons why rural women selected MRM more often than urban women requires further investigation.

#### Information Resources Used in Decision-Making

Important sources of information that women used to assist decision-making focused on people as a resource and included their surgeon, family and GP. However there was no evidence to suggest that either the MRM or the BCT group used either more or less information to assist decision-making. Therefore, having one or the other type of surgery was not associated with the information sources used, apart from the surgeon as a significant resource. This is in contrast to Hughes (1993b) who reported that women selecting Mastectomy received significantly more information prior to their clinic visit in comparison to the BCT group who used fewer information sources. The MRM group in the present study nominated family as a more frequent resource whereas the BCT group nominated their GP.

To assist them make a decision for surgery, other information sources were also accessed by the women and included information obtained from the Internet. Conventional



information sources such as literature from the Cancer Foundation and from their doctors were also important resources highlighting a need for written information, even though women on the whole felt that they had received enough information on which to make their decisions.

Past experiences of the women with family or friends with breast cancer or other types of cancer also influenced women's decision-making. Moreover, knowledge gained through work experiences in health areas related to breast cancer or simply from "their own self", were other information resources. In both studies, Myer, Russo and Talbot (1995) also reported that prior knowledge was an important influence on decision-making. This suggests one type of decision behaviour termed unconflicted change (Janis & Mann, 1977) where individuals look to their past experiences to help make a decision and select the most salient point upon which to focus their decision.

#### Relationship between Participation for Decision-Making and Use of Information Sources

The majority of women felt that they had received enough information upon which to make their decision but no association was found between use of any information sources and type of surgery chosen by the women. The significant association found between the woman's extent for involvement in decision-making (preferred decision-making role) and her GP as an information source, suggests that for those women preferring to retain control of the decision, that their GP was an important resource or someone important whom the women obtained information from.

Clinical experience also suggests that following diagnosis of cancer from mammography screening, women are either referred back to their GP or to a Breast Assessment Clinic. As only 38.20% of women reported attending a Breast Assessment

Clinic and the mean age of the sample was 57.95 years, it would be common for a number of older women to find rapport or familiarity with their GP as an important resource.

#### Decision-Making Control

Similar to the findings of Ward, Heidrich and Wolberg (1989), the majority of women (54.30%) in this study also wanted their decisions for selecting a surgical procedure to be fully their own. As other studies (Beaver, Luker, Owens, Leinster & Degner, 1996; Bilodeau & Degner, 1996; Degner & Russell, 1988; Degner et al., 1997, Hack, Degner & Dyck, 1994; Johnson, et al., 1996) report control over decision-making for treatment following surgery for breast cancer, where decision-makers preferred a passive role or a sharing role with their surgeons, comparisons regarding decision-making control with these studies and results from the present study are restricted.

Further results from the current study found that whilst the majority of women wished to retain control of the decision-making, another group preferred the sharing role (36%) or else delegating control to another person (7.90%). Therefore, women should be consulted as to how they see their personal role in decision-making for surgery for breast cancer and follow up adjuvant treatment protocols. Degner et al. (1997) reported that a small number of women in their study felt that they had been pushed into making decisions. This focuses again on the need to determine from women, their preferences for involvement in treatment decisions.

Whilst many women wished to share their decisions for surgery with their surgeons, other people nominated for this role included family members and/or friends. The person closest to the woman, may in fact not be a legal relative as more individuals obtain support through diverse relationships. Inclusion of family members or other persons close to the individual would be warranted at decision times and throughout treatment. One reason

documented as a factor that influenced decision-making by women who had two surgical procedures, was the fact that they had support of a partner/family.

#### Relationship between Participation for Decision-Making and Surgical Choice

A significant difference was found between the decision-making roles of the two surgical groups. The individuals in the BCT group preferred a more active role in decision-making or preferred to keep control of decision-making in comparison to the MRM group. Reasons for this are unknown, as there were no significant differences in demographic or disease variables between the two groups. Moreover, the BCT group considered their surgeon's preference for a particular surgery and the statement of equivalence between the long-term results of the two surgical procedures as more important than the MRM group. This suggests that whilst the BCT group preferred a more active role in decision-making their surgeon's preference was just as important and the fact that both surgeries resulted in comparable outcomes in the long-term.

However, other researchers have reported different results. Ward, Heidrich and Wolberg (1989), found that there was a trend for women who chose MRM to want the decision for surgery to be fully their own, whilst those who chose BCT wanted to share the decision. Petrisek, Laliberte, Allen and Mor (1997), reported that regardless of the level of participation desired by women for decision-making for surgical and adjuvant treatments for breast cancer, (the majority of whom had received Lumpectomy in their study), the physician's recommendation had the greatest influence

For the MRM group it can be surmised that their surgery may have been viewed as being more distressing than BCT and women consequently wanted someone else to make the decision. Mastectomy patients have reported that their procedure was more disfiguring

than anticipated in contrast to breast conservation patients, where none reported their surgery more disfiguring than expected (Weiss, Wengert, Martinez, Sewall & Kopp, 1996).

#### Relationship between Multidimensional Health Locus of Control and Selected Variables

The following variables were tested with MHLC beliefs of women: preference for involvement in decision-making, enough time for decision-making, adequacy of information for decision-making, level of emotional distress at the time of decision-making and age of the woman. As past researchers have not focused greatly on women with breast cancer, their decision-making for surgery and the effects of locus of control on this process, comparisons with other studies are therefore limited.

##### Preference for involvement in decision-making.

No statistically significant relationship was found between the MHLC beliefs of women and their preferences for involvement in decision-making. Therefore, whether the woman was more internally oriented or externally oriented (PHLC or CHLC) in her health locus of control beliefs was not associated with a particular role for decision-making. This is interesting in view of the fact that the general concept of locus of control suggests that those individuals who are more internally oriented consider themselves as being more in control of health outcomes and would perhaps desire more involvement in making a decision for improving their health. As both surgical groups of women were more internally oriented in their locus of control, the effects of the connotations of a diagnosis of "cancer" may have had some influence on this result.

##### Enough time for decision-making.

Of the total sample, 67.10% of the women felt that they had sufficient time within which to make their decisions. A negative correlation was found between IHLC and enough time for decision-making suggesting an association where those women who were

more internally oriented required reduced time for decision-making. Further, a positive correlation was found between CHLC and enough time for decision-making. Therefore, these women may have deferred their decisions to others or made a decision fairly quickly because of their beliefs that fate or chance controlled the outcomes of their breast cancer in the long-term.

A moderate correlation was found between enough information for decision-making and enough time in which to make a decision with 33.64% of the variance for having enough information, associated with having enough time. This association is validated by the results, that the majority of women (63.50%) felt that they had received enough information and 67.10% had enough time in which to make their decisions. Whilst this was the case for the majority, analysis of comments by women who had two surgical procedures, revealed that for those who felt that they did not have a choice, this was due to being in shock and not having enough time to make a decision.

#### Adequacy of information.

The majority of women (63.50%) felt that they had received enough information on which to make their decisions for surgery. A positive correlation was found between CHLC and adequacy of information for decision-making. Once again, having an external belief in the control of fate or outside forces meant that either women had genuinely had received enough information or else they did not pursue or need a lot of information. Avoiding the need for information (although this was not reported) could also have been a bolstering technique used by women and considered as defensive avoidance decision-making (Janis & Mann, 1977). According to Pierce (1993), information seeking occurred when women had difficulty in interpreting differences between the treatments proposed and consistent information helped them come to a decision.

### Level of emotional distress.

Seventy-seven women (50%) felt that they could think clearly at the time of decision-making and they strongly disagreed or disagreed with the statement that they were so upset at this time. On the other hand, 54 women (35%) strongly agreed or agreed with the fact that they were distressed at the decision time. A negative correlation between CHLC and level of emotional distress was found suggesting that beliefs of chance happenings on health outcomes was associated with lower levels of emotional distress. If one believed in the control of fate on health outcomes the individual would perhaps not be very distressed at the time of decision-making. A resignation of the fact of having cancer, not being able to do much about it and therefore not really able to have a decision was portrayed through some analyses of the written comments.

### Age.

A negative correlation was found between IHLC and age and a positive correlation was found between PHLC and age. These results suggest that younger age women were internally oriented in their locus of control; more inclined to making their own decisions whilst for older women the influence of powerful others such as their surgeon was associated as an influence on their decisions.

Whilst other researchers have not focused on the relationship between MHLC and the age of women selecting surgery for breast cancer, Graling and Grant (1995), found that women older than forty years of age had undergone BCT twice as often than those aged younger than forty. Their finding of an association with age and surgical procedure was attributed to a surgical trend in the geographic area at the time. Similarly, Hughes (1993b) found that women who selected Lumpectomy were in a slightly older age group, in comparison to those who chose MRM.

### Implications for Nursing Practice

The time of decision-making for surgical treatment for their breast cancer is difficult and very stressful for many women. The results of this study provide an insight into the issues of concern for women at the time of decision-making for their surgical treatment of breast cancer and describes the factors that influenced their decisions. By being aware of the factors that influence women's decisions, health professionals including nurses, can provide useful information about these factors at this time.

Whilst nurse presence might be limited in Breast Assessment Centres, nurses would be in contact with women preoperatively, postoperatively, in Oncology departments and also in community centres. Therefore, nurses can help women to clarify issues of concern around the time of decision-making, which in many instances, as reported from past researchers, can resurface weeks after the surgery has been conducted (Johnson et al., 1996) and is related to lack of information given at the time of initial decision-making.

As some women may be reluctant to voice their concerns, they should be given opportunity and encouraged to do so. Johnson et al. (1996) found that women in their study did not disclose specific fears or concerns to health professionals and therefore, missed out on available support and information. No doubt in some instances women may have forgotten the information given to them when they made their decisions. However, in other instances and as documented from this study, women were often not given information about their particular concerns such as loss of arm mobility, lymph node dissection and lymphoedema or information about the alternate surgical procedure.

Listening to the concerns of women regarding their particular choice of surgery can be beneficial to correct any wrong interpretations. Written information such as pamphlets or fact sheets regarding the surgical procedures and follow-up adjuvant treatment is

warranted, so that women have a reference source to refer to. This can also be used as a starting point whereby nurses can identify priority information needs of the woman. Fact sheets should then be reviewed periodically as new information about treatment comes to light.

A support person should be encouraged to accompany the woman (according to her preference) when she is making decision for treatment or getting results of investigative procedures. This will also help the woman remember information at a later date that she may have missed initially. The presence of a person close to the individual woman would also be an added support when nurses initiate care plans. Partners, other family members or close friends also need to be included so that they can continue support following the woman's discharge from hospital as post operative stays are usually short.

Other sources of information such as a brief video which provides details about breast cancer, together with both types of surgery and follow up treatment plans, should be available for those women who would like further information about their disease. This could be provided at the Breast Assessment Centre, following admission to hospital and prior to surgery or at an appropriate time according to the woman's needs.

Whilst women in this study underwent surgery at a relatively short period of time following diagnosis of cancer, for some the waiting interval was difficult and comments documented suggested a need for interim support. Some women (or their doctors) were not aware of services provided by the Cancer Foundation whereby women could talk to someone about their breast cancer and their concerns. A need therefore exists for women to be directed to appropriate support groups in the community that can provide them with further information and support.



Health professionals need also to be aware that women have preferences as to the roles or level of involvement they wish to have when it comes to making decisions for their breast cancer surgery. Therefore, asking women about their preferred role will help them retain some control over their decisions. Furthermore, involving family members or other persons close to the woman would help relieve some of the stress and sense of urgency for an immediate decision. Nurses can also involve women in their treatment plans according to their desired level of involvement and according to their personal health locus of control beliefs.

A final consideration needs to be directed toward those women residing in rural areas. Nurses should be aware that their issues may be somewhat different to those of city women and endeavour to accommodate their information needs and those of family and friends. Access to support and choice for surgery may be limited in view of the restricted medical services in country areas and women may not necessarily be selecting their preferred choice of surgery. Follow-up support groups are also limited in country areas. Providing these women with contact with nurses at regional centres and once again, useful information, would be beneficial in helping women adjust to living with breast cancer.

#### Limitations of the Study

Whilst a satisfactory response rate was obtained for participation in this study, resulting in an adequate sample size, the findings are interpreted with caution given the fact that a non-random sample was used. Consequently, results may not be indicative of the general population of women with Stage I or Stage II Breast Cancer in WA.

Even though the time lapse from month of surgical treatment to completion of questionnaires was a mean of 4.38 months with a maximum of eight months, some women may have been unintentionally biased in their recollections of events at the time of

decision-making. They may have answered questions in socially acceptable ways rather than admit that they could not remember details of such an important event even though, “cannot recall” was added as a response item for most questions. Perceptions of events can change over time for the better or the worse.

Whilst it was known by the researcher (through receiving telephone calls regarding the issue) that four women had questionnaires completed on their behalf, others may well have been in the same situation and therefore some responses may also not be entirely the woman’s personal view.

Many women also had difficulty in interpreting the meaning of the word “rank” which was written to determine important sources of information which they may have used to help them make their decisions. As a result, the sources of information whilst valid does not necessarily mean that any one source of information was statistically more important than another or similarly whether one surgical group found a particular source more useful compared to the other. In addition, women also had some difficulty in determining how many doctors (including surgeons and oncologists) they had consulted for opinions for surgical treatment. The terminology or the sequence of these questions could have posed a problem. Because of inaccuracies in respondents’ answers regarding number of doctor consultations, these findings were not reported. Using simpler words and a different format would help solve these problems even though no comments regarding these issues were reported from the pilot test of the questions.

A final limitation of the study was the placement of the MHLC as the last section in the questionnaire format. Whilst this questionnaire stated that it was related to health beliefs in general, some women (17.10%) related the questions to their current health status and experience with breast cancer as they wrote comments next to the questions about their

current health. Alternatively, some women compared the statements to health beliefs before their diagnosis of cancer and their current health beliefs. Placing the MHLC Scale as the first questionnaire or conducting a telephone interview a few weeks later for this section would help solve this problem.

### Recommendations for Future Research

Knowledge about treatment of breast cancer will change over time, as will women's knowledge and reasons for selecting one versus the other surgery. Consequently, a replication study is recommended. This would be useful to monitor changes, so that nurses continue to support women and provide them with information according to changing health trends, empirical knowledge and woman's personal needs. Furthermore, a study using a random sample and guided by the Conflict Theory of Decision Making (Janis & Mann, 1977) is also warranted as this theory has not been used widely in the past with breast cancer populations and factors that influence their decision-making for surgery.

Other studies should also focus on how women adjust to their breast cancer at varying time intervals in the future, with particular attention to satisfaction with treatment decisions and/or decision regret. This would help all health professionals to consider ways of facilitating "better" decision-making. As MHLC has not been widely considered as a factor in women's decision-making for surgical treatment for breast cancer, further work with this construct and its role in decision-making is also suggested.

Further investigation as to the factors that influence decision-making by rural women including indigenous women is also warranted if nurses are to better care for women living in these areas. Informed consent leading to appropriate choices for all women should be encouraged by all health professionals.

### Conclusion

This study has identified and described factors that women with Stage I and Stage II Breast Cancer in WA perceived to be important considerations when selecting their surgical treatment. Implications for clinical nursing practice and recommendations for future research have been provided.

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## APPENDIX A

### Definition of Terms

Definitions of terms specific to this study are provided in this section.

#### Adjuvant Therapy

“Any treatment used in conjunction with another to enhance its efficacy” (Burr, Brooker, Weller & Wells, 1991, p. 11). Depending on the stage of breast cancer, type of surgery chosen for treatment and the oestrogen receptor status of the individual, adjuvant therapy includes a combination of radiotherapy, systemic chemotherapy or hormonal treatment.

#### Breast Conserving Treatment (BCT)

A term used to describe surgical treatment for early stage breast cancer where the aim is to conserve the breast and remove only the tumour. Also termed Breast Conserving Surgery, Breast Conservation, Tumourectomy and Lumpectomy.

#### Breast Reconstruction

A breast reconstruction is a surgical technique whereby either breast implants, tissue expanders or the patients’ own tissue is used to reconstruct the breast following Mastectomy. The procedure may be carried out at the time of Mastectomy or at a later date (Allen, 1997).

#### Cancer

“A general term which describes malignant growths in tissue” (Burr, Brooker, Weller & Wells, 1991, p. 83).

#### Chemotherapy

A specific treatment of disease which uses chemical compounds (Burr Brooker, Weller & Wells, 1991). Common adjuvant chemotherapy for early stage breast cancer

includes a systemic course of “Cyclophosphamide, Methotrexate and 5-Fluorouracil (CMF)” (National Health and Medical Research Council, 1995, p. 49).

### Lumpectomy

Best conserving treatment which involves surgical removal of the breast lump together with an area of surrounding breast tissue with clear histologic margins and axillary dissection. This is later followed by a course of breast irradiation (Kinne, 1990). The aim is to only remove the breast lump and preserve the remainder of the breast in a cosmetically acceptable manner.

### Metastasis

The term used to describe the way disease (in particular, cancer) is transferred or spread from one part of the body to another. This spread occurs through blood vessels, via lymph channels or across body cavities (Burr, Brooker, Weller & Wells, 1991).

### Modified Radical Mastectomy (MRM)

A surgical procedure whereby the breast is removed with or without division or excision of the pectoralis minor muscle of the chest. The pectoralis major muscle is left intact. Axillary lymph node dissection may range from sampling to full dissection (Henderson, Harris, Kinne & Hellman, 1989). Often referred to as Mastectomy.

### Radiotherapy

The use of radiation which includes x-rays or gamma rays to destroy tumours (National Health and Medical Research Council, 1995). Used as an adjuvant treatment in early stage breast cancer following BCT. A course of treatment usually involves daily return visits for approximately six weeks. Radiotherapy is also referred to as XRT.

### Staging of Cancer

An expression which describes the anatomic extent of the disease based initially on clinical assessment. Assessment includes the initial physical examination, pathology and radiological evaluation. This clinical staging system is adopted by the International Union against Cancer (UICC) and the American Joint Commission on Cancer Staging and End Results Reporting (AJC). It is based on the tumour-nodes-metastases (TNM) system (Henderson, Harris, Kinne & Hellman, 1989).

#### Stage I Breast Cancer.

The first stage of breast cancer which involves breast tumours two centimetres or less (or no tumour as such), with or without fixation to the underlying pectoral fascia or muscle. Axillary nodes may not be palpable or may be movable, but not considered to contain growth. There is no distant spread of the disease (Henderson, Harris, Kinne & Hellman, 1989).

#### Stage II Breast Cancer.

The second stage of breast cancer. This stage includes:

1. no palpable breast tumors, but movable axillary nodes considered to contain growth with no evidence of distant spread of the disease,
2. breast tumours two centimetres or less with or without fixation to the chest wall with movable axillary nodes considered to contain growth but no evidence of distant metastasis; and
3. breast tumours greater than two centimetres, but not more than five centimetres with no palpable axillary nodes or movable axillary nodes which may or may not be considered to contain growth, but with no evidence of distant metastasis (Henderson, Harris, Kinne & Hellman, 1989).

### Tamoxifen

A synthetic drug used as an adjuvant treatment following surgical treatment of breast cancer. It blocks the effect of oestrogen (a naturally occurring hormone in the body) on which breast cancer tumours are dependant. It is more effective in women who have oestrogen receptor (ER) positive tumours although women with ER negative tumours sometimes take the drug as well (National Health and Medical Research Council, 1995).

## APPENDIX B

### Demographic Questionnaire

These questionnaires are only for women who were diagnosed with stage one or stage two breast cancer within the last twelve months.

If you have stage three or stage four breast cancer you only need to answer question number 1. Then please return all of the questionnaires in the envelope provided. Thank you for your interest.

For those women with stage one or stage two breast cancer please circle the relevant answer from the following questions or complete the blank spaces.

If you are unsure of the stage of your breast cancer at diagnosis or want help with any of the items, please ring Barbara Mastaglia on 4465324 or Davina Porock on 2738623.

1. What stage of breast cancer did you have when you were first diagnosed?

(1) Stage One: breast lump less than two centimetres and negative lymph nodes.

(2) Stage Two: breast lump between two to five centimetres with positive or negative lymph nodes but no spread of the disease.

(3) Stage Three: breast lump greater than five centimetres with invasion of the chest wall and positive lymph nodes but no spread of the disease.

(4) Stage Four: breast lump of any size with positive or negative lymph nodes and distant spread of the disease.

(5) Do not know

(6) Not sure

2. How old were you at your last birthday? \_\_\_\_\_

3. Please indicate your marital status:
- (1) Never married
  - (2) Married
  - (3) Widowed
  - (4) Divorced
  - (5) DeFacto
4. What is the highest level of education you completed?
- (1) Primary school
  - (2) Year 10 (lower secondary school)
  - (3) Year 12 (upper secondary school)
  - (4) TAFE
  - (5) University diploma or degree
  - (6) Higher Degree
  - (7) Other, please describe \_\_\_\_\_
5. In which country were you born? \_\_\_\_\_
6. Is English your first language spoken at home?
- (1) Yes
  - (2) No
- If No, please indicate language spoken \_\_\_\_\_
7. Where do you live?
- (1) Metropolitan area
  - (2) Country region
8. Please insert your postcode \_\_\_\_\_



9. Do you have private health insurance?
- (1) Yes
- (2) No
10. Please indicate your religious denomination \_\_\_\_\_
11. What type of surgery for breast cancer did you have?
- (1) Removal of breast (Modified Radical Mastectomy, Mastectomy)
- (2) Removal of lump (Lumpectomy)
- (3) No surgery
12. Did you attend a Breast Assessment Clinic (special breast clinic)?
- (1) Yes
- (2) No
- (3) Not sure
13. When were you first diagnosed with breast cancer?
- Year \_\_\_\_\_ Month \_\_\_\_\_
14. Please state the date of your surgery:
- Day \_\_\_\_\_ Month \_\_\_\_\_ Year \_\_\_\_\_
15. Did you have Radiotherapy (x-ray treatment) after your surgery?
- (1) Yes
- (2) No
16. Did you have Chemotherapy (anti cancer drug treatment) after your surgery?
- (1) Yes
- (2) No

17. Are you currently taking any tablets such as Tamoxifen?

(1) Yes

(2) No

(3) Not sure of treatment

If Yes, please name the treatment \_\_\_\_\_

18. Have any other members of your family such as your mother, grandmother or sister had breast cancer?

(1) Yes

(2) No

(3) Not sure

(4) Don't know

If Yes, please indicate their relationship to you \_\_\_\_\_

19. What work did you do before you had surgery for your breast cancer?

\_\_\_\_\_

20. What work do you do now? \_\_\_\_\_

21. Do you have any dependant children in your care?

(1) Yes

(2) No

If Yes, please indicate their age or ages \_\_\_\_\_

## APPENDIX C

### Factor List

This questionnaire looks at possible factors which you may have considered when deciding on treatment for your breast cancer.

Please read each of the following statements and think about when you were making **your decision** for surgery for your breast cancer.

Consider whether the statements reflect something that was important to you when you made your decision or whether it reflects something, which you feel, made you decide in favour of either a Modified Radical Mastectomy (removal of breast), Lumpectomy (removal of lump) or not having surgery.

Indicate how important the following statements were to you. There are no right or wrong answers to these questions. I am interested in knowing what really influenced **your** decision.

Please circle an answer from the following statements that best reflects that statement's importance for you when you made your decision.

0 = Not at all important

1 = Not very important

2 = Important

3 = Very important

4 = Extremely important

5 = Cannot recall

6 = Not applicable to my situation (applies only to some questions)

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| 1. Knowing of a friend or family member's experience with breast cancer and/or mastectomy (any type of mastectomy). | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Knowing of a friend or family member's experience with Lumpectomy.   | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. Knowing of my surgeon's preference for the type of surgery I should have.  | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. Knowing the preference of someone important to me for the type of surgery I should have.                         | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. Fear of the cancer returning.  | 0 | 1 | 2 | 3 | 4 | 5 |   |
| 6. The inconvenience of daily return visits for Radiotherapy treatment.   | 0 | 1 | 2 | 3 | 4 | 5 |   |

- 0 = Not at all important
- 1 = Not very important
- 2 = Important
- 3 = Very important
- 4 = Extremely important
- 5 = Cannot recall
- 6 = Not applicable to my situation (applies only to some questions)

7. Fear of Radiotherapy.	0	1	2	3	4	5	
8. Wanting to avoid the possible side effects of Radiotherapy.	0	1	2	3	4	5	
9. How I would feel about losing a breast.	0	1	2	3	4	5	
10. How I think my partner would feel about my losing a breast.	0	1	2	3	4	5	6
11. The fact that there is no difference between either a Modified Radical Mastectomy or Lumpectomy with Radiotherapy in long-term survival.	0	1	2	3	4	5	
12. The possibility of breast reconstruction in the future.	0	1	2	3	4	5	
13. Wanting to ensure that no further surgical treatment would be required in the future.	0	1	2	3	4	5	
14. Fear of dying from cancer.	0	1	2	3	4	5	
15. Concerns about the loss of mobility or strength in arm.	0	1	2	3	4	5	
16. Concerns about the amount of pain involved.	0	1	2	3	4	5	
17. The financial cost of surgery.	0	1	2	3	4	5	

18. Please list any other factors which influenced your decision.

19. Below are sources of information you may have used when making your decision. Please rank them from 1 to 10 to indicate how important they were in helping you make your decision about surgery.

1 = highest importance

10 = lowest importance

☐ Friends

☐ Scientific Journals

☐ Surgeon

☐ Cancer Foundation

☐ Nurse

☐ Family

☐ Breast Assessment Clinic (special breast clinic)

☐ Magazines, Newspapers and TV

☐ General Practitioner (family doctor)

☐ Information from elsewhere, please indicate \_\_\_\_\_

\_\_\_\_\_

Women may have different feelings about how much they wished to be involved in making a decision about having a Mastectomy, a Lumpectomy, or no surgery.

Please read each of the following statements and circle the number that best describes how you felt about being involved in making this decision.

20. I participated in the decision as much as I wanted to.

1. Strongly agree
2. Somewhat agree
3. Neither agree nor disagree
4. Somewhat disagree
5. Strongly disagree
6. Cannot recall

21. I had enough time to make my decision.

1. Strongly agree
2. Somewhat agree
3. Neither agree nor disagree
4. Somewhat disagree
5. Strongly disagree
6. Cannot recall

22. I had enough information to make my decision.

1. Strongly agree
2. Somewhat agree
3. Neither agree nor disagree
4. Somewhat disagree
5. Strongly disagree
6. Cannot recall

23. I was so upset at the time of the decision that I had a hard time thinking clearly about what I wanted to do.

1. Strongly agree
2. Somewhat agree
3. Neither agree nor disagree
4. Somewhat disagree
5. Strongly disagree
6. Cannot recall

---

The following questions relate to medical advice you may have received **before** making your decision about surgery. Please circle the relevant answer from the following questions.

24. With how many medical doctors did you discuss your breast cancer surgery?

1. Please insert number \_\_\_\_\_
2. Cannot recall

25. (A) Did you see a General Practitioner (family doctor) about your breast cancer surgery?

1. Yes
2. No
3. Cannot recall

(B) Did he/she express a preference for a particular surgery?

1. Yes
2. No
3. Cannot recall

(C) What was his/her preference?

1. Modified Radical Mastectomy/Mastectomy (removal of breast)
2. Lumpectomy (removal of lump)
3. No surgery

26. (A) Did you see a surgeon about your breast cancer surgery?

1. Yes
2. No
3. Cannot recall

(B) Did he/she express a preference for a particular surgery?

1. Yes
2. No
3. Cannot recall

(C) What was his/her preference?

1. Modified Radical Mastectomy/Mastectomy (removal of breast)
2. Lumpectomy (removal of lump)
3. No surgery

27. (A) Did you see another surgeon for a second opinion about your breast cancer surgery?

1. Yes
2. No
3. Cannot recall

(B) Did he/she express a preference for a particular surgery?

1. Yes
2. No
3. Cannot recall

(C) What was his/her preference?

1. Modified Radical Mastectomy/Mastectomy (removal of breast)
2. Lumpectomy (removal of lump)
3. No surgery

28. (A) Did you see a Medical Oncologist (specialist in Chemotherapy) about your breast cancer surgery?

1. Yes
2. No
3. Cannot recall

(B) Did he/she express a preference for a particular surgery?

1. Yes
2. No
3. Cannot recall

(C) What was his/her preference?

1. Modified Radical Mastectomy/Mastectomy (removal of breast)
2. Lumpectomy (removal of lump)
3. No surgery

29. (A) Did you see a Radiation Oncologist (specialist in Radiotherapy) about your breast cancer surgery?

1. Yes
2. No
3. Cannot recall

(B) Did he/she express a preference for a particular surgery?

1. Yes
2. No
3. Cannot recall

(C) What was his/her preference?

1. Modified Radical Mastectomy/Mastectomy (removal of breast)
2. Lumpectomy (removal of lump)
3. No surgery

30. (A) Did you consult alternate therapies before making your decision about surgery?

1. Yes
2. No
3. Cannot recall



If No or Cannot recall please go to question 31. If Yes, please answer the following:

(B) Which alternate therapists did you see?

1. Homeopath
2. Naturopath
3. Other, please describe \_\_\_\_\_

(C) What was his/her advice about surgery? Please comment:

31. (A) Did someone important to you express a preference for the type of surgery you should have?

1. Yes
2. No
3. Cannot recall

(B) If Yes, please indicate who that person was by circling the correct answer from the following list. If No or Cannot recall please go to question 32.

1. Partner
2. Friend
3. Family Member
4. Clergy or Spiritual Adviser
5. Other person, please indicate who \_\_\_\_\_

(C) Please indicate what that person's preference was:

1. Modified Radical Mastectomy/Mastectomy (removal of breast)
2. Lumpectomy (removal of lump)
3. No surgery
4. Other advice, please describe \_\_\_\_\_

32. In thinking about your answers to questions 24 to 31, did you receive conflicting advice from any of the sources you used?

1. Yes
2. No
3. Cannot recall

Please comment:

33. To what extent did you want to participate in the decision about whether to have a Modified Radical Mastectomy/Mastectomy, a Lumpectomy or no surgery?

Please circle one of the following:

1. I wanted it to be fully my decision
2. I wanted it to be partly my decision and partly someone else's
3. I wanted someone else to make the decision
4. I cannot recall

34. If you wanted the decision to be partly yours or someone else's, whom did you want that person to be?

Please circle one of the following:

1. Spouse or Partner
2. Surgeon
3. Friend
4. Nurse
5. General Practitioner (family doctor)
6. Other person, please indicate who \_\_\_\_\_
7. Cannot recall

35. Did you feel that you really had a choice about the type of surgery you wanted to have?

1. Yes
2. No
3. Cannot recall

Please comment:

36. If you could have changed anything about the decision-making process, what would you have changed?

Please comment:

37. Please feel free to comment on any other issues you had regarding decision making for surgery for your breast cancer.

## APPENDIX D

## Multidimensional Health Locus of Control Scale: Form B

This is a questionnaire to look at beliefs that individuals have about general health issues. There is no right or wrong answer to any of these questions.

Please indicate your response to the following statements by circling the number which best reflects your personal beliefs.

1. If I become sick, I have the power to make myself well again.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

2. Often I feel that no matter what I do, if I am going to get sick, I will get sick.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

3. If I see an excellent doctor regularly, I am less likely to have health problems.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

4. It seems that my health is greatly influenced by accidental happenings.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

5. I can only maintain my health by consulting health professionals.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

6. I am directly responsible for my health.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

7. Other people play a big part in whether I stay healthy or become sick.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

8. Whatever goes wrong with my health is my own fault.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

9. When I am sick, I just have to let nature run its course.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

10. Health professionals keep me healthy.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

11. When I stay healthy, I'm just plain lucky.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

12. My physical well being depends on how well I take care of myself.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

13. When I feel ill, I know that it is because I have not been taking care of myself properly.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

14. The type of care I receive from other people is what is responsible for how well I recover from an illness.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

15. Even when I take care of myself, it's easy to get sick.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

16. When I become ill, it's a matter of fate.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

17. I can pretty much stay healthy by taking good care of myself.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

18. Following doctor's orders to the letter is the best way for me to stay healthy.

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Slightly agree
5. Agree
6. Strongly agree

**Thank you for your time in answering these questions.**

## APPENDIX E

## Letter of Permission from Professor Sandra Ward



School of Nursing  
University of Wisconsin-Madison

Center for Health Sciences  
Clinical Science Center  
600 Highland Avenue  
Madison, Wisconsin 53792-2455  
FAX: 608/263-5332

May 24, 1996

Barbara Mastaglia  
46 Marian Street  
Innaloo  
Western Australia 6018

Dear Ms. Mastaglia:

Enclosed you will find a copy of the BCIT and BCIT-R, the instrument reported in Cancer Nursing in 1989 and 1990, respectively. The 1990 article includes information about reliability and validity. You have my permission to use both the BCIT and the BCIT-R in your research project. I would like to receive a summary of any findings that result from your work with these instruments.

Best wishes in your endeavors. Please feel free to call or write if you have any questions that are not answered in the 1989 and 1990 articles.

Sincerely,

  
Sandra Ward, PhD, RN

SW:rrk

## APPENDIX F

## Letter of Permission from Confidentiality of Health Information Committee, Health

Department of Western Australia



Western Australia

Health Department of Western Australia

Yours truly  
 Ours truly  
 Enquiries

Ms Barbara Mastaglia



Dear Ms Mastaglia,

re: #96020 Factors Which Influence Women's Decisions for  
 Choice of Primary Surgery for Stage I and Stage II  
 Breast Cancer.

The protocol for the above project has been reviewed by the Confidentiality of Health Information Committee (CHIC) on behalf of the Commissioner of Health.

Approval has been granted to Barbara Mastaglia and Davina Poroch for the purposes of the above project expected to end November 1997, subject to the covering letter of introduction to be sent out by the Cancer Registry of the Health Department of Western Australia.

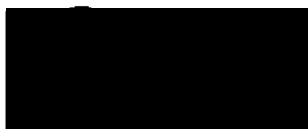
Dr Tim Threlfall, Senior Medical Officer of the Cancer Registry has been notified of this approval.

CHIC has a mandate to monitor the use of any data released for access. This monitoring includes the possibility of spot personal visits, a progress report which will be required annually (for long term projects), and a report on the outcome of the project required at the completion of the project. *If the project is requested to be greater than three years, a comprehensive major review will be conducted.* Forms regarding these will be sent to you at the appropriate times.

Yours sincerely



Myra Cane  
 CHAIRPERSON  
 CONFIDENTIALITY OF HEALTH INFORMATION COMMITTEE



Dr Ian Rouse  
 COMMISSIONER'S REPRESENTATIVE

15 April 1997

189 Royal Street East Perth Western Australia 6004 Tel (09) 222 4222 TTY 1800 067 211  
 Letters PO Box 8172 Stirling Street Perth Western Australia 6849

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## APPENDIX G

## Letter of Introduction from Manager of Health Information Centre, Health Department of

Western Australia



Health Department of Western Australia

Western Australia

Your ref  
Our ref  
Enquiry no.

## HEALTH INFORMATION CENTRE

Dear Madam

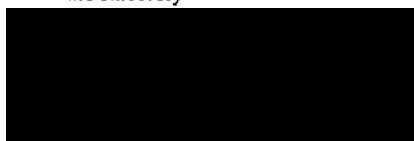
**Factors which influence women's decisions for choice of primary surgery for breast cancer**

I am writing to invite you to participate in a research study being carried out by Ms Barbara Mastaglia from Edith Cowan University. I have enclosed the information she has supplied to us for your consideration. As required by law, your name has been notified to the Cancer Registry of the Health Department of Western Australia as a result of medical tests. However neither your name nor any personal details have been released to Ms Mastaglia or to any other person.

This project has been considered by the Health Department's Confidentiality of Health Information Committee, which believed that the project could be of significant public health benefit. This committee directed that no names should be released, but rather that the Department should approach you on Ms Mastaglia's behalf. Should there be any problems with the study or with the material supplied, please direct enquiries directly to Ms Mastaglia by telephone, on (09) [REDACTED]. If you would like to discuss any other aspect please call Dr Tim Threlfall, Medical Officer of the WA Cancer Registry on (09) 222 4022.

Thank you for considering this request.

Yours sincerely



Dr Ian Rouse  
GENERAL MANAGER,  
HEALTH INFORMATION CENTRE  
/5/- May 1997

(r/letters704231f1)

189 Royal Street East Perth Western Australia 6004 Tel (09) 222 4222 TTY 1800 067 211  
Letters PO Box 8172 Stirling Street Perth Western Australia 6849

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## APPENDIX H

## Cover Letter to Participants

**FACTORS WHICH INFLUENCE WOMEN'S DECISIONS FOR CHOICE OF  
PRIMARY SURGERY FOR STAGE I AND STAGE II BREAST CANCER.**

My name is Barbara Mastaglia and I am a Registered Nurse currently undertaking a study on factors which influence women's decisions for choice of surgery for early stage breast cancer. This study is part of my Bachelor of Nursing (Honours) degree course at the Edith Cowan University at Churchlands in Western Australia.

The purpose of this study is to identify what factors women with Stage I and Stage II breast cancer in Western Australia see as important when choosing between either a Mastectomy or Lumpectomy.

Knowledge gained from this study will provide a greater understanding of what information women require in order to help them in the decision making process. It will also assist health professionals to enhance their care of women and their families around the time of decision making and during subsequent treatments by providing useful information and support.

As you have recently had a diagnosis of breast cancer notified to the Cancer Registry at the Health Department of Western Australia, your name has been selected in order that you might consider taking part in this study. Participation is voluntary and should you decide not to take part your decision will be respected. Naturally your decision will not affect any aspect of your ongoing support or treatment for your breast cancer.

If you are willing to take part, please complete the three questionnaires enclosed which will take approximately 30-45 minutes. A FreePost envelope is provided to return the answers.

If you do not wish to take part, please tick the box at the bottom of this page and return the questionnaires in the enclosed envelope.

Your name will remain anonymous, only your responses will be coded and analysed. You will not be identified by your written responses to open questions as these will be summarised in group form.

**Please do not write your name or specific names of others such as hospitals, clinics or doctors on the questionnaires.**

There is the possibility that in recalling the decision-making experience from the past, you may experience some discomfort in going over this period of time again. This might be relevant if the decision time was particularly difficult for you or other members of your family. The Cancer Foundation of Western Australia (who are not involved in this study) has a help line number available; **Tel: 131120** if you feel the need for support as a result of taking part in this study and you need to talk to someone about your feelings.

However, this study provides you with the opportunity to share your experience of decision making by describing what the relevant issues were for you at the time. This will help women in the future.

Should you have any queries or concerns about this study feel free to contact me on Tel: [REDACTED] or my research supervisor Ms Davina Porock at the School of Nursing at Edith Cowan University, Churchlands on Tel: 2738623.

Thank you for considering my request to take part in this study.  
Yours sincerely

BARBARA MASTAGLIA

-----  
I do not wish to participate [ ]

## APPENDIX I

## Reminder Letter to Participants

**FACTORS WHICH INFLUENCE WOMEN'S DECISIONS FOR CHOICE OF  
PRIMARY SURGERY FOR STAGE I AND STAGE II BREAST CANCER.**

A letter was sent to you approximately two weeks ago asking you to consider taking part in the above research study.

Because no names or code numbers were used on the letter or questionnaires, I have no way of knowing whether you have returned your questionnaire. Therefore this reminder letter is to let you know that there is still time for you to take part.

If you would like to take part just complete the questionnaires and return them in the envelope which was provided.

If you do not wish to take part in the study or you have already returned the questionnaires please ignore this letter.

Thank you for your interest in my study.

Yours sincerely

BARBARA MASTAGLIA

## APPENDIX J

### Summary of Telephone Calls from Women

The researcher, her supervisor and Dr Timothy Threlfall at Health Information Centre, Health Department of Western Australia received a number of telephone calls regarding aspects of this study. A summary of calls received by each individual is provided.

#### Telephone Calls to Researcher

Ten telephone calls were received by the researcher following the initial mail out of questionnaires. Thirteen calls were taken after the reminder letters were sent.

#### Queries Following Initial Mail Out

1. Query regarding stage of breast cancer, Confidentiality of Health Information Committee and a general discussion about radiotherapy and personal circumstances of the caller.
2. Caller discussed her story of treatment for breast cancer and wondered if she could participate in the study, as she felt she did not have a choice regarding her surgery.
3. The caller questioned whether she could type her history separate to the questionnaire.
4. Concern was voiced regarding a question in the Factor List. The caller had not discussed this particular point with her doctors and there was also concern for other women that they likewise may have had a problem with this particular question. There also was some concern by the caller regarding the validity of the study in general.
5. The caller was going to have radiotherapy at a later date and wished to mention this fact and also wanted to discuss her personal circumstances.
6. A daughter phoned on behalf of her elderly mother asking advice regarding completing the questionnaire.

7. A mother phoned on behalf of her daughter who was unable to complete the questionnaire due to an intellectual disability and requested advice regarding completing the questionnaire.
8. The caller had lost the envelope for returning the questionnaires and was sending them to the HDWA.
9. A country caller wished to discuss her circumstances and what resources were available regarding seminars and other sources of information for women with breast cancer.
10. Help was requested in determining stage of breast cancer.

#### Queries Following Mail Out of Reminder Letters

1. Query regarding stage of breast cancer.
2. Caller wished to notify researcher that she had returned her questionnaires shortly after receiving them.
3. Whilst the caller wished to take part in the study, she had lost the questionnaires and requested another set.
4. The caller discussed her health following breast reconstruction and required help in interpreting three questions in the questionnaire.
5. Caller discussed her medical circumstances and experience with breast cancer and requested the researcher's address as she had lost the envelope in which to return the questionnaires.
6. Three callers stated that they had sent their replies.
7. The caller required help regarding how to enter her stage of breast disease.
8. Caller had lost the reply paid envelope and requested the researcher's address to return questionnaires.

9. Even though the caller worked in a health related area, she was unaware of the Cancer Registry and wanted some information about it. The caller also wanted to know if she still had time to return her questionnaires.
10. A Registered Nurse called on behalf of an aboriginal client requesting advice regarding completing the questionnaires.
11. A caller had been on holidays and wanted to know if she still had time to complete the questionnaires.

#### Telephone calls to Dr Threlfall HDWA

Dr Threlfall received approximately six telephone calls concerning aspects of this study. These were:

1. An elderly woman enquired about the study.
2. A nurse who had many years of nursing experience was unaware of the Cancer Registry.
3. Caller explained that her mother was unable to speak English and that she would complete the questionnaires on her behalf.
4. A caller questioned why she had received a reminder letter.
5. After receiving her reminder letter, a caller stated that she had not received the questionnaires, so another set was posted to her.
6. Caller questioned why it was necessary to do the study and queried the ethics of this.

#### Queries Received by Researcher's Supervisor

At the time of the mail out the researcher's supervisor was undertaking a study in a Radiology department of a Perth hospital. Three women who had received an invitation to take part in the present study also attended this clinic and recognised the name of the supervisor and consequently met her. The two calls received by the supervisor concerned

firstly whether there was still time to take part in the study, and secondly, why a reminder letter had been sent to the woman.



## APPENDIX K

## Ethics Approval from Edith Cowan University



**EDITH COWAN  
UNIVERSITY**

PERTH - WESTERN AUSTRALIA

Pearson Street, Churchlands  
Western Australia 6018  
Telephone (09) 383 8333  
Facsimile (09) 383 8661

7 November 1996

**Committee for the Conduct of Ethical Research**

Ms Barbara Mastaglia  
Health & Human Sciences  
Churchlands Campus

Dear Ms Mastaglia

**Re: Ethics Approval**

**Code:** 96-117

**Project Title:** *Factors which influence women's decisions for choice of primary surgery for Stage I and Stage II breast cancer*

This project was reviewed by the Committee for the Conduct of Ethical Research.

I am pleased to advise that the project complies with the provisions contained in the University's policy for the conduct of ethical research, and has been cleared for implementation.

Period of approval is from 28 February 1997 to 30 November 1997.

Yours sincerely



**ROD CROTHERS**  
Executive Officer

*Please note: Students conducting approved research are required to submit an ethics report as an addendum to that which they submit to their Faculty's Higher Degrees Committee.*

cc. Ms Davina Porock, Supervisor  
Mrs Genie Sherratt, Administrative Officer

**JOONDALUP CAMPUS**  
Joondalup Drive, Joondalup  
Western Australia 6027  
Telephone (09) 405 5555

**MOUNT LAWLEY CAMPUS**  
2 Bradford Street, Mount Lawley  
Western Australia 6050  
Telephone (09) 370 8111

**CHURCHLANDS CAMPUS**  
Pearson Street, Churchlands  
Western Australia 6018  
Telephone (09) 383 8333

**CLAREMONT CAMPUS**  
Goldsworthy Road, Claremont  
Western Australia 6010  
Telephone (09) 383 0333

**BUNBURY CAMPUS**  
Robertson Drive, Bunbury  
Western Australia 8230  
Telephone (097) 91 0222

## APPENDIX L

## Letter of Permission from Cancer Foundation of Western Australia

Telephone: 381 4515  
Fax: 381 4523



1  
AUSTRALIAN  
CANCER RESEARCH  
FOUNDATION

4 December 1996

Barbara Mastaglia  
[REDACTED]

Dear Barbara

Thank you for your letter requesting permission to include the Cancer Helpline number in your introductory letter. I have asked the coordinator of the Breast Cancer Support Service to review the letter and on the strength of her comments, can see no reason why permission to use the Helpline number should not be given.

We do feel however, that you could explain the process of accessing the Cancer Registry so women will be not be left feeling exposed because they believe their details are available to just anyone.

If you have not already done so, I would suggest that you contact the National Breast Cancer Centre to acquaint them of your proposed research and to ascertain if anyone else has conducted similar research. I know that they are very interested in the choices women make regarding their treatment.

Good luck with your project, I would be very interested in seeing the end results.

Yours sincerely

[REDACTED]

Anne Tocher  
Patient Services Manager.