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Women's decision styles and decision satisfaction related to their choice of surgical treatment for early breast cancer: Implications for a systematic decision support role for nurses.

by

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DEDICATION

Firstly, the research study outlined in this thesis is dedicated to my "greatest achievements", my children *Jessica* and *Hayden,* and husband *David* for his support and patience for the study. Secondly, and certainly not least, this work is dedicated to the exceptional generosity of the women who participated in the study to help other women diagnosed with breast cancer.

"Nothing is more difficult, and therefore more precious, than being able to decide"

Napoleon Bonaparte (Maxims, 1804)

And finally to my parents *Charlie* and *Norma*, and my brother *Gregory* who
have always given me unconditional love and support, I have been truly blessed.

"*There are ways of thinking that we don't know about. Nothing could be more important or precious than the knowledge, however unborn. The sense of urgency, the spiritual restlessness it engenders, cannot be appeased"*

Sussan Sontag (1933) US writer and critic

ABSTRACT

Background: Over 13,000 Australian women are diagnosed with breast cancer each year. Women diagnosed with early breast cancer are generally asked by their doctor to choose between either mastectomy or breast conservation surgery with radiation therapy as initial treatment. Following a breast cancer diagnosis, women's cognitive resources and abilities are often overloaded; subsequently they often feel distressed and confused about making the treatment choice between the surgical options offered to them. Women frequently turn to nurses for decision support and information at this time. Recently developed decision aids are available but these are not evidence-based nor do they assess women's decision styles to profile individual decision support interventions. Research shows that women's process for making decisions are affected not only by their decision styles but also by their levels of distress. This initial decision-making process and treatment decision ultimately affect women's decision satisfaction and psychological outcomes. No published studies, nationally or internationally, have investigated the relationships between these variables.

Research design and methods: The purpose of this prospective, longitudinal exploratory cohort study was to investigate the relationship between Queensland women's decision styles and decision satisfaction, three to four months *after* their initial surgical treatment for early breast cancer. The non-probability sample of women (N = 132) were recruited from three locations in Queensland *after* women were diagnosed with early breast cancer and *before* treatment commenced. Data were collected using the *Michigan Assessment of Decision Styles* (*MADS*, Pierce 1995), and the *Patient Treatment Decision Satisfaction* questionnaire (*PTDS*) developed by the researcher (Budden & Pierce, 2001). The *MADS* questionnaire consists of 16 items describing patients' pre-decision behaviours under the following four factors: *Deferring Responsibility* (α= 0.76); *Avoidance* (α= 0.63)*; Information Seeking* (α= 0.80); and *Deliberation* (α= 0.85). The *Patient Treatment Decision* (TDS) questionnaire contains 16 items divided into three dimensions namely: *Decision Process Satisfaction* (α= 0.91); *Decision Outcome Satisfaction* (α= 0.95); and *Global Decision Satisfaction* (α= 0.95).

Results: Data were analysed using descriptive and inferential statistics, which included stepwise multiple linear regression techniques. Specifically, a statistically significant positive relationship was identified between women's decision styles and their decision satisfaction at three to four months (n = 104) following their initial surgery. A positive relationship was identified between women's *Information Seeking* and *Decision Process Satisfaction; Deliberation* and *Decision Outcome Satisfaction; Deferring Responsibility* and *Decision Outcome Satisfaction;* and *Deferring Responsibility* and *Global Decision Satisfaction*. In contrast, a significant negative relationship was found between women's *Avoidance* and *Global Decision Satisfaction*. The majority of women agreed, or strongly agreed, with all the *Deliberation* items (75.1%) and *Deferring Responsibility* items (84.8%). A smaller proportion (2.3%) of women agreed, or strongly agreed, with all the *Avoidance* items and the *Information Seeking* items (37.8%). Over half (53.7%) of the women agreed, or strongly agreed, with all the *Decision Process Satisfaction* items; 67.8% of women agreed, or strongly agreed, with all the *Decision Outcome Satisfaction* items; and 55.9% agreed, or strongly agreed, with all the *Global Decision Satisfaction* items.

Conclusions: The major outcome of this research was the clear relationship between women's decision styles to their decision satisfaction at three to four months following early breast cancer treatment. Nurses caring for women with breast cancer do not currently have any evidence-based assessment tools to guide decision support interventions based on women's decision styles. The *MADS* instrument is an efficient and feasible assessment instrument that can be used by nurses to profile women's decision styles to direct evidence-based decision support interventions. Thus, the delivery of individual decision support interventions by nurses using the *MADS* instrument can increase women's post-treatment decision satisfaction following early breast cancer treatment.

Clinical Implications: This study contributes to the discipline of nursing science by building evidence for best practice guidelines in the delivery of decision support interventions pre-treatment. The application of these guidelines will increase women's decision satisfaction post-treatment after a diagnosis of early breast cancer. The ultimate goal of evidence-based decision support interventions provided by nurses is to improve women's informed decision-making processes; minimise their psychological distress; and increase their decision satisfaction in selecting and following treatment for early breast cancer.

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STATEMENT OF SOURCES

DECLARATION

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution or tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

(Lea Budden) (Date)

STATEMENT OF OTHER CONTRIBUTIONS

I was privileged to be awarded five consecutive (2000-2004) competitive Merit Research Grants from James Cook University. This funding allowed me to access women in three costal locations in Queensland. However, I could not have completed this study without the enthusiasm, mentoring, knowledge, wisdom and unwavering support from my supervisors. Firstly, Professor Barbara Ann Hayes the Foundation Professor of Nursing Science at James Cook University, who travelled with me up and down the Queensland coast to discuss and gain support for the project from doctors and nurses. Her unwavering support and professionalism provided me with many opportunities and opened doors for data collection in the study.

Petra Gertrund Buettner my biostatistician supervisor at James Cook University, who helped me to understand and actually enjoy multivariate analysis. She quietly, patiently and persistently guided me to expand my knowledge of quantitative research. Without her flexibility, openness and support I would not have been able to complete the data analyses of this project.

Penny Fay Pierce my supervisor in decision science at University of Michigan, USA. Penny generously invited me to build on her work and develop new knowledge. Her beneficial knowledge and encouragement to my study are deeply appreciated. The time I spent with her at the University of Michigan was endlessly, inspiring and special.

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In addition, my heartfelt gratitude to Dr Elizabeth Beattie who introduced me to Penny Pierce PhD, RN and others at the University of Michigan. Liz always believed in my intellect and always wanted me to have a good education with the leading world scholars in and outside Australia. She also, introduced me to Shake Ketefian PhD, RN Dean of the Doctoral Program in the School of Nursing, University of Michigan. The commitment of Shake to the doctoral education of nurses outside the United States of America was overwhelming and forged my official link with Penny Pierce.

This journey as a part-time doctoral student has had many challenges, with twists and turns along the way. However, I have been fortunate to be surrounded by very talented people. My sincere thanks to Janese, Rosemary and Margo for their meticulous editorial comments and to Tara for her amazing computer processing skills (throughout the whole journey).

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CHAPTER 1- OVERVIEW OF STUDY

Introduction

The purpose of this prospective, longitudinal, cohort study is to investigate the relationship between the decision styles and decision satisfaction of Queensland women (N =132), three to four months after their choice of surgical treatment for early breast cancer. The hypotheses for this study are to test the relationship between women's decision styles and their decision satisfaction following treatment for early breast cancer.

There are no published studies, to date, nationally or internationally that have investigated the relationships between these variables. This is the first prospective, longitudinal study to use the *Michigan Assessment of Decision Styles* (*MADS*) questionnaire (Pierce, 1995a) and the newly developed questionnaire the *Patient Treatment Decision Satisfaction* (Budden & Pierce, 2001) as instruments to measure the relationship between women's decision styles and decision satisfaction following a surgical treatment choice for early breast cancer.

Background

Breast cancer remains a major cause of illness and death in women, particularly in the western world. Each year, approximately 13,000 Australian women are diagnosed with breast cancer with approximately 24% of these women aged younger than 50 years (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). A total of 2,641 Australian women in 2004 died of breast cancer (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). On the other hand, the mortality rate for breast cancer in Australia has fallen 2.0% per annum since 1990 and this positive trend has been primarily attributed to the introduction of the national breast-screening program. The availability of breast screening modalities, such as mammography, has resulted in more Australian women being diagnosed at earlier stages of the cancer. Using the international staging classification, the National Breast Cancer Centre defines early breast cancer in Australia as Stage I-IIA (National Breast Cancer Centre, 2001). This classification corresponds with tumours (nodes and metastases) that are T1-2, N0-1, M0 as currently defined by the International Union Against Cancer (National Health and Medical Research Council, 2001). Although in some cases women's mortality may not be reduced, the early detection and diagnosis of the disease allows them more choices for treatment.

Women and patients in general are now more informed about health care options through education and increasing technology and are often encouraged by their doctors to participate in choosing their medical treatment. Consequently, the treatment decisions are jointly shared between women and their doctor/s, and decision support is given by nurses. Shared decision-making with doctors allows women the opportunity to choose treatment that is more likely to be consistent with their values, preferences, and lifestyle (Charles, Whelan, Gafni, Willan & Farrell, 2003). For primary treatment of early breast cancer, women may choose between a modified radical mastectomy (with or without breast reconstruction) or breast conservation surgery (BCS) (i.e. lumpectomy with axillary lymph node clearance and postoperative radiation therapy) (National Breast Cancer Centre, 2001). Both of these surgeries (including axillary clearance) are reported to be equally effective in the treatment of early breast cancer (Early Breast Cancer Triallists' Collaborative Group, 1995; Fisher et al., 1989). After primary surgical treatment, some women must then decide whether to accept or decline adjuvant chemotherapy or hormonal therapy.

The diagnosis of a potentially life threatening disease such as breast cancer creates intense, emotional and sometimes psychological distress in women. At diagnosis, women are vulnerable to high levels of stress. Further the upheaval to women's emotional wellbeing following diagnosis and surgery places them at risk of developing body image concerns, sexuality problems and interpersonal difficulties in their relationships (National Health and Medical Research Council National Breast Cancer Centre, 2000). One Australian survey identified that 34% of women following diagnosis of breast cancer had high levels of psychological distress, 35.4% of women were still experiencing distress three months post diagnosis and up to 20% of women at twelve months post diagnosis (National Health and Medical Research Council National Breast Cancer Centre, 2000).

The evidence-based health care movement and the development of organisations such as the Cochrane Collaboration Centre and the Johanna Briggs Institute have captured the attention of health professions in the Western world. Accurate health information is now widely available to the public through the media and internet websites. This has lead to a paradigm shift in the last two decades from health professionals as being considered the 'expert' who assumes all responsibility for treatment decisions to inclusion of patients in sharing the responsibility in their own treatment decision. Thus, the resulting decision support interventions for patients are intended to provide better access to information, which is critical for informed treatment decisions. Such access will help patients form realistic expectations, which include their own values and preferences related to the treatment outcomes (Titler, Reoter & Corry 1996). In contrast to the current generic one-dimensional decision aids, research has found that decision support interventions result in patients experiencing higher In conclusion this chapter has provided a brief overview and introduction of the research study presented in this thesis. This included an outline of the background, research problem, significance and context of this research. Further, the following research components were described: the underpinning theoretical paradigm of the conceptual model Michigan Assessment of Decision Styles (*MADS)* (Pierce 1995); the ethical considerations of the study; and the key four questions with the central hypotheses. A summary of research methodology, data analysis and definitions of key terms were also used in this chapter. This chapter links logically to Chapter 2, which is a review and critique of the multidisciplinary literature relevant to this research treatment satisfaction and better health outcomes (Titler, Reoter & Corry 1996) post-treatment.

Research Problem

These psychologically vulnerable women are required, in a short time, to choose among options such as following the recommended treatment of the doctor; seeking a second opinion; or refusing any form of treatment. The responsibility by women to choose a treatment coupled with the cancer diagnosis can add to their already emotional burden and cognitive overload. Choosing a treatment option is further complicated for women who seek intervention, because they are asked to decide between alternate treatment options, and weigh up each modality's risks and benefits. Thus, women can become confused and unsure of how to make the decision and fear making the wrong one, which they may later regret.

Patient advocacy is a pivotal role for nurses and is demonstrated by the facilitation of patients' treatment decisions (Titler, Reiter & Corry, 1996). This role may be formalised by the introduction nationally of a small number of Specialist Breast Nurses (SBNs) or informally, by nurses caring for breast cancer patients. Nurses are in the frontline of healthcare for providing support and brokering treatment information between women and their doctors in both public and private health services. Breast cancer patients often seek further explanation from nurses about the treatment outcomes and possible consequences. Currently women's access to specialist services is limited, those that are available are located only in urban areas of Australia, and their distribution fluctuates between States and Territories. For example, in some states, private hospitals have specialised breast cancer services and in others, this care is provided by pubic hospitals. This situation often results in fragmented care received by breast cancer patients.

Many women do not know what process to use when choosing among medical and surgical treatments for early breast cancer and often seek decision support from nurses. The nursing role in supporting women in decision-making in this area is vital, because women often reflect at depth on their decision both before and after consulting doctors. Furthermore, women in regional, rural and remote areas often use a Registered Nurse as the primary health care provider, which is evidenced by the anecdotal reports by nurses who are regularly contacted in these regions for further information and support by these women. Unfortunately, there are no studies that guide nurses on how to assess women's decision styles and individually profile decision support interventions (evidence-based) when they are asked for assistance from women and their families.

Thus, the following main hypotheses were tested in this study.

Hypotheses and Questions

Hypotheses

The following hypotheses were tested in this study:

H0: There is **no** relationship between Queensland women's decision styles (*MADS-Information Seeking*, *Deliberation*, *Avoidance* and *Deferring Responsibility*) and women's decision satisfaction (*PTDS Decision Process Satisfaction*, *Decision Outcome Satisfaction* and *Global Decision Satisfaction*) as assessed 3 to 4 months after choosing surgical treatment for early breast cancer.

HA: There is **a** relationship between Queensland women's decision styles (*MADS-Information seeking*, *Deliberation*, *Avoidance* and *Deferring Responsibility*) and their decision satisfaction (*PTDS Decision Process Satisfaction*, *Decision Outcome Satisfaction* and *Global Decision Satisfaction*) as assessed 3 to 4 months after choosing surgical treatment for early breast cancer.

Research Questions

The research questions included in this study were:

1) What are the decision styles and processes of Queensland women who are choosing treatment for early breast cancer?
2) What are the psychological distress levels of Queensland women when choosing and following treatment for early breast cancer?
3) What is the decision satisfaction of Queensland women following treatment for early breast cancer?

4) Is there a relationship between Queensland women’s decision styles, their levels of psychological distress and decision satisfaction following early breast cancer treatment?

Significance of Research Study

Internationally, there is limited information known about how women, and indeed patients, choose among medical treatments for cancer. Furthermore, there are no published studies examining women’s decision styles, psychological distress levels and decision satisfaction, and how these factors influence the decision-making process and satisfaction of women. Few studies have been conducted to guide nurses in the most effective ways of providing women with information and support that suit women’s personal preferences, decision styles and which lead to their satisfaction. If nurses are to provide women with individualised decision support interventions, more evidence is needed to assist in developing tailored interventions for women’s decision-making in breast cancer treatment. For nurses to fulfil their role as holistic caregivers, evidenced-based interventions that empower women to participate in treatment decisions need to be developed. The desired outcome for decision support interventions is to improve women’s quality of life following a diagnosis of breast cancer. Improving women’s quality of life after breast cancer includes being satisfied with their chosen treatment/s as this is the rationale behind this thesis.

This information is particularly important for women with breast cancer because they may be offered different medical therapies, which may have equivalent success rates. When the outcomes seem equivalent, it can be difficult for women to choose among options all of which have undesirable adverse effects. However, if women are offered assistance in their decision-making, and if this assistance is matched to their values and personal preferences, it is proposed that women are more likely to be satisfied with their decision in both the short and long-term and have better psychological outcomes. Whereas, if women experience dissatisfaction with their decision following breast cancer treatment they are likely to experience post-decision regret and varying degrees of physical and psychological morbidity, well after the surgery and the treatment are completed.

Women frequently seek help from nurses on how to reach a decision that is, what process to follow to choose their preferred treatment option. Nurses currently do not have any structured methods to tailor this care. Yet, if nurses are to provide women with evidence-based decision support interventions, this information is mandatory in developing supportive measures for women when choosing between treatment options for early breast cancer and improve their decision satisfaction.

However, before evidenced-based decision support interventions can be further developed and evaluated, it is critical to obtain an understanding of women's decision styles, psychological distress levels and decision satisfaction regarding breast cancer. This information can only be determined through clinical investigation of women and by developing and testing assessment tools that specifically measure these variables. Increasing the understanding of women's decision-making processes and factors that influence women's treatment decisions can aid nurses in designing evidence-based decision support interventions. Evidence-based decision support by nurses can help facilitate women's informed consent to make quality decisions, which improves their decision satisfaction, post-surgical adjustment, and leads to less post-decision regret.

The ultimate goal of evidence-based decision support interventions provided by nurses is to improve women's informed decision-making process; minimise their psychological distress; and increase their decision satisfaction in selecting and following treatment for early breast cancer. The importance of this information has been acknowledged by the National Breast Cancer Centre who has identified, "that further research is needed about women's decision-making process and how it is affected by stress" (NBCC 2001, p. 109).

Thus, the significance of this groundwork research is to provide new knowledge and evidence that can be transferred to the existing knowledge of nurses, which allows them to assess women's individual profiles to guide decision support interventions. This knowledge can be used by nurses and other health professionals to form a foundation to design and evaluate future evidence-based decision support interventions. This model of care can lead to better psychological outcomes such as greater decision satisfaction, better post-surgical adjustment, improved convalescence and less post-decision regret for women related to the treatment decision.

Conceptual Model

Decision Styles

The conceptual underpinnings of this study are embedded in the model of decision styles developed by Pierce (1988; Pierce, 1993), following a Grounded Theory study of 48 American women newly diagnosed with early breast cancer. Three primary decision style groups of women were identified by Pierce (1988 p.277) through qualitative analysis namely: Delayer, Deferrer, and Deliberator (see Table 1).

Table 1 Summary of empirical indicators of three decision styles (Pierce 1988 p. 277).

Decision Style	Salience of Alternatives	Conflict	Information Seeking	Risk Awareness	Deliberation	Decision Rule
Deferrer (N = 17, 41%) M age = 56yrs	Immediate attraction to one option	None	None	Risk -averse	None	Simple Preference
Delayer (N = 18, 44%) M age = 45yrs	Consideration of at least two options	Yes Minimal	Minimal (prefers non-technical sources)	Risk-averse	Vacillation	“First difference”
Deliberator (N = 6, 15%) M age = 40yrs	Consideration and decomposition into at least two options	Yes Moderate	Extensive (prefers technical sources)	Risk-seeking	Strategy	“Last difference”

Deferrer

Women in the Deferrer group usually select the treatment option that is recommended by their doctor; that is, defer this decision to his or her expert judgement. A consistent characteristic of these women's decision styles is their lack of interest in information and their tendency to rely more on their feeling and intuition instead of facts and details. In fact, details about the risks and technical treatment aspects can be viewed as potentially threatening and are often avoided by these women. For women with this type of decision style the major emotional distress was caused by the diagnosis of cancer more than having to choose a treatment (Pierce, 1985, 1988; Pierce, 1993).

Delayer

Women who use this decision style (Delayer) to structure the decision problem recognise and consider more than one treatment option and tend to have more concerns about the long-term effects of the options. Information plays a critical role for these women in being able to choose between the options and to maintain some personal control of their illness. The provision of appropriate information and emotional support is essential to these women's well-being. These women usually rely on others to find out the information, refer to knowledgeable resources, and prefer to discuss their experiences with women who are breast cancer survivors (Pierce, 1985, 1988; Pierce, 1993).

Deliberator

Women using the decision style of Deliberator are reportedly the most complex and demanding of the decision groups in relation to the provision of medical care. These women take personal responsibility for making a quality informed treatment decision. They also initiate social contact and seek information from anybody that they consider a knowledge source. Information is crucial to the well-being of these women in the Deliberator group and they can be become psychologically distressed if they are unable to obtain accurate information from expert sources (Pierce, 1985, 1988; Pierce, 1993).

Michigan Assessment of Decision Styles (*MADS*)

Pierce developed a series of 46 questions from the data obtained in a Grounded Theory study (Pierce, 1995a). This instrument was then tested in the study of 483 American women (Pierce, P.F., personal communication. December 2, 1997). Exploratory factor analysis of this data reduced this instrument (*MADS*) to 16 items consisting of four factors namely: *Avoidance* (α= 0.64); *Deferring Responsibility* (α= 0.76); *Information Seeking* (α= 0.80); and *Deliberation* (α= 0.85). The *MADS* instrument provides a valid and feasible description of patients' pre-decision behaviours. Model testing (detailed in the methodology section in Chapter 3) suggests that scores on the four factors represent the patient's position on a continuum from total avoidance to active engagement in the decision-making process. The instrument is reported by Pierce (1995) to have content and construct validity.

Ethical Considerations

Ethics approval was obtained from James Cook University (H1218, see Appendix 1), and each of the three associated Health Service Districts, which were the sites of data collection. The total data collection for the study occurred over five years and thus extensions were sought and granted from the university and all of the involved Health Service Districts. In the present study, the women's autonomy and non-maleficence were protected by a research protocol, which was developed with the researcher's supervisors after extensive consultation with the doctors and nurses at each site, and with the Cancer Council of Queensland. The protocol as outlined in each ethics application was rigorously applied in accordance with National Health and Medical Research Centre (NHMRC) guidelines for research of human subjects.

Methodology

This prospective, longitudinal, exploratory cohort study specifically investigated women's decision styles, and decision satisfaction when choosing surgical treatment for early breast cancer after initial diagnosis. The researcher spent a total of six months over a three-year period consulting with Associate Professor Penny Pierce on the University of Michigan (USA) campus about the study. The *Michigan Assessment of Decision Styles* (*MADS*) (Pierce, 1995a) instrument was used to measure women's decision styles in the present study. The *Brief Symptom Inventory-18* (*BSI-18*) (Derogatis, 1993) was used to assess women's psychological distress levels (measured as a confounder). No suitable instrument existed to measure decision satisfaction and necessitated the researcher to develop an instrument called the *Patient Treatment Decision Satisfaction* (*PTDS*) questionnaire (Budden & Pierce, 2001). A full discussion of each instrument and its psychometric testing are detailed in the Methodology Chapter (see Chapter 3).

The data collection of the non-probability sample of women (N = 132) occurred at two periods. namely:

1. Baseline Data Collection- Survey - A structured interview was conducted to determine women's decision styles (*MADS*); and psychological distress levels (*BSI-18*) prior to their initial surgery for early breast cancer.

2. Follow-up at three to four months – Mailed questionnaire - Women's decision satisfaction (*Patient Treatment Decision Satisfaction- PTDS*) and psychological distress levels (*BSI-18*) were assessed at 3 to 4 months following their initial surgery for early breast cancer.

The data collection for this study was undertaken over a five-year period (researcher enrolled as a part-time student).

Statistical Data Analysis

A descriptive analysis of all the data were performed following the data cleaning process under the guidance of the researcher's supervisor Dr Petra Buettner (a biostatistician). Depending on the data's distribution, numerical variables were described as median values and inter-quartile ranges (IQR) or as mean values and standard deviations (SD). Sometimes mean values and SD are also presented for comparisons with previously published data. Chi-square tests and non-parametric tests were used to assess bivariate associations between socio-demographic variables, and variables of decision styles (*MADS*) (Pierce, 1995a) and *Decision Treatment Process* (Pierce, 1995b), psychological distress levels (*BSI-18*) (Derogatis, 2000) and decision satisfaction (*PTDS*) (Budden & Pierce, 2001) as appropriate. In further testing of the main hypotheses, multiple linear regression analyses were used to test the relationships of the independent variable of decision styles (*MADS*) (Pierce, 1995a) and the dependent variable decision satisfaction (*PTDS*) (Budden & Pierce, 2001). Throughout the thesis, and in particular the results chapter (Chapter 4), only p-values are included when referring to the results of a statistical test. Test statistics and degrees of freedom have not been given (a) to improve readability; and (b) because p-values alone provide the same information as the test statistic with the degrees of freedom included. The definitions of terms used in the study are described in Table 2. The American Psychological Association (APA, 2001) referencing style has been incorporated throughout this thesis. However, some alteration to this referencing style such as bolding and shading in tables, have been used to enhance the visual readability of the thesis.

Table 2 Definitions of key terms.

Breast Cancer	
Early Breast Cancer	Defined according to the National Health and Medical Research Centre (National Breast Cancer Centre – Australia, 2000) guidelines as: tumours not more than five centimetres in diameter, with either impalpable or palpable but not fixed lymph nodes and with no evidence of distant metastases. This classification corresponds with tumours that are T1-2, N0-1, MO as currently defined by the International Union Against Cancer (NHMRC and National Breast Cancer Centre, 2001).
Decision-making	
Decision-making behaviour	Decision-making processes and decision styles used to choose treatment for early breast cancer.
Decision Treatment Process	A 25-item questionnaire (Pierce, 1995b) asking about influential considerations deemed important when choosing medical treatment for early breast cancer.

Table 2 (continued). Definitions of key terms.

Decision Styles	
Decision Styles	Three decision styles model called Deferrer, Delayer and Deliberator originating from a Grounded Theory study by Pierce (Pierce, 1985, 1988; Pierce, 1993).
Decision Style Factors (*MADS*)	Relates to *Michigan Assessment of Decisions Styles* (*MADS*) (Pierce, 1995a), which consists of scores on the four decision style factors of *Deferring Responsibility*, *Avoidance*, *Information Seeking* and *Deliberation*. These factors (originating from decision style model) represent the patient's position on a continuum from avoidance to engagement in the decision-making process.
Decision Style Factors (*MADS*)	
Avoidance	Indicates a tendency or preference to minimise personal involvement in the decision consisting of 4 items (Pierce, 1995a).
Deferring Responsibility	Indicates a tendency or preference to defer the responsibility to another person measured by 3 items (Pierce, 1995a).
Information Seeking	Indicates an inclination to seek further information and contains 4 items (Pierce, 1995a).

Table 2 (continued). Definitions of key terms.

Decision Style Factors (*MADS*) *(continued)*	
Deliberation	Indicates an inclination for involvement in the decision-making process consisting of 5 items (Pierce, 1995).
Decision Satisfaction *(PTDS)*	
Patient Treatment Decision Satisfaction (PTDS)	A 16-item questionnaire developed by the researcher to measure decision satisfaction (6 items relating to decision process satisfaction and 10 items relating to the decision outcome satisfaction) (Budden & Pierce, 2001).
Decision Process Satisfaction	The 6 items relating to the satisfaction with the decision process contained on the *Patient Treatment Decision Satisfaction* questionnaire (*PTDS*) (Budden & Pierce, 2001).
Decision Outcome Satisfaction	The 10 items relating to the satisfaction with the decision outcome contained on the *Patient Treatment Decision Satisfaction* questionnaire (*PTDS*) (Budden & Pierce, 2001).
Global Decision Satisfaction	The score of the total 16 items contained on the *Patient Treatment Decision Satisfaction* (*PTDS*) questionnaire (Budden & Pierce, 2001).

Table 2 (continued). Definitions of key terms

Psychological Distress (BSI-18)	
Psychological distress levels (*BSI-18*)	Measured by the *Brief Symptom Inventory–18* (*BSI-18*) (screening for symptoms only, not a psychiatric diagnostic tool) instruments, which have 18 items, six each on the *Somatization*, *Depression*, and *Anxiety* dimensions (Derogatis, 2000).
Somatization	Six items on the *BSI-18* instrument which reflect psychological distress caused by the perception of bodily dysfunction, focussing on symptoms arising from cardiovascular, gastrointestinal, and other physiological systems that have a powerful autonomic mediation (Derogatis, 2000, p.5).
Depression	Six items on the *BSI-18* instrument, which represent core symptoms of various syndromes of clinical depression and are identical to those found on the *Depression* dimension on the *BSI-18* instrument (Derogatis, 2000).
Anxiety	Six items on the *BSI-18* instrument, which is composed of symptoms that are prevalent in most major anxiety disorders and are identical to those found on the *Anxiety* dimension on the *BSI-18* instrument (Derogatis, 2000).
Global Severity Index (GSI)	The *GSI* represents the global or total score, which summarizes the respondent's overall level of psychological distress (Derogatis, 2000).

In conclusion, this chapter has provided a brief overview and introduction of the research study presented in this thesis. This included an outline of the background, research problem, significance and context of this research. Further, the following research components were described: the underpinning theoretical paradigm of the conceptual model Michigan Assessment of Decision Styles (*MADS)* (Pierce 1995a); the ethical considerations of the study; and the key four questions with the central hypotheses. A summary of research methodology, data analysis and definitions of key terms used in the study were also included. This chapter links logically to Chapter 2, which is a review and critique of the multidisciplinary literature relevant to this research.

CHAPTER 2- LITERATURE REVIEW

Introduction

The purpose of this literature review is threefold: (a) to place the study in the context of current knowledge of women's decision-making for breast cancer treatment; (b) to synthesise and analyse the evidence of the conceptual and empirical knowledge of decision science and each variable of interest (decision-styles and decision satisfaction) in the study into a coherent whole; and (c) to provide an understanding of the decision support needs of women with early breast cancer. This chapter situates the dependent and independent variables of this study within the scientific and scholarly literature and identifies at the end gaps in the literature, which this study addresses.

Scope and Limitations of Review

This chapter reviews the published literature directly related to decision science and women's decision-making for breast cancer, decision satisfaction and other important background literature. Published studies from the electronic databases such as the Cochrane Library, Medline, CINAHL, Psycho Info, SocioInfo, ERIC were searched for literature between 1998-2007. The chapter is divided into the following six sections: incidence of breast cancer in Australia; overview of early breast cancer treatment; psychological impact of breast cancer; theoretical approaches to decision science; breast cancer treatment decision-making; and treatment decision satisfaction.

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Incidence of Breast Cancer in Australia

Throughout the industrialised world, breast cancer remains a major cause of morbidity and mortality in women. The following statistics provide a snapshot of the occurrence of this disease in Australia to highlight the enormity of the number of women and families affected by this indiscriminate, life-threatening cancer. The incidence of breast cancer was recently re-calculated as 1 in 8 in a woman's lifetime (up to an average lifespan of 85 years of age from 75 years) by the Australian Bureau of Statistics (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). This statistic was revised to 1 in 8 in 2006 to account for the fact that the average life span for non-indigenous Australian women is 83 years. Disturbingly, up to one third of these women diagnosed with breast cancer are aged under 50 years (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). These Australian figures are similar to the incidence of breast cancer in women reported in other countries. For example, in the United Kingdom the incidence of women developing the disease during their lifetime is calculated at 1 in 9 (National Health Scheme Breast Cancer, 2006) and in the United States of America the figure is 1 in 8 (American Cancer Society, 2006).

In terms of the number of women affected by this cancer, it is reported that over 13,000 Australian women are diagnosed with breast cancer each year and the number of new cases has been increasing 2 per cent annually (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). For example, in 1994, 1,604 women were diagnosed, and in 2004, 2,260 women developed breast cancer in Queensland (Queensland Cancer Registry, 2007). From a national perspective, 113,801 women have been diagnosed with this cancer in the past 20 years in Australia (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006).

These figures represent a large number of women in the community requiring emotional and psychological support, with medical treatment, which may last for several years, for those who survive the disease. In 2004, 456 women in Queensland died (Queensland Cancer Registry, 2007) and nationally 2,641 Australian women died from this cancer (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). Fortunately, with the introduction of the national breast screening program (mammography) in 1990 and improved medical treatment, the death rate of women has declined by an average of 2 per cent per annum (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). In fact, overall 87 per cent of Australian women diagnosed with breast cancer can expect to be living five years after their diagnosis, compared to 71 per cent in 1982-1986 (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). The diagnosis of breast cancer at earlier stages of the disease provides a better prognosis for women of all ages than more advanced cancer. However, in some cases women's mortality may not be reduced by earlier detection. Australia has taken an international lead and developed guidelines for the psychosocial care of cancer patients (Luxford & Fletcher, 2006).

Overview of Early Breast Cancer Treatment

Over recent years, the surgical management of breast cancer has dramatically changed from all women with the disease having disfiguring, radical mastectomy surgery, to women with early stage cancer now being offered less invasive surgery (breast conservation surgery BCS or sometimes called lumpectomy). Currently, women who are diagnosed with early stage breast cancer have more treatment choices than women who have developed an advanced form of the disease. A brief overview of shared decision-making literature, the definition and management of early breast cancer is provided to set the context for the type of surgical options women are usually offered by their doctors to treat the disease.

The recent fundamental paradigm shift from the traditional, paternalistic model of health care to consumer-focussed health care in western countries, such as Australia, encourages doctors to shift the decision-making responsibility about treatment for early breast cancer to women (Pierce & Hicks, 2003; Charles, Whelan, Gafni, Willan, & Farrell, 2003). The information given by doctors allows women the freedom to choose a preferred medical option and treatment plan that is more likely to match their personal values and lifestyle. In addition, with more screening programs available, diseases are diagnosed at an earlier stage and, in the case of early breast cancer, women can choose their preferred treatment option. Not only have the treatment decisions shifted to the women and patients in general, but also there is far more information about breast cancer treatment options available to the public through the internet and media. Consequently, women are becoming more informed and knowledgeable about medical options and many, not all, expect and want to be involved with their doctors in the selection of treatment.

Most doctors encourage women to be involved in choosing a treatment for early breast cancer. Women diagnosed with early breast cancer usually are offered a couple of surgical options. For primary treatment, women may choose between a modified radical mastectomy (with or without breast reconstruction) and breast conservation therapy that is, lumpectomy/segmentectomy, axillary lymph node dissection following sentinel node biopsy and postoperative radiation therapy (NHMRC and

National Breast Cancer Centre, 2001). The current evidence from several randomised clinical trials indicate that both options have equal outcomes in the treatment of women with early breast cancer (Craft, Primrose, Lindner, & McManus, 1997; Early Breast Cancer Trialist's Collaborative Group, 2000; Fisher et al., 1995; Fisher et al., 1989; Morris et al., 1997; van Dongen et al., 1992; Veronesi et al., 1993).

Similar to other cancer therapeutics, many women experience distressing effects from the treatment of breast cancer. Each type of surgery and adjunct treatment can lead from mild to severe adverse effects for women, which can affect their quality of life for many years after the completion of the treatment. Also, each type of surgical approach has different probabilities for the risk and type of adverse side effects that can occur during treatment (National Breast Cancer Centre, 2003b; NHMRC and National Breast Cancer Centre, 2001). Women who have mastectomy surgery, can experience problems such as surgical pain, scarring, swelling and numbness in the breast, as well as body image disturbance or lymphoedema (National Breast Cancer Centre, 2003b; NHMRC and National Breast Cancer Centre, 2001). Unfortunately, for many Australian women, the out of pocket expense of breast reconstruction is beyond their financial capability, or access is unrealistic with the extended long current public surgical waiting lists. Furthermore, many doctors may only offer younger women the option of breast reconstruction surgery (Alderman, Hawley, Waljee, Morrow, & Katz, 2007). Therefore, even if women prefer to have breast implants and breast reconstruction to improve their body image (Reaby, 1998b; Reaby, Hort, & Vandervord, 1994) may not be able to do so, and consequently may suffer long-term psychological morbidity.

In the case of women who choose breast conservation surgery (BSC), they need to understand that, following the surgery, they are usually required to undergo radiation therapy for as long as eight weeks, in some cases. The uncomfortable side effects of this treatment can include skin redness and burning of the irradiated section, tiredness, lethargy, soreness and swelling of the breast, and sometimes lymphoedema causing difficulty for women moving their arm on the affected side (NHMRC and National Breast Cancer Centre, 2001).

After their primary treatment, some women must then also decide whether to accept or decline adjuvant chemotherapy or hormonal therapy. Depending on the drug and regime decided between women and their doctors, the chemotherapy may be given in cycles such as a 3-week cycle over 12 weeks or a 4-week cycle over 24 weeks. The distressing side effects of chemotherapy can include nausea and vomiting, loss of hair, depression, anxiety, chemo-brain (feeling vague, mildly confused or experiencing poor memory) (National Breast Cancer Centre, 2003b) and mouth ulcers (National Breast Cancer Centre, 2001).

Other adjunct treatment including ovarian ablation, or hormonal therapy such as tamoxifen, may be additional to the surgery with or without radiation therapy. These therapies are mostly applicable to breast tumours containing oestrogen or progesterone receptors because drugs such as tamoxifen or aromatase inhibitors are anti-oestrogens (National Breast Cancer Centre, 2003b; NHMRC and National Breast Cancer Centre, 2001). The possible side effects for women from these types of drugs are menopausal symptoms, blood clots, stroke, cancer of the uterus, and changes in vision (National

Breast Cancer Centre, 2001). As the reader will appreciate, all of these side effects are life changing and some are life threatening for women.

In Australia, the trend has been for more women to have mastectomy surgery rather than BCS (Back & Morgan, 2000) and there can be vast difference in rates across rural and regional health sectors (Hill et al., 1998). Mastectomies are more frequent in Australian rural areas possibly because of the distance to radiation oncology services (Craft et al., 1997; Kok et al., 2006; McGrath, Patterson, Yates, Treloar, Oldenberg et al., 1999; McGrath, Patterson, Yates, Treloar, Oldenburg et al., 1999; Wilkes, White, & Beale, 2002). Also the out of pocket expenses of accommodation required during treatment influence women's treatment choice (Butler & Howarth, 1999; Hegney, Pearce, Rogers-Clark, Martin-McDonald, & Buikstra, 2005; Martin-McDonald, Rogers-Clark, Hegney, McCarthy, & Pearce, 2003). Younger Australian women (Craft et al., 1997; Taylor, Stubbs, Langlands, & Boyages, 1999; Young, Marks, Kohler, & Hsu, 1996) and those living in urban regions (Craft et al., 1997) are more likely to choose Breast Conservation Surgery (BCS) and reconstruction (Reaby, 1998b; Sandelin, King, & Redman, 2003).

However, in different urban and rural regions of Australia this picture has been changing to a higher number of women undergoing Breast Conservation Surgery (Koshy et al., 2005). More doctors are encouraging women's participation in the treatment decision for early breast cancer. Thus, for many women, they are able to choose a treatment option (mastectomy or breast conservation surgery with radiation therapy) that is more likely to meet their personal values and preferences concerning their quality of life. Regrettably, the timing for the choice of cancer treatment occurs when women are often distressed (Holland & Mastrovito, 1980; Steginga, Occhipinti, Wilson, & Dunn, 1998; Turner, Wooding, & Neil, 2004) and cognitively overloaded (Cimprich, 1992; Cimprich & Ronis, 2001) from information given by their doctors, and this increases the difficulty for women making a decision. Many women during this bewildering time seek decision support from their doctors, nurses, families, or other women who have survived breast cancer.

Psychological Impact of Breast Cancer

A diagnosis of breast cancer may create fear, uncertainty, distress, and havoc in the lives of women and their families. Women face challenges throughout the trajectory phases of diagnosis, treatment and survival of the disease phase and their quality of life can be adversely affected (Spagnola et al., 2003). The women's reaction to a diagnosis of breast cancer can be a complex array of psychiatric and psychological reactions; with a sequelae of symptoms ranging from mild distress to severe distress to affective disorders such as anxiety and depression. If these symptoms are undetected and untreated they can diminish women's long-term quality of life (Harrison & Maguire, 1994; Tjemsland, Soreide, & Malt, 1998).

The study of psychological distress and psychosocial needs of women with breast cancer has only recently received the much-deserved attention by researchers. The term "distress" was chosen by an American group called the National Comprehensive Cancer Network (NCCN) (National Comprehensive Cancer Network, 2003) to overcome the stigma attached to psychological problems occurring in cancer patients. This network has defined distress in cancer as a "multifactorial unpleasant emotional experience of psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and extentsial and spiritual crisis" (National Comprehensive Cancer Network, 2007 p.4). Furthermore, the National Comprehensive Cancer Network (2007) has recently developed distress management guidelines that incorporate a 10-point visual analogue scale called the "distress thermometer" to screen oncology patients for distress.

Given that women often experience extreme psychological distress following a diagnosis of breast cancer their individual subjective coping mechanisms (Folkman & Moskowitz, 2004; Lazarus, 1993) and adjustment are influenced by their personality, genetic loading, and previous exposure to traumatic experiences. Furthermore, women's quality of life can be adversely affected from the time of diagnosis, through the treatment, recovery, and survival phase. The emotional turmoil places them at risk of developing: interpersonal difficulties; body image and sexuality problems; or depression and anxiety (National Health and Medical Research Council National Breast Cancer Centre, 2000). Events such as receiving inadequate information and/or limited understanding of the treatment options and outcomes to make informed decisions can create psychological distress for the woman. Throughout the treatment phase: concerns by women related to their body image and sexuality; emotional and physical functioning; and family coping usually emerge (Spagnola et al., 2003). During the trajectory phases of the cancer journey, women require different amounts and types of emotional and practical support by nurses about ways to manage the adverse effects of the treatment.

There is a plethora of international research on the well-being and quality of life of women with breast cancer. The way women appraise the harm and uncertainty of breast cancer treatment influences their quality of life (Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). However, it is only in more recent years that researchers have studied the psychological distress of women as opposed to quality of life. Many of these studies have been of a cross-sectional nature rather than of a longitudinal design, and therefore little is known about the levels of psychological distress of women over the phases of the breast cancer trajectory (Love, Grabsch, Clarke, Bloch, & Kissane, 2004).

In addition, the studies that have measured this phenomenon have used many different instruments, and subsequently, have lead to difficulty for comparison of the results by researchers and clinicians. In fact, a recent report (National Breast Cancer Centre, 2004b) identified over 22 different instruments have been used in studies to screen women with breast cancer for psychological distress. Some of the psychological instruments used (National Breast Cancer Centre, 2004b) in breast cancer studies are: the Beck Depression Inventory (Beck, Steer, & Garbin, 1988); General Health Questionnaire (Goldberg, 1978); Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); and the Brief Symptom Inventory (Derogatis, 2000; Derogatis & Melisaratos, 1983). Also, separate instruments have often been used to assess the symptoms of somatization distress and thus may explain the huge differences in reported incidence rates of psychological distress in women (30-50%) after a breast cancer diagnosis (National Breast Cancer Centre, 2004b).

During the breast cancer journey, women can experience different levels of psychological distress. Most women report the days and weeks prior to the surgery are the worst; filled with despair, worry and indecision (Massie & Holland, 1991). Studies have shown women's psychological distress is usually the highest near diagnosis and declines over ensuing months (Dean, 1987; Ford, Lewis, & Fallowfield, 1995). Women undergoing mastectomy often express the following: fears of death; concerns about their changed appearance; and feelings of diminished sense of femininity and sexual attractiveness (Lewis & Bloom, 1978; Meyerowitz, 1980; Yurek, Farrar, & Andersen, 2000). International studies have reported one in five women two months to two years after being diagnosed with breast cancer have significantly high levels of distress and intrusive thoughts (Baider, Goldzweig, Ever-Hadani, & Peretz, 2006; Irvine, Brown, Crooks, Roberts, & Browne, 1991). For some women this distress can lead to a psychiatric illness such as anxiety or depression.

These figures of psychological distress in women are comparable to the findings of Australian studies (National Health and Medical Research Council National Breast Cancer Centre, 2000). It is reported that over a third (34%) of Australian women diagnosed will be highly distressed or will experience high levels of psychological disturbance; 35.4% were still experiencing distress 3 months post diagnosis, and up to 20% at 12 months post diagnosis (National Health and Medical Research Council National Breast Cancer Centre, 2000). Another study (Kissane et al., 1998) identified 45% of women with early stage breast cancer three months after surgery met the DSM-IV criteria for affective disorders such as minor (27.1%) and major depression (9.6%); anxiety (8.6%); and mood disorders (36.7%). This figure was more than double the annual prevalence rates (18%) of women in the general Australian population (Andrews, Hall, Teeson, & Henderson, 1999). Other studies of Australian women have reported over a third (34.2%) experienced psychological morbidity two months after diagnosis using the General Health Questionnaire-12 (GHQ-12) (Gallagher, Parle, & Cairns, 2002).

Other Australian studies have reported higher figures of women experiencing psychological morbidity. One study reported that as many as 67% of women at 16 weeks post-breast cancer surgery were anxious or depressed (Dunn, Steginga, Occhipinti, Wilson, & McCaffrey, 1998) using the psychological subscale of the Rotterdam Symptom Checklist. These women's anxiety and depression were related to the difficulty of women reporting psychological and physical symptom, inadequate information support and decisional uncertainty (Steginga et al., 1998).

Many predictors of psychological distress have been identified in socio-demographic profiles. Women who are in a high risk group for developing psychological and/or psychiatric problems are often younger (Compas et al., 1999; Siegel, Gluhoski, & Gorey, 1999; Stanton et al., 2000; Turner, Wooding, & Neil, 1998; Wenzel et al., 1999). Other predictors of distress are women with lower education levels (Epping-Jordan et al., 1999) and those with a pessimistic personality (Carver et al., 1993; Schou, Ekeberg, Ruland, Sandvik, & Karesen, 2004). Other risk factors identified are those women who do not socialise during the disease trajectory, and have intrusive thoughts during this time (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000). Women with a lower sense of personal control (Compas et al., 1999); those who feel chronically anxious; and those with suppressed negative emotion (Iwamitsu et al.,

2005) are also at risk of developing psychological morbidity. Furthermore women with a previous history of a psychiatric illness (Baider, Andritsch, Uziely, Ever-Hadani et al., 2003); those with avoidant coping style (Turner et al., 1998) and (Dean, 1987; Kissane et al., 1998; Maunsell, Brisson, & Deschenes, 1992); and those who have dependants under 21 have also been identified for having the potential for psychological problems (National Breast Cancer Centre, 2004b).

There is mounting evidence that women's pre-operative psychological state impacts on their post-operative outcomes and increase symptoms such as nausea, fatigue, discomfort (Montgomery & Bovbjerg, 2004), and their psychological morbidity and distress (Fukui, Kugaya, & Okamura, 2001; Meyer, Russo, & Talbot, 1995). Also, fatigue post-operatively has been significantly associated with anxiety and depression (Tchekmedyian, Kallich, McDermott, Fayers, & Erder, 2003) and other symptoms of distress have been found related to depressive symptoms (Pasacreta, 1997).

There is still no evidence that women with early breast cancer who undergo breast conservation surgery rather than mastectomy surgery have less psychiatric morbidity such as anxiety and depression after treatment (Fallowfield, Hall, Maguire, & Baum, 1990; Kissane et al., 1998; Maguire et al., 1978). The cosmesis of breast conserving surgery (lumpectomy) is accepted by women in the same category as a breast reconstruction (McCormack, Yahalom, Cox, Shank, & Massie, 1989; (Nano et al., 2005), as being less invasive on the body and is often associated as not as threatening on body image and sexuality (Andrykowski, Cordova, Studts, & Miller, 1998; Moyer, 1997a; Parle, Gallagher, Gray, Akers, & Liebert, 2001) as mastectomy surgery (Yurek et al., 2000). However, studies have indicated that women who have mastectomy surgery often have harder sexual adjustment and worse body image than woman who have BCS (Fallowfield, Hall, Maguire, & Baum, 1990; Kiebert, de Haes, & van de Velde, 1991; Moyer, 1997b; Omne-Ponten, Holmberg, Burns, Adami, & Bergstrom, 1992).

Despite psychological distress being common in cancer patients, it is often unrecognized and untreated. Patients may not discuss their concerns with their doctors because they may feel embarrassment or consider their distress is not a concern for doctors (Ryan et al., 2005). Open and honest communication with the provision of adequate available time (Thind & Maly, 2006) is critical between doctors and cancer patients to elicit their expectations, preferences and values (intuitive decision-making) in terms of treatment outcomes (Redelmeier, Rozin, & Kahneman, 1993). Patient studies have found factors such as the amount of information, mode of expression (descriptive vs. probabilistic), framing (negative or positive) of information (Siminoff & Fetting, 1989; Tversky & Kahneman, 1981) and doctors communication style can influence their (patient's) selection of medical treatment (Mazur & Hickam, 1994; McNeil, Pauker, Sox, & Tversky, 1982; O'Connor, 1989). The most important information at the time of diagnosis for most women with breast cancer is the likelihood of cure, the possibility of the spread of the disease and the treatment options (Adachi, Ueno, Fujioka, Fujitomi, & Ueo, 2007; Lobb, Kenny, Butow, & Tattersall, 2001; Luker et al., 1995). (National Health and Medical Research Council, 2001; National Health and Medical Research Council National Breast Cancer Centre, 2000).

Fortunately, best practice guidelines have been developed to help doctors with the process of 'breaking bad news' to patients (Campbell & Fisher, 1998; Back, 2002).

These suggested guidelines for doctors help prepare the patient by using the following protocol steps: prepare the encounter; assess the patient's understanding; discuss the news; respond to the patient's emotions; offer to discuss implication of the bad news; summarise the discussion; arrange a follow-up time for patient and family questions and concerns; and document the discussion in the medical record (Back, 2002 p.179).

Brief Symptom Inventory (BSI)

Many women following a breast cancer diagnosis experience psychological distress, which may go unnoticed and unmanaged by health professionals. Nurses are in the frontline of healthcare and are ideally placed to assess women's (and other cancer patient's) psychological distress. The identification of women with high psychological distress by nurses allows the referral of these women to the appropriate specialist services for management.

The Brief Symptom Inventory 53 is an instrument that can be used to screen the psychological status of cancer patients. The Brief Symptom Inventory-53 is a self-report instrument originating as a brief version of the Symptom Distress Check List (SCL-90R) (Derogatis & Cleary, 1977; Derogatis, Rickels, & Rock, 1976) which was developed and used to measure psychiatric and medical patients psychological status (Derogatis & Melisaratos, 1983). The Brief Symptom Inventory-53 (BSI-53) comprises of 53 items on a 5-point Likert scale representing nine primary symptom dimensions or subscales, plus three global distress indices in a shorter measurement scale (Derogatis & Melisaratos, 1983). The nine primary symptom constructs or dimensions of the BSI-53 are somatisation, depression, anxiety, obsessive-compulsive, interpersonal sensitivity, hostility, phobic anxiety, paranoid ideation, psychoticism. The three indices for global psychological distress are the General Severity Index (GSI); Positive Symptom Distress Index (PSDI); and Positive Symptom Total (PST).

The Brief Symptom Inventory-18 (*BSI-18)* (Derogatis, 2000) instrument was developed as a shorter version of the Brief Symptom Inventory-53 *(BS1-53)* (Derogatis, 1993). The *BSI-18* (Derogatis 2000) instrument contains 18 questions that measure three dimensions namely: *Somatization* (6 items), *Anxiety* (6 items), and *Depression* (6 items). The 18 items of the *BSI-18* are totalled to provide the Global Severity Index (*GSI*) score. It is a self-report symptom inventory designed to serve as a highly sensitive screen for psychological distress in medical and community populations (Derogatis, 2000) and in cancer patients (Jacobsen et al., 2005; Recklitis et al., 2006; J. Zabora, BrintzenhofeSzoc, Jacobsen et al., 2001).

The Brief Symptom Inventory (53 and 18) is an instrument which has been found to be an efficient and effective method for psychosocial screening of cancer patients (Morlan & Tan, 1998; National Breast Cancer Centre, 2004b; J. R. Zabora, Smith-Wilson, Fetting, & Enterline, 1990). This instrument (BSI-53), and the new shorter version (BS1-18), have evidence of strong psychometric properties in reliability and validity measures (these *BSI-18* scores are detailed in the next chapter relating to methodology) (Derogatis, 2000; J. Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001; J. Zabora, BrintzenhofeSzoc, Jacobsen et al., 2001; J. R. Zabora et al., 1990).

The Brief Symptom Inventory-53 has been used to screen for global psychological distress: in women with gynaecological cancer (Sneed, Edlund, & Dias, 1992) and adolescents with cancer (Neville, 1996); in couples adjustment to breast cancer (Ben-Zur, Gilbar, & Lev, 2001; Northouse, 1989; Northouse, Dorris, & Charron-Moore, 1995; Northouse & Swain, 1987; Northouse, Templin, Mood, & Oberst, 1998); and women with breast cancer (Andritsch, Dietmaier, Hofmann, Zloklikovits, & Samonigg, 2007; Baider, Andritsch, Uziely, Goldzweig et al., 2003; Baider, Goldzweig, Ever-Hadani, & Peretz, 2007; Ben-Zur et al., 2001; Grassi, Biancosino, Marmai, & Righi, 2004; Hanson Frost et al., 2000; Payne, Hoffman, Theodoulou, Dosik, & Massie, 1999; Sneed et al., 1992; Spagnola et al., 2003).

Table 3 gives a brief overview of some of the more recent studies that have used the BS1-53 instrument to screen the psychological status of women with breast cancer. Unfortunately, no breast cancer studies using the *BSI-18* were found and thus, direct comparison with the results in the current study is difficult. In Table 3 only the symptom dimensions from BSI-53 that are contained in the *BS1-18* (*Somatization*, *Depression*, *Anxiety* and *Global Severity Index*) instrument are presented, to aid comparison with the finding in the present study (no available *BSI-18* studies). The predominant methods of reporting the BSI-53 in these studies are by providing the mean of each of the symptom dimensions.

Table 3 Studies using the BSI-53 (Derogatis, 2000; Derogatis & Melisaratos, 1983).

Author, Year **Country Origin**	**Sample**	**BSI** **Instrument**	**Symptom Dimension** **Mean**
Andritsch et al., 2007 Austria	N = 210 Breast cancer	BSI- 53	Somatization = 55.8 Depression = 47.7 Anxiety= 48.8 GSI= 52.0
Baider et al., 2003, Israel	N = 48 Breast cancer Stage I-II 1-5 yrs after diagnosis < 49 yrs	BSI- 53	Somatization = 58.6 Depression = 56.8 Anxiety= 60.3 GSI= 60.0

Table 3 (continued). Studies Using BSI-53 (Derogatis, 2000; Derogatis & Melisaratos, 1983).

Author, Year Country Origin	**Sample**	**BSI Instrument**	**Symptom Dimension Mean**
Hanson Frost et al., 2000, USA	N =35 Newly diagnosed breast cancer Within 6 weeks	BSI-53	Somatization = 55.2 Depression = 53.3 Anxiety= 54.4 GSI= 52.6
Payne et al., 1999, USA	N =275 Breast cancer	BSI- 53	Somatization = 55 Depression = 56 Anxiety= 58 GSI= 56

No studies are known or located by the author that have used the *Brief Symptom Inventory 53* (*BSI-53*) or *Brief Symptom Inventory-18* (*BSI-18*) instrument to measure psychological distress in Australian women with breast cancer. Since the *BS1-18* was published in the year 2000 (Derogatis, 2000) the only study yet to report their findings using the *BSI-18* instrument is a small study of 30 cancer patients in Iceland (Hjorleifsdottir, Hallberg, Bolmsjo, & Gunnarsdottir, 2006). With the strong psychometric properties of the BS1-18 and its administration brevity more cancer patient's studies will no doubt begin to appear in the literature.

Theoretical Approaches to Decision Science

Historical Background

Decision science is the branch of theory concerned with how individuals make decisions. No unified theory for the study of thinking, judgement, or decision-making exists and, given the complex nature of individual's circumstances, it is unrealistic to expect one approach would ever fit every conceivable decision context. In decision science a decision is defined as "a choice of action" (Baron, 2000 p.6) and a decision problem is theoretically defined by "the acts or opinions among which one must choose, the possible outcomes of all consequences of these acts, and the contingencies of all conditional probabilities that relate to these outcomes and acts" (Tversky & Kahneman, 1981, p.453). The decision processes of an individual are multidimensional and consist of complex perceptual, cognitive and affective activities (Pierce & Hicks, 2001).

There are different aspects to this science as it has been applied in diverse subjects such as philosophy, economics, law, medicine, and nursing. Some decision theories emerged in the 18th century when the philosophers of the day were influenced by the Age of Reason and rationalism. During the 18th century, Thomas Bayes (1764-1858) developed a model of decision-making called Bayes Theorem (model). This theorem involves a statistical formula for evaluating hypotheses with changing probabilistic values (Solso, 1995). This calculation determines the possibility of an event to another event sometimes called the cause and effect, or the hypothesis and data. The formula includes three probability concepts: prior probability, which is the probability of an event before further information is known; posterior probability, which is the probability of an event after the new information is known; and conditional probability, which is the probability that one event or proposition is true given another is true (Plous, 1993).

The Bayesian model has been widely applied to the analysis of clinical decision problems, especially in medicine, and is still employed today. This mathematical and rationalistic model has influenced the development of decision theory and is useful for calculating probabilities and predicting risks under uncertainty in future situations, such as outcomes of medical treatment by doctors. Connection with mathematics in decision theory has been strong and individuals and groups have often been viewed to make decisions on purely rational and economic grounds. However, in relation to patient's treatment decision-making the theory's application is limited. When making treatment choices patients are often bewildered and psychologically distressed and often make intuitive decisions (Kelly-Powell, 1997; Redelmeier et al., 1993) based on their personal preferences, values, and what is important for their family.

Further theories of decision-making began to emerge after WWII. After WWII, research into decision-making evolved and abundant decision literature began to appear in disciplines such as economics, business, law, medicine, politics, defence, and psychology. In particular, the disciplines of economics and psychology have produced vast amounts of knowledge based on experiments dealing with individuals and organisational decision-making. These data have aided diverse model and theory building which have been driven by real world problems and applications in different disciplines. However, most of these studies have consisted of scenarios given to individuals in simulated laboratory settings and therefore do not necessarily capture the decision-making processes of individuals making real life choices, such as deciding on medical treatment that has profound long-term implications.

Paradigms in decision science range from very detailed mathematical models to broadly applied models; and the evolutionary process continues. Ward Edwards, an American Professor of Psychology published a book called *The Theory of Decision-making* (1954) which proposed a theory based on the assumption that individuals are ‘rational’ and ‘logical’ decision-makers, whose decisions are based on selecting optimal choices to meet their goals. This theory is known as the normative approach and aims to predict an individual’s decision-making when given two or more options, and consider the preferences and values of the outcome or consequences by the decision-maker. This theory has been the template for the development of other decision science paradigms.

Decision approaches can be broadly classified as belonging to one of four categories: normative decision-making; prescriptive decision-making; descriptive decision-making; and the more recent paradigm of naturalistic decision-making. The normative paradigm has been a benchmark for the development and continuing evolution of the other paradigms (Bell, Raiffa, & Tversky, 1988). The next section takes a broad-brush approach to discuss in brief, each of the current decision science paradigms. Each decision science paradigm contains many different theories and only the aspects directly applicable to patient treatment decision-making are mentioned in this chapter.

Normative Decision-making

Normative models describe what people should do and use an individual's utility (or subjective value) to construct a rational and logical model of decision-making in an ideal world, and are usually based on statistical approaches such as the theory of probability. For instance, this approach has a useful role in clinical decision-making for nurses when performing patient's risk assessment by using statistical modelling techniques (Thompson & Dowding, 2002). Normative models are widely applied in economics and business and are often concerned with how good the judgment or the decision is (the outcome) and are often used in the field of decision analysis (Pierce, 1985). The steps in rational decision-making using this model involve an individual's ability to recognise and define the decision situation; identify and evaluate possible alternatives; select the best alternative; and implement the chosen alternative (Bell et al., 1988).

However, the normative approach or model has limited utility for decision support given by nurses to patients. But the model is useful when explaining the risks of alternative treatment options by doctors to patients and has been used in some decision aids (Whelan et al., 2004). In addition, another limitation with these normative models is most of the knowledge gained from studies has been generated through interviews, archival objects, hypothetical scenarios and training studies (Baron, 2000) and therefore does not necessarily reflect real life decision-making. Therefore, this research is not helpful in understanding and explaining how individuals like patients, makes decisions in medical contexts, which are stressful; time pressured, and has quality of life implications.

Normative models are based on the notion that individuals can always process information unimpeded by other influences. However, in the "real world", this is clearly not the case. When individuals are making decisions they can often became cognitively overloaded by the information which they are given related to the alternative medical options. In the case of patients, the information and decisions process about their medical treatment frequently involves undesired risk and uncertainty about the outcomes of each option and their long-term prognosis, leading to further cognitive overload and attention fatigue (Cimprich, 1999; Cimprich & Ronis, 2001; Cimprich, So, Ronis, & Trask, 2005). Thus, the development of other decision science paradigms such as, prescriptive decision-making, were derived to understand an individual's decision-making in "real life" situations.

Prescriptive Decision-making

Prescriptive decision-making models developed from disciplines such as psychology and law to focus on how to help, predict and train individuals to make good decisions (Bell et al., 1988). Some decision scientists (Pierce, 1985; Yates, 1990) consider the prescriptive approach as a branch of the classical normative theory and use the terms interchangeably. These approaches consist of techniques to help individuals use: algorithms; scientific reasoning; computer expert systems; logic; and legal arguments in decision-making (Baron, 2000).

One of the theories that developed in this paradigm was Subjected Expected Utility, which proposes that individuals choose the options (based on their preferences and values or utilities) which are most likely to lead to the preferred goals (Baron, 1994; Edwards, 1954; Weinstein et al., 1980). This approach is used in both decision-making under risk (where the probabilities are explicitly given) and in decision-making under uncertainty (where the probabilities are not explicitly given). Subjective Expected Utility theory considers, unlike the normative approach, that real life decisions often contain risky decisions with uncertain outcomes and therefore provides a useful benchmark for these conditions. This model is used in medical settings for clinical decision-making by doctors and nurses when they are performing decision analysis and formulating decision trees about patient's treatment outcomes.

Nobel Laureate Herbert Simon (1956) proposed that when individuals make decisions they 'satisfice' (settle for a choice which is close enough) or choose (called Limited or Bounded Rationality) a decision to meet their important needs, even if this choice may not be ideal or optimal (Plous, 1993). For instance, a women living in rural Australia may choose to have mastectomy surgery because of the associated expense and time required away from home for radiation therapy following breast conservation surgery. Her preferred option may be to keep her breast, but she decides to have mastectomy surgery because it still is an effective treatment of the cancer.

The theoretical perspective of Limited Rationality and aspects of the prescriptive paradigm contributes to helping professionals such as doctors and nurses develop clinical decision-making skills. In addition, some aspects of this theory can help explain patient decision-making, as indicated in the example above; however, studies using the descriptive decision-making approach are more applicable in understanding real life decision dilemmas.

Descriptive Decision-making

The descriptive decision-making model was developed to study empiric decision-making in real life situations. This approach concentrates on describing how individuals make decision choices in real life (Bell et al., 1988) and are a major focus for psychological decision theorists. This alternative approach to classical normative decision-making, recognises that, in the real world, individuals do not always know with certainty the consequences and outcomes of choices. A good example is when patients are making treatment choices for life threatening illness such as cancer, which involve risk and uncertain outcomes or consequences. This paradigm like the other approaches contains many models and theories; only the ones that have been used to assist patient decision-making will be briefly mentioned in this section.

Many cognitive or decision psychologists have conducted studies to understand the process of decision-making. A relevant approach from psychology research called the Prospect Theory (Kahneman & Tversky, 1979), developed and replaced the notion of ‘utility’ with ‘value’ in the process of decision-making. This approach predicts an individual’s preference will be influenced by the way the problem is framed (Tversky & Kahneman, 1981) and this discovery has important application for doctors and nurses and has been used in Australian psychosocial guidelines when caring for cancer patients (National Breast Cancer Centre, 2003a; National Health and Medical Research Council National Breast Cancer Centre, 2000).

Through studies examining individuals in various situations the theory of Heuristics and Biases was developed to help understand potential judgement errors and improve the process of decision-making (Kahneman, Slovic, & Tversky, 1982). Inherent in this approach are the use of ‘heuristics’ (or rules of thumb or sometimes called mental shortcuts) believed to be used by individuals to streamline information, time and reduce cognitive load into manageable pieces (Baron, 2000; O'Neill, 1995). However, these mental shortcuts can lead to decision errors (D. Kahneman et al., 1982; Tversky & Kaheman, 1974, 2000), such as not carefully evaluating the information about alternatives and their consequences. The findings from these studies have been enormously helpful in applying principles to determine the amount and way information is given by doctors to oncology patients about their treatment options. However, solely using this approach with patients is one-dimensional in nature, as it does not consider the dynamic decision-making context and stress involved when patients are making treatment choices.

The application of an approach known as Information Processing theory has been more helpful to assist patients in their treatment decision-making. According to Information Processing theory (also known as the hypothetico-deductive approach), an individual is viewed as an information processing system (similar to the principles of computer programs), interacting in a problem task with limited amount of information or symbols held; which cannot normally process more than 5 or 7 chunks (bits or pieces of information) at a time in the short and long-term memory (Simon, 1974; Simon & Newell, 1964). It is posited that information is processed in the brain through a series of unique stages and operations before being passed along to the next stage of processing by the individual decision maker (Solso, 1995). This theory acknowledges that, in real world situations, individuals can experience serious limitations in: perception, attention, memory comprehension, communication and, at times, biological constraints that affect information processing for decision-making. This approach has been used in studies of patient decision-making behaviour (Pierce, 1988; Pierce, 1993, 1996). Nurses can use this knowledge to break down information about treatment options into smaller amounts that are given at times when patients are not cognitively or physically fatigued.

One other theory called the Conflict-Theory of Decision-making (Janis & Mann, 1977) has closer applications and utility to understand the phenomenon of patient decision-making. This model developed by behavioural scientists Janis and Mann (1977), recognises it is inherently stressful for individuals (or decision-makers) when they are making choices about important issues that have serious consequences. At this time of decision-making, individuals frequently experience decisional conflict, which can either impede or facilitate their information processing ability. Individuals experience high levels of stress when they have to choose between decision alternatives, both of which contain unpleasant consequences. When making a serious decision, individuals can experience symptoms such as: hesitation; vacillation; signs of stress (emotional and physical); and feelings of uncertainty. This model describes five coping patterns individuals may use depending on the level of stress and decision conflict they experience when making decisions in serious situations. These coping patterns are called: 1) Unconflicted Adherence; 2) Unconflicted Change; 3) Defensive Avoidance; 4) Hypervigilance; and 5) Vigilance (Janis & Mann, 1977).

In the coping pattern of "Unconflicted Adherence", the individual is committed to continue the current action and they ignore all other information about the risk or losses related to the decision choice. If individuals use the pattern of "Unconflicted Change", they accept the most strongly recommended course of action or choice. Whereas, in the coping pattern of "Defensive Avoidance" individuals tend to attempt to reduce their decision conflict by procrastinating, not listening to accurate information and shifting the responsibility for the decision-making to someone else (Janis & Mann, 1977). In the "Hypervigilance" coping pattern individuals quickly make a decision to reduce their stress level but in doing so, they do not consider the consequences of their declared choice. The final coping pattern in the model is described as the best coping pattern, which leads to quality decision-making, and information processing is called "Vigilance". Individuals using the coping pattern of "Vigilance" thoroughly investigate the information about the choices and their consequences before making a decision (Janis & Mann, 1977).

This Conflict-Theory of Decision-making has been used in studies to research the decision-making of women for breast cancer treatment (Pierce, 1993) and for breast reconstruction following surgery (Reaby, 1998a). To date his prescriptive theory has the closest application to the science of patient decision-making because it includes the concept of an individual's stress levels and information processing interwoven with the decision process. However, patient decision-making for treatment is a complex process, which incorporates multiple factors and contexts, and this one theory cannot capture the phenomenon.

Naturalistic Decision-making

More recently, a newer paradigm has emerged out of the other decision science paradigms called naturalistic decision-making. This approach describes how individuals use their experience in decision-making in real life contexts to solve problems (Pliske & Klein, 2003). Naturalistic decision-making consists of four key features it: is a dynamic process with changing conditions; has real time reactions to these condition changes; has ill-defined goals and ill structured tasks; and it involves knowledgeable people (Hogarth, 1994; Klein, Oransanu, Calderwood, & Zsambok, 1993; Zsambok, 1997). Studies using this paradigm have mainly concentrated on group decision-making in organisations. It is hoped, further research from this paradigm incorporated with the knowledge gained from the other decision science paradigms, will be more useful to study and understand patient treatment decision-making in the future.

In the real world, individuals make decisions based on far more diverse reasons than purely economic gain, or mathematical probability. Real life decision-making is far more complex than merely being influenced by mathematical probability. Decision-making is influenced by an individual’s conscious (analytic or deliberate) and unconscious (or intuitive) (Redelmeier et al., 1993) cognitive processes: such as the formulation of the problem; their norms; habits; personal characteristics; preference for alternatives (utility); expectations; values or worth of decision outcomes (Barclay et al., 1977; Luce & Raiffa, 1957; Matheson & Howard, 1977; Tversky & Kahneman, 1981); and religious and cultural values (Pierce, 1997).

Individuals approach a decision by using styles to structure the problem, integrate information, and determine their desired involvement in making a choice (Pierce & Hicks, 2001). Furthermore, an individual's satisfaction is often related to choices consistent with their personal values and expectations (O'Connor & O'Brien-Pallas, 1989). If individuals do not, or cannot, make decisions based on their personal values and expectations they can experience post-decision regret, which is defined as a "more or less painful cognitive/affective state of feeling sorry for losses, transgressions, shortcomings, or mistakes" (Landman, 1987, p. 153).

In reality, many individuals often experience intense conflict and stress when making important decisions. When individuals attempt to choose from alternatives that have competing values, they can experience conflict about choices. This situation has been described by Janis and Mann (Janis & Mann, 1977) as decisional conflict and refers to "simultaneous opposing tendencies within the individual to accept and reject a given course of action" (p.46). The consequent distress can be overwhelming for individuals when the choices involved in the decision have uncertain risks and outcomes, such as decisions about medical treatment. This extreme psychological distress in some women can further (Dunn et al., 1998; Kissane et al., 1998) develop into affective disorders such as anxiety and depression. Unfortunately, there is little known about how decisional conflict affects the psychological equilibrium of individuals when they are making decisions about medical treatment (Pierce & Hicks, 2001).

It is only over the last two decades that increased empirical attention has focussed on the application of decision science theories to the understanding and development of patient decision-making. The treatment decision-making by patients for medical treatment is a complex phenomenon, which is influenced by a multitude of individual factors such as the following patient characteristics, their personal values and expectations; decision-styles; preferences for participation; psychological and physical state; risk perceptions about the treatment options; context; and appraisal of the decision problem (Pierce & Hicks, 2001). Many of these factors influence a patient's treatment choice and their decision satisfaction.

Unfortunately at the current time, it remains unclear how adverse events such as life threatening illness and pre-decision emotional states affect the perception and processing of information by patients which is required for efficient cognitive functioning for decision-making (Pierce, 1988). While there are many decision-making approaches, these do not adequately explain the decision processes, which occur in a naturalistic setting when a person is deciding on medical treatment for a life threatening disease under uncertainty, in an intensely stressful and, time limited situation (Pierce, 1997; Pierce & Hicks, 2001). Also, these decision-making approaches have been criticized as being too rational, inflexible and probabilistic when applied to stressful decisions related to treatment for life threatening illness (Balneaves & Long, 1999).

Many unanswered questions remain about the phenomenon of patient decision-making for medical treatment. There is little direction in the literature of how patients choose between equally effective treatment options, or how they understand the treatment options and their possible consequences, particularly when the problem is beyond their understanding or experience. In addition, it remains unknown how patients make treatment decisions when they do not have previous experience in the area. The patient's decisions may be suboptimal if they do not thoroughly examine and evaluate all the information about the risks and consequences associated with each treatment option (Pierce & Hicks, 2001). Other unknowns in the black box of patient decision-making are how patient's personal preferences influence their value assessment of treatment options or vice a versa. Also, little information exists about how patients' decision processes are influenced by the probability of risks and the uncertainty outcomes related to treatment (Pierce & Hicks, 2001). Unfortunately, no unified conceptual or theoretical model yet exists to guide nurses in the decision support they provide to patients. Regrettably, the timing for the choice of treatment occurs when women are often distressed (Holland & Mastrovito, 1980; Steginga et al., 1998; Turner, Wooding et al., 2004) and cognitively overloaded (Cimprich, 1992; Cimprich & Ronis, 2001) from information given by their doctors, which increases the difficulty for women making a decision. Many women during this confusing time seek decision support from their doctors, nurses, families, or women who have survived breast cancer.

Breast Cancer Treatment Decision-making

As stated previously, women's treatment decision-making for early breast cancer is complex and multifaceted. Once women are given the feared diagnosis of cancer, they often experience shock, extreme emotional and psychological turmoil. When their doctor attempts to give them information about treatment options women can be distressed and cognitively overloaded (Cimprich, 1999) and may not have the cognitive and emotional resources to deal with the monumental decisions at this time (Pierce, 1993). Women may not hear, or be able to cope with understanding the information and this situation can impede their participation in the treatment decision (Chen, Diamant, Thind, & Maly, 2008; Degner et al., 1997; Waljee, Rogers, & Alderman, 2007).

Psychological stress can jeopardise women's ability to be involved in decision-making and make quality decisions about their preferred treatment (Katz & Hawley, 2007; Pierce, 1993). In decision science, quality decisions are believed to occur when individuals are able to use an adaptive pattern of cognitive and behavioural processes which limits any post-decision regret and increases adherence to the final choice (Campora et al., 1992; Janis & Mann, 1977). For women to make informed quality decisions they need to clearly understand the risks, benefits and uncertainty of each treatment and carefully appraise and evaluate each option (Yates, 1992).

The problem for women participating in the treatment decision is compounded by the fact that up to 30 percent of women with breast cancer experience clinically significant anxiety problems (Kissane et al., 1998; Maraste, Brandt, Olsson, & Ryde-Brandt, 1992; Pinder et al., 1993) as mentioned earlier in this chapter. If women do participate in the decision-making about the treatment, many report less depression and anxiety, regardless of their choice (Fallowfield et al., 1990), and it positively influences their psychological well being and the quality of their decision (Hack, Degner, Watson, & Sinha, 2006; Katz & Hawley, 2007). This has been the case even when the woman's decision has been to defer the choice to their doctor (Kaplan, Greenfield, & Ware, 1989). Early work by Janis and Mann (1977) investigated the concept of stress in individual decision-making (as discussed earlier in this chapter); however further investigation is required to fully understand the impact of distress and its management on patient treatment decisions and decision satisfaction after treatment is completed.

The process for women in making a treatment choice is problematic and made more complex by the treatment information given by doctors. These treatment alternatives are often: explained in "foreign" statistical language (Lobb et al., 2001; NHMRC National Breast Cancer Centre, 1998) and probabilities (Hughes, 1993); and the way the information is framed can influence women's decision-making (Duric et al., 2007; Siminoff & Fetting, 1989). Unfortunately, there is little guidance in the literature about how patients understand statistical probability, or how they use their values and preferences to choose between alternatives and make trade offs in choosing medical treatments (Pierce & Hicks, 2001). Furthermore, the amount and type of information wanted by women (Hawley et al., 2007; Temple et al., 2006) and their preferences for involvement in the decision are often very different to their actual experiences (Hawley et al., 2007; Temple et al., 2006; Vogel, Helmes, & Hasenburg, 2007). These factors alone can complicate women's participation in treatment decisions, but other considerations such as close proximity to health services also influence the final choice (Mastaglia & Kristjanson, 2001).

Australian women's treatment decisions are dramatically affected by the vast geographical distances to access doctors and specialist health facilities. Furthermore, the care of women in Australia has been compounded by a number of health system barriers such as: a lack of continuity and fragmentation of care for women with breast cancer; the short time between diagnosis and treatment; and inconsistency of information given; and the geographical distance of treatment options. Fortunately, the National Breast Cancer Centre (NBCC) in Australian has been a world leader in the improvement and delivery of care to women by developing evidenced based guidelines for the management (National Breast Cancer Centre, 1995; NHMRC and National Breast Cancer Centre, 2001); psychosocial care (National Health and Medical Research Council National Breast Cancer Centre, 2000); and information for women about the disease (National Breast Cancer Centre, 2003b). The National Breast Cancer Centre has also developed Best Practice psychosocial guidelines: for women with breast cancer (NHMRC, 2000) and younger women with breast cancer (National Breast Cancer Centre, 2004a); as well as developing the role of Australian Specialist Breast Nurses and their specific competency based standards (National Breast Cancer Centre, 2005).

Moreover, a number of Australian initiatives and courses by the National Breast Cancer Centre (NBCC) have been established over the last five years to overcome deficiencies in communication skills training for oncologists (Boyle, Dunn, & Heinrich, 2003; P. Butow et al., 2007) and techniques to detect patients distress levels (Ryan et al., 2005). Equally as important, shared decision-making has been introduced into medical curricula to help doctors to develop better communication skills and understanding of their personal beliefs and values (Thistlethwaite & Ewart, 2003; Thistlethwaite, Raynor, & Knapp, 2003) and how this communication impacts their interactions with patients.

In the last 10 years, there have been many international and some Australian studies and investigations about women's choices for breast cancer treatment. These studies have identified relationships between women's socio-demographic profile and their involvement in treatment decision. Women's age (Beisecker, 1988; Johnson et al., 1996; Meyer et al., 1995) and level of education (Graling & Grant, 1995; Siminoff & Fetting, 1991; Street, Voigt, Geyer, Manning, & Swanson, 1995) have been identified as influencing factors. Older women have been reported to make faster decisions with equal quality by seeking less information than younger women (Meyer et al., 1995; Petrisek, Laliberte, Allen, & Mor, 1997).

Other influencing factors cited on the process of treatment decision-making are women's values, expectations, psychological and physical state and risk perceptions about the treatment options (Pierce & Hicks, 2001). Other studies have reported that women's treatment decision-making for breast cancer is mostly influenced by the doctor's recommendation (Johnson et al., 1996; Nold, Beamer, Helmer, & McBoyle, 2000; Siminoff & Fetting, 1991; Smitt & Heltzel, 1997; Stafford, Szczys, Becker, Anderson, & Bushfield, 1998).

Most of the literature in decision-making for breast cancer has been related to women's preference for involvement in the treatment decision with the doctor. A template for these studies has been developed by Degner and Sloan (1992), and relates to women's preference for control of the treatment decision. Many studies have used this instrument in measuring women's preferences (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner et al., 1997; Hack, Degner, & Dyck, 1994; Hack et al., 2006;

Hawley et al., 2007; Janz et al., 2004; Katz et al., 2005; Sabo, St-Jacques, & Rayson, 2007; Vogel et al., 2007).

The instrument contains five statements cards that women sort in order of their preferred role in decision-making (active, collaborative, or passive) for medical treatment. The statement on the cards is as follows: 1) The Passive role has two cards with the statements, “I prefer that my doctor make the final decision about which treatment will be used but seriously consider my option” and, “I prefer to leave all decisions regarding treatment to my doctor”; 2) The Collaborative Role has one card with the statement, “I prefer that my doctor and I share responsibility for deciding which treatment is best for me”; and 3) The Active Role has two cards with the statements, “I prefer to make the final decision about my treatment after seriously considering my doctor’s opinion” and, “I prefer to make the final decisions about which treatment I receive”. Table 4 provides information about studies that have used the Control Preferences Scale (Degner & Sloan, 1992) and the percentage of women in each of their preferred role in decision-making.

Table 4 Studies using the Control Preference Scale (Degner & Sloan, 1992).

Author, Year **Country Origin**	**Sample**	**Instrument**	**Findings %**
Degner & Sloan, 1992, Canada	N = 436 Newly Diagnosed cancer patients	Control Preference Scale	Passive= 59.0 Collaborative= 29.0 Active= 12.0
Hack, Degner & Dyck, 1994, Canada	N = 35 Early Breast cancer Stage I-II	Control Preference Scale	Passive= 20.0 Collaborative= 57.0 Active= 23.0
Bilodeau & Degner, 1996, Canada	N = 74 Breast cancer Within 6 months of diagnosis	Control Preference Scale	Passive= 43.0 Collaborative= 37.0 Active= 20.0
Bilodeau & Degner, 1996, Canada	N =150 Newly diagnosed within 4 weeks breast cancer	Control Preference Scale	Passive= 52.0 Collaborative= 28.0 Active= 20.0

***Table 4 (continued). Studies using the Control Preference Scale* (Degner & Sloan, 1992).**

Author, Year **Country Origin**	**Sample**	**Instrument**	**Findings** **%**
Beaver et al., 1996, UK	N = 1012 Breast cancer	Control Preference Scale	Passive= 34.0 Collaborative= 44.0 Active= 22.0
Degner et al., 1997, Canada	N = 101 Stage I-II Breast cancer	Control Preference Scale	Passive= 14.0 Collaborative= 47.0 Active= 38.0
Janz et al., 2004, USA	N = 1, 844 DCIS Breast cancer	Control Preference Scale	Passive= 22.0 Collaborative= 37.0 Active= 41.0
Katz et al., 2005, USA	N = 1,844 DCIS & Breast cancer	Control Preference Scale	Passive= 46.0 Collaborative= 42.0 Active= 35.6

Table 4 (continued). ***Studies using the Control Preference Scale*** (Degner & Sloan, 1992)**.**

Author, Year **Country Origin**	**Sample**	**Instrument**	**Findings** **%**
Hack et al., 2006, Canada	N = 205 Breast cancer 3 year Post baseline	Control Preference Scale	Passive= 16.0 Collaborative= 40.0 Active= 38.0
Sabo et al., 2007, Canada	N = 611 Stage I-II Breast cancer	Control Preference Scale	Passive= 40.2 Collaborative= 29.2 Active= 30.6
Vogel, Helmes & Hasenburg, 2008, Germany	N = 137 Breast cancer	Control Preference Scale	Passive= 22.0 Collaborative= 38.0 Active= 39.0
Hawley et al., 2007, USA	N= 1101 Breast cancer	Control Preference Scale	Passive= 22.0 Collaborative= 38.0 Active= 39.0

As shown in the previous table (Table 4), the Control Preferences Scale (Degner & Sloan, 1992) has been used in many studies across the world, although none in Australia could be found. Also, it can been seen in Table 4 (The Control Preferences Scale) (Degner & Sloan, 1992) that many more women in recent years want a more active role in treatment decision for breast cancer. The use of this scale in studies has greatly contributed to knowledge related to women's preferred control in treatment decisions. The studies indicate that women are different, and their preferences for involvement in treatment decisions vary over their illness trajectory. Importantly, it also needs to be noted that in the acute phase following diagnosis many women want to play a passive role in choosing a treatment. This knowledge highlights the importance of doctors and nurses frequently checking with women with respect to the amount of control they prefer at different treatment junctions. As women become more experienced with making treatment choices they are more likely to actively participate in the decision process with their doctors (Pierce & Hicks, 2001). However, there are no evidenced-based guidelines for nurses, once they determine women's control preferences. In addition, sole use of the Control Preferences Scale provides only a small piece of the puzzle for decision support given by nurses. The one-dimensional nature of this instrument does not provide a complete profile of women's decision support needs and required comprehensive interventions.

There are differences between the issues and measures used in breast cancer studies, which cause problems for the development of empirical knowledge. An annotation and critique of recent studies which have examined women's treatment decisions for early breast cancer, is now included. A recent Canadian survey (Sabo et al., 2007) was conducted on a convenience sample of 611 women with early breast cancer (Stage 1-

11). The aim of the study was to determine women's preferred role and their level of satisfaction. The data were collected using a number of instruments such as the: Control Preferences Scale, (Degner & Sloan, 1992); Cancer Decision Role Preference; Decision Satisfaction; Role Satisfaction Cancer Decision Role Preference; Decision Satisfaction; Role Satisfaction; and Information Satisfaction. The results relating to the satisfaction scale will be discussed in the next section of this chapter. Analyses identified correlations between socio-demographic profiles of the women and their decision-making process. Women with a higher income and higher education were twice as likely to adopt an active role in decision-making compared to other women. This study contributes to the literature with data obtained from a large sample of women diagnosed with early breast cancer and determination of their decision satisfaction using a well-tested instrument. The study does not clearly identify the time intervals for data collection except to state it was retrospective, and so it is difficult to compare the results to other studies and limits the strength of its findings.

A recent American study also investigated factors involved in women's involvement in surgical treatment for early breast cancer and the match between their preferred and actual experience of involvement in decisions (Hawley et al., 2007). The data were collected from a dataset of 1101 women and 227 surgeons who were asked to complete a self-administered questionnaire. The components of the questionnaire consisted of the following scales: Duke-UNC Social Support; Center foe Epidemiologic Studies Depression Scale; Self Rated Health; Index of Relational Satisfaction; Index of Sexual Satisfaction; Quality of Life Uniscale; Affect Balance Scale; Self-Efficacy Scale and Control Preferences Scale. The main finding of this study was the variations between women's preferred and actual decisional involvement. Women who preferred more involvement were more likely to be younger and women who wanted less involvement had less education.

Recently, studies conducted by American medical researchers have been published that relate to women's surgical choices for early breast cancer. A study of 1844 women with Ductal Carcinoma Insitu (DCIS) or invasive breast cancer were surveyed to determine their knowledge about survival and recurrence rates for mastectomy and breast conservation surgery (Fagerlin et al., 2006). The questionnaire consisted of items scored in binary format such as true or false. Less than a fifth (16%) of women answered the questions correctly about recurrence rates relating to each type of surgery. Also less than half (48%) knew the survival rates were equal across each surgical treatment. Another publication relating to this sample (Katz et al., 2005) reported most of the women wanted to share the treatment decision and those more involved in the process were more likely to choose mastectomy surgery. This study asks pertinent questions about women's knowledge about surgical treatment options. The findings of women not understanding the risks and losses related with each treatment suggests that women may not be making fully informed decisions and raises serious ethical consent issues. Therefore, this study identifies more research is required to determine women's understanding of each treatment options for early breast cancer.

Other breast cancer studies have shared consistent findings that relate to the mismatch of preferred and actual involvement of women in their treatment decisions (Janz et al., 2004; Vogel et al., 2007) and the information they prefer (O'Leary, Estabrooks, Olson, & Cumming, 2007; Temple et al., 2006). An Australian qualitative study consisting of 40 women (Stage I-II breast cancer) were interviewed face-to-face one year after first treatment to investigate the way women perceived the process of selecting treatment (Kenny, Quine, Shiell, & Cameron, 1999). Women who preferred not to participate in making the decision also neglected to recognise the importance of considering values as well as medical expertise in the treatment decision process. Interestingly, some women did not think they should be responsible for the consequences of the treatment. These women believed that doctors should be totally responsible for their treatment plan.

There is a dearth of Australian studies specifically investigating the quality of treatment decision-making of women for breast cancer. However, one Australian study used a mixed design (Reaby, 1998a) with the conceptual framework of the “Conflict Model” (Janis & Mann, 1977), to analyse the quality of 95 women’s treatment decision after having mastectomy surgery in the previous two to seven years. The data were collected using a semi-structured interview using open-ended questions developed by the researcher for the study. The women in the sample predominantly consisted of being married, white and required no post-mastectomy radiation or chemotherapy and therefore were diagnosed and treated at an early stage of the disease. Almost half of these women were 55 years or younger. The majority (78%) of women indicated that the surgeon made the treatment decision. Just over a third (34%) of women cited the doctor did not offer them breast conservation surgery. These women left the decision up to the surgeon using the coping patterns of: Satisficing, Complacency, and Defensive Avoidance. Moreover, none of these women used the coping pattern of vigilance (quality decision-making). This study contributes to knowledge of Australian women’s treatment decision-making by identifying the importance of helping women to understand treatment information so they can make quality decisions.

The above studies have investigated what preferences women want for involvement in the decision-making process for medical treatment and associated influencing factors but they do not provide specific guidance for assessment and provision of individual decision support by nurses. Few studies have attempted to capture and describe the decision-styles and processes of decision-making of women when they are asked to choose between equal treatments for early breast cancer. As previously mentioned one qualitative Grounded Theory study (Pierce, 1993) attempted to describe the decision-making process of 48 women for early breast cancer, using qualitative analysis and identified three primary decision style groups: Deferrer, Delayer and Deliberator.

Women in the Deferrer group (41%) were strongly influenced by the salience (attractiveness) of an alternative and made rapid, conflict free decisions. Women in the Delayer (44%) decision style group tended to put off making a decision until a salient feature of one of the alternatives influenced the preference. Delayers tended to use an unstructured approach and were strongly influenced by the emotional response to characteristics of various treatment options.

In contrast, the women in the Deliberator group (15%) usually identified decision-making as their personal responsibility and investigated each alternative in a systematic and thorough manner (Pierce, 1993). This study has significantly contributed to the knowledge of patient decision-making by providing the first multidimensional profile of decision-styles which has been further developed into a first generation assessment instrument (Michigan Assessment of Decision Styles) (Pierce, 1995a). The *MADS* instrument can guide the development of evidence-based decision support interventions given by nurses to patients. This instrument's evolution and psychometric testing is described in detail in Chapter 3 (Methodology) of this thesis. Budden (Budden, Pierce, Hayes, & Buettner, 2003) conducted the first internationally published study using Pierce's (Pierce, 1995a) Michigan Assessment of Decision Style (MADS) instrument. The pre-diagnostic decision-making behaviour of Australian women (N=377) undergoing routine mammography screening were surveyed about their treatment choices for early breast cancer. The aim of this research was to investigate women's preferred treatment choice if they were hypothetically diagnosed with early breast cancer. Of 366 participating women, 19.9% strongly agreed to all three items of the MADS factor Deferring Responsibility, 0.3% strongly agreed to all four factors of Avoidance, 32.7% strongly agreed on all four items of Information Seeking, and 63.4% strongly agreed to all five items of Deliberation.

In this research, women showed a variety of preferred decision-styles, depending on age, education, occupation, and employment status. Only 36% of women indicated it was critically important to "get the treatment over as soon as possible"; 55% to "participate in selecting treatment"; and 53% to "read a lot of information" (Budden et al., 2003). Women from this study indicated the most important factors in choosing a treatment was that the cancer would not return (95.6%); increased length of their life (82.1%); and let them be healthy (80.4%) (Budden, Hayes, Pierce, & Buettner, 2007). In addition, these women indicated that it was important that the treatment: "did not make you depressed" (88.6%); or "sad" (90.4%); "should keep you from worrying" (97%); and "give you peace of mind" (98.6%). Influencing socio-demographic variables such as age, employment, education and a family history were found to be significant influencing variables on the women's treatment values. This research (see Appendix 2 and 3 for journal articles) informed and laid the foundation for the present study discussed in this thesis.

Evidence-based decision support interventions currently do not exist to help women when they are choosing treatment for early breast cancer. However, decision aids have been developed and are in an early stage of development and evaluation. Decision aids have been developed to help patients clarify their values; improve their knowledge; satisfaction; participation in decision-making; and help reduce their decision conflict (Hawley et al., 2007; O'Connor, Drake et al., 1999; Pierce & Hicks, 2001). These decision aids have involved educational computer interaction programs (Molenaar et al., 2001) and predominantly consist of educational material to help women make their treatment choice for early breast cancer.

For examples, an instrument called a 'decision board' was developed by Whelan and colleagues (1999) to help doctors inform women about their breast cancer treatment options. The decision board is a visual aid that presents information about treatment choices for early breast cancer in a standardized manner (Whelan, Gafni, Charles, & Levine, 2000). The decision board was administered to 175 Canadian women diagnosed with breast cancer prior to them declaring a treatment choice. An overwhelming majority (98%) of women reported the decision board was easy to understand and 81% believed it had helped them choose their preferred treatment option. The decision board was also used in a clustered randomised study (Whelan et al., 2004) on 208 newly diagnosed Canadian women with early breast cancer (Stage I-IIA). Results of this study found women using the decision boards had higher knowledge levels, less decisional conflict, and were more likely to choose Breast Conservation Surgery.

A randomised control trial for a decision aid for women choosing surgical treatment for early breast cancer was undertaken in Canada (Goel, Sawka, Thiel, Gort, & O'Connor, 2001). The intervention group for the decision aid consisted of 86 women and, the control group with the pamphlet consisted of 50 women (N=136). The decision aid was given pre-operatively (prior to decision and after the decision aid prior to surgery) and consisted of a package including a tape, workbook, and photographs of treatment options. A questionnaire included: the Anxiety Inventory; knowledge and regret items; and Breast Cancer Information Test Revised (BCIT-R) (Ward & Griffin, 1990). The Decision Conflict Scale (O'Connor, 1995) was also administered to both groups pre-operatively and six months post-operatively. No differences between the groups were found in their anxiety, knowledge, or decision regret.

However, there is a decision support framework developed by Canadian researchers for patients if they are experiencing decision conflict when deciding on a treatment choice. This intervention is called the Ottawa Decision Support Framework (O’Connor et al, 2002). Decision conflict (as mentioned earlier) can be described as “the simultaneous opposing tendencies with the individual to accept and reject a given course of action” (Janis & Mann, 1977 p.46). In this framework, there are questions to assess the patient's information needs and plan interventions. This tool is in its early evolution and application in clinical settings. This approach may be useful if patients verbalise uncertainty and anxiety in the treatment dilemma and also as a follow-up after they have received decision support interventions based on their decision styles (*MADS*) (Pierce, 1995a).

Unlike decision support interventions, decision aids have recognised limitations for facilitation of patient decision-making. One major limitation related to the first generation decision aids is that they are one-dimensional and are usually generic across patients and conditions. On the other hand, research findings have reported decision support interventions resulting in better health comes and higher patient satisfaction with their treatment experience (Titler, Reoter & Corry 1996).

A systematic review on the use of decision aids (O'Connor et al., 2001) conducted by the Cochrane Collaboration Centre, concluded that studies have shown: decision aids have improved patients' knowledge; reduced their decisional conflict; aided participation in treatment decision-making without increasing their anxiety; but they have had little effect on satisfaction and an inconsistent effect on the patient's decision (O'Connor, Rostom et al., 1999). These findings suggest more clinical studies are required to develop evidence-based decision aids, which individualise the decision support given to patients, improve the quality of their decisions, and increase their decision satisfaction and quality of life. Other the hand research findings have reported decision support interventions result in better health comes and higher patient satisfaction with their treatment experience (Titler, Reoter & Corry 1996).

Treatment Decision Satisfaction

Studies of patient satisfaction have increased in the last decade, not only in response to the new awareness of patients' rights, but also in response to the spiralling cost of health care. The term patients satisfaction is defined in various ways (Sainfort & Booske, 2000). Patient satisfaction can be described as a subjective judgement which "reflects the degree to which an individual's actual experience matches his or her preferences regarding an experience" (Brennan, 1995 p.250). Patient's use certain styles in approaching decisions (Pierce & Hicks, 2001) and their satisfaction with a decision is often determined by the degree to which their choice was consistent with their values (O'Connor & O'Brien-Pallas, 1989).

Previous studies have been limited to measuring patient's satisfaction in the following ways: with their medical providers (Dolan et al., 2001; Jones et al., 1999; Shilling, Jenkins, & Fallowfield, 2003); treatment and care received (Hogan, 2000; Merkouris, Papathanassoglou, & Lemonidou, 2004; Schulmeister, Quiett, & Mayer, 2005; Shilling et al., 2003; Waljee, Hawley, Alderman, Morrow, & Katz, 2007; Wiggers, Donovan, Redman, & Sanson-Fisher, 1990); the outcomes of this care (Abu-Nab & Grunfeld, 2007; Al-Ghazal, Fallowfield, & Blamey, 2000; Arving et al., 2006; Aspinal, Addington-Hall, Hughes, & Higginson, 2003; Noyan, Sertoz, Elbi, Kayar, & Yilmaz, 2006); treatment information received (Griggs et al., 2007; Mallinger, Griggs, & Shields, 2005); resulting judgement of their Quality of Life (Engel, Kerr, Schlesinger-Raab, Sauer, & Holzel, 2004; Fasching et al., 2007); and breast cancer treatment (Arving et al., 2006; Contant, van Wersch, Wiggers, Wai, & van Geel, 2000; Griggs et al., 2007; Mallinger et al., 2005; Rehnberg, Absetz, & Aro, 2001).

There have been even fewer studies conducted in the area of women's decision satisfaction with their breast cancer treatment. Decision satisfaction is defined in the current study as women's satisfaction with their process, outcome and globally with their treatment decision. The studies that have included measuring satisfaction, regard it as a side issue and frequently have only had few questions to measure this phenomenon and therefore have severely limited validity (see Table 5). Therefore, these studies do not aid the development of knowledge in this area. Nonetheless, an annotation and critique of the recent studies in this area is provided.

Table 5 Studies measuring breast cancer satisfaction.

Author	Sample	Instrument	Focus
Griggs et al., 2007, USA	N = 231 Breast cancer	Information Needs Scale	Satisfaction with breast cancer information
Arving et al., 2006, Sweden	N = 120 Breast cancer	Patient satisfaction questionnaire	Satisfaction with psychosocial interventions by nurses
Mallinger et al., 2005, USA	N = 182 Breast cancer	Information Needs Scale	Satisfaction with breast cancer information
Rehnberg, Absetz & Aro 2001, Finland	N =45 Benign & malignant breast lump	Information needs & satisfaction	Information needs & satisfaction

Table 5 (continued). Studies Measuring Breast Cancer Satisfaction.

Author	Sample	Instrument	Focus
Contant et al., 2000, Netherlands	N = 73 Breast cancer with breast reconstruction	Satisfaction with breast reconstruction (BCR) & information	Satisfaction with BCR & information

Other studies are published regarding aspects of women's satisfaction (not decision satisfaction) but these do not contribute to the current discussion and therefore only recent literature is included hereon. As mentioned earlier, there are limited studies specifically examining decision satisfaction; therefore studies which have investigated the general area of "women's satisfaction", are reviewed. An American study of 182 women breast survivors were administered a questionnaire to determine their satisfaction with information they had received. The findings of the study revealed these women were highly satisfied with information related to treatment, but less satisfied with information related to the long-term impact of the treatment (Mallinger et al., 2005). This study provides some information about American women, however it provides limited insight and knowledge in other countries and cultures such as Australian women's satisfaction.

Lantz and colleagues (Lantz et al., 2005) investigated American women's (N = 1,633) decision processes and satisfaction with surgical outcomes following breast cancer or Ductal Carcinoma Insitu (DCIS). A revised version of Holmes-Rovner (Holmes-Rovner et al., 1996) Satisfaction with Decision Scale (SWD) was administered. Sixty-four percent of women had Breast Conservation Surgery, 23% had a mastectomy, and 12.2% had a mastectomy with reconstruction. Eleven point seven percent of women indicated low satisfaction with the surgery and 19.4% reported low satisfactions with the decision process and 11.4% indicated felling regret or ambivalence with their decision. Women from ethnic minority groups with low incomes were more likely to report low satisfaction and decision regret. Decision satisfaction and regret/ambivalence were found to be strong indicators with the match between women’s preferences regarding decision involvement and actual level of involvement. Having less involvement or more involvement than preferred with treatment decision-making was a risk factor for low satisfaction and regret. This research utilised a large sample and the focus on women’s decision process and decision satisfaction provides a springboard for developing stronger evidence in further studies. The use of the SWD in this research is useful in answering some questions about women’s decision satisfaction but larger instruments are required to explore the complex phenomenon of decision satisfaction.

A retrospective survey using a convenience sample of 611 Canadian women, was conducted to investigate women’s decision-making and satisfaction with their decision following early breast cancer treatment (Sabo et al., 2007) (also referred to in the literature section on decision-making). The survey included items measured on a 4-point Likert scale related to Decision Satisfaction; and a yes/no binary response for measuring the domains of Role Satisfaction and Information Satisfaction which were adapted from the well tested instrument by Degner and Sloan (1992). In the study, 88.1% of women rated being satisfied or very satisfied with their treatment choice; 89% were satisfied with their role in decision-making; and 83.6% satisfied with the amount and type of information they received to support their decision-making. Significant associations were found between Decision Satisfaction and the number of ‘helpful’ information providers. Older women were often more satisfied with their role in decision-making and the amount of information they received. Women who adopted an active role in the decision-making process were more satisfied with process than less active women. Whereas, those women who adopted a less active role such as a collaborative one were more satisfied with the type and amount of the information they received than women who used a more active role. Studies of women's satisfaction with large sample sizes are useful in informing doctors and nurses about the type and amount of information needed to make informed treatment decisions.

Some Australian studies have measured women's satisfaction. An Australian study (Wiggers et al., 1990) using a convenience sample assessed the perceptions of 232 (n = 55 were women and 38% breast cancer patients). Most patients were satisfied with the interaction with doctors but had less satisfaction with the information about their disease, treatment and symptom control and the provision of care in the home and to family. The data were collected using a 60-item questionnaire developed by the investigators. The items measured technical competence, communication skills, interpersonal skills, accessibility of care, continuity of care, hospital and clinical care, non medical care, finances and family care (Wiggers et al., 1990). This published study was one of the first in the area of Australian cancer patients' evaluating the care they had received.

The National Breast Cancer Centre performed a national survey of Australian women's perceptions of care following early breast cancer (National Breast Cancer Centre, 2004c) to evaluate the implementation of their guidelines for care (National Breast Cancer Centre, 1995; NHMRC and National Breast Cancer Centre, 2001). A survey consisting of 83 items devised by the centre was administered to 544 women in a telephone interview six to twelve months after a diagnosis of breast cancer. Twenty-four percent of women in the sample were aged less than 50 years, 32% were 50-59 years, 24% were 60-69 years, and 20% were 70 and over years. Using a five-point

Likert scale women were asked about their overall perceptions of care. The majority (81%) of women felt they had received enough information about their treatment and 83% felt they received enough support during the diagnostic and treatment phases. However, 21% of women who had a mastectomy would have preferred more information about breast reconstruction. Twenty percent of women reported not receiving enough information about the psychosocial impact of breast cancer including the availability of support and counselling and 24% the costs of treatment; 21% would have liked more information on lymphoedema and how to prevent it.

The majority (73%) of women in the study perceived they had achieved their preferred level of participation in the treatment decision-making and 16% of these women had left the decision to the doctor; 58% collaboratively decided and 24% chose the option solely with family and friends. Over a fifth (22%) reported they were given only one treatment choice and these women were more likely to receive mastectomy surgery. Over half of the women (56%) believed they had enough time to consider the treatment options, even though 41% reported they were told not to make the decision straight away. Eighty-two percent (82%) of women rated the overall standard of the breast cancer treatment as highly satisfied, and were more likely to be satisfied with their involvement with decision-making for treatment and encouragement for family involvement. The knowledge obtained from this study provides strong evidence for the understanding of Australian women's breast cancer experience and provides the groundwork for the direction of care.

The patients' perception of their health care treatment is a subjective and dynamic and their view fluctuates and provide different feedback at various times (Bredart et al., 2002). Patients may be influenced by adverse symptoms from their treatment. Therefore, when measuring patient satisfaction it is crucial to understand the stage of the patient's illness, treatment and context. Often these aspects of the patient experiences are not considered and discussed by authors in studies related to satisfaction and thus can lead to response bias (Noyan et al., 2006). The majority of the studies cited are cross-sectional, and consequently do not reflect and provide useful information about patients' needs and the support they require over their entire illness trajectory. Moreover, the patient satisfaction definitions and instruments used in studies have been inconsistent and no studies, until the last decade, have specifically investigated the unique construct of patient's satisfaction with their decision for medical treatment (Holmes-Rovner et al., 1996).

To try to address this need, Holmes-Rover and colleagues (1996) developed an instrument called the, "Satisfaction with Decision Scale" (SWD) consisting of six items (α= 0.86). The SWD instrument was developed using a community based convenience sample of 120 American university women, recruited through the local media who were asked questions about taking hormone replacement therapy for menopausal symptoms. The Satisfaction with Decision (SWD) scale consisted of six items rated on a 5-point Likert scale from strongly agree to strongly. The six items on the SWD are: 1) "*I am satisfied that I am adequately informed about the issues important to my decision"*; 2) "*The decision I made was the best decision possible for me personally*; 3) "*I am satisfied that my decision was consistent with my personal values"; 4)* "*I expect to successfully carry out (or continue to carry out) the decision I made"; and 5)* "*I am satisfied that this was my decision to make*; and 6) *I am satisfied with my decision".*

The limitations of this instrument are that only four of the six items have the word "*satisfaction*" in the statement: and one of these items relates to information; while one relates to consistency of decision with values. Further, one relates to continuing the current course of action; while only two of the items relate to satisfaction with the decision process; and one relates to overall decision. The small number of items relating to satisfaction of the decision process and outcome severely limits the construct validity of the scale. Decision satisfaction has different meaning for different people and the statements do not specifically relate to medical treatment, and the questions could be used for any decision. Furthermore, the developments of the instrument from an optimal decision choice such as hormone replacement therapy in a highly educated cohort of women does not necessary reflect the decision-making process for life threatening illness. The context of this decision-making is very different from being diagnosed with cancer and patients needing to make a decision between two options with undesired side affects and uncertain risks. This instrument has not yet been applied in any studies of breast cancer patients known to the researcher and has only been used in a small sample of depressed primary care patients (Wills & Holmes-Rovner, 2003). Nonetheless, this instrument has contributed to potential studies of patient decision-making for medical treatment, by identifying treatment decisions as a separate construct requiring attention and further investigation.

In summary, the literature indicates that more women in Australia are being diagnosed with early breast cancer (National Breast Cancer Centre, 2006). At the current time, both treatments (mastectomy or breast conservation surgery with radiation therapy) have been found to have equivalent outcomes (Early Breast Cancer Trialist's Collaborative Group, 2000; Early Breast Cancer Triallists' Collaborative Group, 1995). Many Australian women may choose their less preferred treatment option (mastectomy) because of the distance and expense of accommodation for their preferred treatment (breast conservation and radiation therapy) (Kok et al., 2006).

In Australia, women are generally encouraged by their doctors to choose their preferred surgical treatment, however for many women this is difficult because at this time, they feel psychologically distressed (Coyne & Borbasi, 2006), and some may experience affective disorders, such as anxiety and depression (Sharpley & Christie, 2007). Some women, not all, want to share the treatment decision with the doctor (Degner et al., 1997) but are cognitively overloaded (Cimprich, 1999; Cimprich et al., 2005) and are bewildered by the treatment information (Lobb, Butow, Kenny, & Tattersall, 1999). Women during this time seek decision support from doctors and nurses. The decision science literature does provide some theories on how individuals process information (Newell & Simon, 1984) and the impact of stress on their decision-making (Janis & Mann, 1977). However, these rational theories do not adequately explain or help understand the decision-making that occurs in naturalistic settings. Thus, these rational theories have limited application in the science of patient decision-making (Pierce & Hicks, 2001).

Most of the studies, which have investigated women decision-making for early breast cancer treatment have focussed on their preference for involvement in the treatment decision. However, these studies (Degner, 1992; Hack et al., 2006) have not linked the assessment of women’s preference for decision involvement with structured decision support interventions. Furthermore, there is little information about the phenomenon of decision satisfaction and even less about patient decision satisfaction. The science of patient decision-making is still in its infancy and little is currently know about the phenomenon. Therefore, nurses do not have evidenced-based guidelines to guide decision support interventions to women, in order to decrease their distress and improve their decision satisfaction. The development of the *Michigan Assessment of Decision Styles* (*MADS*) (Pierce, 1995a) is an assessment measure that can be used to guide the decision support interventions given to women.

In conclusion, large numbers of Australian women each year develop breast cancer. Women diagnosed with early stage breast cancer (Stage I-IIA) are usually asked by their doctors to choose between equally effective surgical options: mastectomy surgery; or breast conservation surgery followed by radiation therapy. Doctors often share the responsibility of treatment decisions with women, who at the time are frequently overwhelmed and psychologically distressed by the diagnosis consequences.

Furthermore, many women are inexperienced in making treatment decisions, which severely affect their long-term quality of life and psychological distress, and ask for support from doctors and nurses. These women may in fact not want to or are unable to, because of the level of their psychological distress, participate in the decision choice about treatment with the doctor. In the decision science literature, some of the knowledge gained by other disciplines such as psychology, can inform and assist nurses help women in the process of treatment decision-making. However, many of the theories and much of the research gained from these disciplines stem from hypothetical scenarios and laboratory simulations, which do not include the complicated, multiple contexts, issues and uncertainty that exist for patients making treatment decisions.

Many women are inexperienced in choosing medical treatment and require decision support from nurses. The development of decision aids are at present in their infancy and systematic reviews have concluded that while they improve patients knowledge and reduce their decision conflict, they have little effect on satisfaction. Currently, no decision aids exist to guide nurses in the provision of evidence-based decision support interventions for women with breast cancer. The *MADS* questionnaire is unique assessment instrument with strong psychometric properties that provides a profile of women's decision styles for decision support interventions. In fact, by using the *MADS* instrument new knowledge can be developed about women's decision-making (other studies only describe influencing factors) and it can be used a template to drive individual decision support interventions by nurses.

Chapter 2 reviewed and critiqued the literature from medicine, nursing sciences and decision psychology, providing a theoretical rationale for the development and testing of the hypotheses. By adopting a multidisciplinary approach a number of gaps were identified, contributing to the development of the hypotheses guiding the research in this thesis. The next chapter thus leads into the methodology used and the conduct of this research.

CHAPTER 3-METHODS

Overview of Study

The purpose of this chapter is to explain the method selected to test the hypotheses in answer to the research questions. This study employed a prospective, longitudinal, exploratory, cohort study design using a non-probability sample (convenience sample) on multi-sites. The aim was to investigate the decision styles and decision satisfaction of women diagnosed with early breast cancer who were in the phase of selecting treatment options. Data collection occurred at two periods. Firstly, a structured interview (Questionnaire 1- see Appendix 4) was used for Baseline Data Collection Stage 1, and secondly participants were surveyed 3 to 4 months after their initial surgery using a mailed self-report questionnaire (Questionnaire 2- see Appendix 5) for Data Collection Stage 2. These times were selected as the most pertinent and viable after consultation with clinicians and reviewing the literature on the treatment outcomes.

A cohort study design originates from epidemiology and is sometimes called a follow-up, incidence, or panel study by some authors (Polit & Beck, 2004) and its purpose is to investigate disease characteristics over time in populations. This type of study design has been applied in nursing studies and is considered important in understanding patients' illnesses to develop nursing interventions (Burns & Grove, 2005; Polit & Beck, 2004). In addition since, "cohort, studies are of forward directionality they have the advantages of being statistically efficient, can study rare phenomenon and can adjust for withdrawals and study natural phenomenon" (Gerstman, 1998 p.152). Cohort studies are considered the most powerful designs in observational epidemiology (Gerstman, 1998) and thus the most rigorous for this study.

Participants

Setting

The researcher was awarded five consecutive competitive research grants (2001-2004) by James Cook University and therefore was able to extend the research data collection to three coastal locations in Queensland differentiated as: Health Region A; Health Region B; and Health Region C. The names and details of the participating centres were purposely not included in this thesis to maintain the anonymity of the participants as far as possible and their region. Furthermore, women who were using private health services from Health Region B surgeons (five surgeons out of the available nine) were also included in the sample. These five surgeons mainly performed the breast cancer surgery in the region. Three locations were used to obtain the desired sample size in a feasible time, to allow for attrition of participants and to collect information from women with different socio-demographic profiles. The researcher and her supervisor met with nurses and surgeons in each location to inform them of and outline the study, and obtain their support, prior to applying for ethics approval. These consultations also helped the researcher determine the feasibility and protocols for the study. Brief details of each Health Region are as follows:

Health Region A

Health Region A is a suburban health service district of a large city, with an estimated population of people of 780, 853 people in 2005. The female population of this district consisted of 395,135 women. Chemotherapy was available in this health region; however, it is approximately 30-35kms travelling distance to the two-city radiation oncology clinic from this health region.

Health Region B

This site health service district in 2005 consisted of a total population of 213,213 residents and 108,402 females. Chemotherapy and radiation oncology services were both available in this district.

Health Region C

This health district contained a female resident population of 105,782 out of estimated total population of 215,921 people in 2005. Chemotherapy services were available in this health region, but it did not have a radiation oncology centre. The nearest oncology radiation centre was 400kms away.

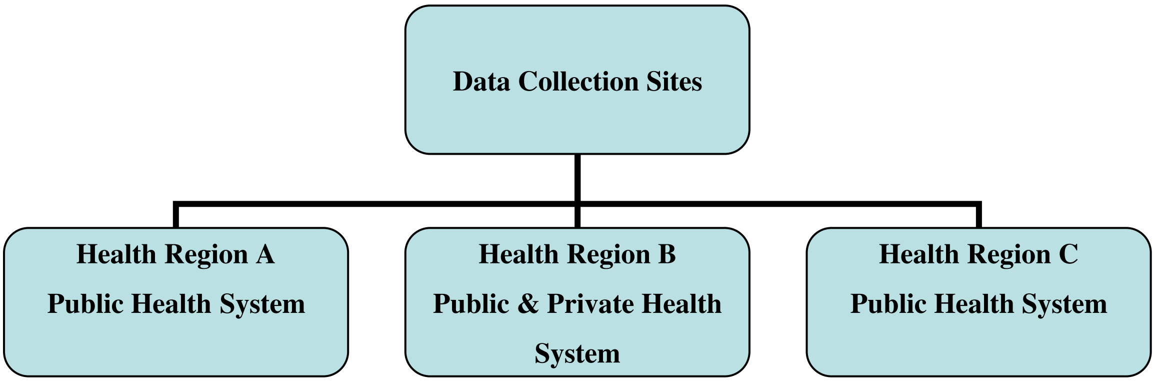
Sampling and Recruitment

The sensitive steps taken to recruit women in the study following their diagnosis were that (1) the treating doctors were originally informing the women about the study (see, Appendix 6 for letter of support), and (2) only a selected few research nurses (chosen and in some cases trained by the researcher) were approaching the women. These research nurses were experienced in caring for women with breast cancer. Every woman was given a list of contact numbers where she was able to obtain support from the Cancer Council of Queensland. The sampling occurred at multiple sites (1 site Health Region A Hospital; 5 sites in Health Region B surgeons-Private, Hospital and Private Rooms; and 1 site Health Region C Hospital) in three locations (Health Regions A, B, and C).

Having these sites enabled the sampling of a more representative socio-demographic cross-section of women with early breast cancer. It also increased the feasibility of data collection within the scope of time for the doctoral candidacy and the level of funding. To test the null hypotheses a power analysis was conducted. A sample size calculation was originally performed to determine the minimum sample size required to detect small differences (effect size $\gamma = 0.2$) in the hypotheses variables (decision styles and decision satisfaction) with a power of 0.8 and an alpha of 0.05. The calculation determined that a minimum of 400 participants was needed to detect small differences in the variables. A power analysis was also calculated to detect large differences (effect size $\gamma = 0.8$) in case the number of participants was difficult to recruit and indicated a minimum of 126 participants would be needed in the sample. Expected differences in decision satisfaction dependent on the decision styles of the women were difficult to predict, as the present study is the first of its kind. Thus, the present study was considered explorative and the candidate aimed to recruit at least 126 women into the study.

As the reader will appreciate, the window of opportunity for recruitment is very narrow. Women who were diagnosed with early breast cancer (using the criteria outlined below) and consulting a surgeon in any of the three locations for treatment were invited to join the study (non-probability or convenience sampling). In the public system, this occurred at the weekly Breast Clinic, and in the private system, the surgeon informed and invited the women into the study and contacted the researcher. Specific details about the data collection procedure are discussed later in this chapter. While data collection did occur over three years in all locations, the number of participants recruited into the study was only 132 women. Therefore, the statistical testing only had the power to identify large differences in the analyses. Throughout the results section (Chapter 4) the term “participants” has been replaced by “women”, to personalise and enhance the interpretation and reading. The data collection sites are summarised in Figure 1.

Figure 1 Diagram of data collection sites



Selection Criteria of Study

The inclusion and exclusion criteria were devised by the researcher and supervisor through intensive consultation with surgeons and reference to the Australian National Breast Cancer Centre (NBCC) guidelines for the management of early breast cancer (NHMRC and National Breast Cancer Centre, 2001). The definition of early breast cancer has been developed through international consensus using the TNM Clinical Classification (NHMRC and National Breast Cancer Centre, 2001) and is classified into stages. This staging usually includes clinical and pathological findings of the tumour, and the presence of nodes and metastases (TNM). Early breast cancer is categorised in Stage I-IIA of this classification namely:

1. A tumour less than 5cm;
2. No skin dimpling on breast;

3. No palpable lymph nodes;
4. No known metastases.

(NHMRC and National Breast Cancer Centre, 2001, pp. 139-140)

Inclusion Criteria

The inclusion criteria for women to be invited into the study were as follows:

1. Women who have a confirmed diagnosis of early breast cancer (Stage I-IIA);
2. Women who could read and write in English;
3. Women who have not yet received treatment for early breast cancer;
4. Women who were referred from a general practitioner to a surgeon for treatment for early breast cancer;
5. Women who were consulting with a surgeon for treatment options.

Exclusion Criteria

The criteria used to exclude women from being eligible for the study were as follows:

1. Women diagnosed with breast cancer in a stage more advanced than Stage IIA;
2. Women who could not speak or read in the English language;
3. Women with cognitive impairment;
4. Women diagnosed with Ductal Carcinoma Insitu (DCIS - which is considered as a precursor to invasive breast cancer by the Australian NBCC) and therefore not classified as breast cancer.

Ethical Considerations

Prior to data collection, ethics approval was obtained from the James Cook University Ethics Review Committee (Human Ethics Sub-Committee Approval H128- see Appendix 1); Health Region A Ethics Committee (Approval Number 01/10/06); Health Region B Ethics Committee (Local Protocol 44/0); and Health Region C Ethics Committee (Health Reference Number 233). The total time taken to conduct the study (to obtain minimum sample size of 126 determined through power analysis) was five years and therefore extensions to the ethics approval were sought and obtained from the university and each of the involved Health Service Districts.

Autonomy and Non-Maleficence

In this study, the women's autonomy and non-maleficence was protected by the following measures:

1. The researcher requested permission from doctors for their patients to be invited to participate in the study;
2. Women diagnosed with early breast cancer were informed by their doctor that a study was being conducted and that participation was strictly on a voluntary basis;
3. The doctors and women were reassured by the researcher that no attempts would be made to influence the women's decisions;
4. Women were informed that they did not need to be involved in the study to access breast cancer treatment;
5. Women's written informed consent (see Appendix 7) was obtained after they had been given a written plain language statement and a verbal explanation of the aims and eligibility of the study by the researcher or research nurse;

6. Women were informed that they could leave the study at any time;
7. The written information sheet (Appendix 8) given to eligible women included the researcher's contact details if the women had any concerns about the study;
8. Women eligible for the study were given the information for breast cancer support services (such as the Cancer Council Queensland (CCQ) and Specialist Breast Nurse (SBN) and psychological services they could access for support);
9. Women who required specialist counselling were referred to public and private psychologists for further support;
10. The Cancer Council Queensland was informed of and consulted about the study.

Confidentiality and Anonymity

The researcher carried out her duty of care to protect the women's confidentiality and anonymity in the following ways:

1. Women were informed and assured of their confidentiality and anonymity in the project;
2. Confidentiality and anonymity were maintained through the detachment of consent forms from the questionnaires and no names (only code numbers) were placed on the questionnaires;
3. No participants' names or identifying data will be used in any reports or publications from this study.

Data Protection and Storage

The researcher carried out her duty of care to protect the data from harm in the following ways:

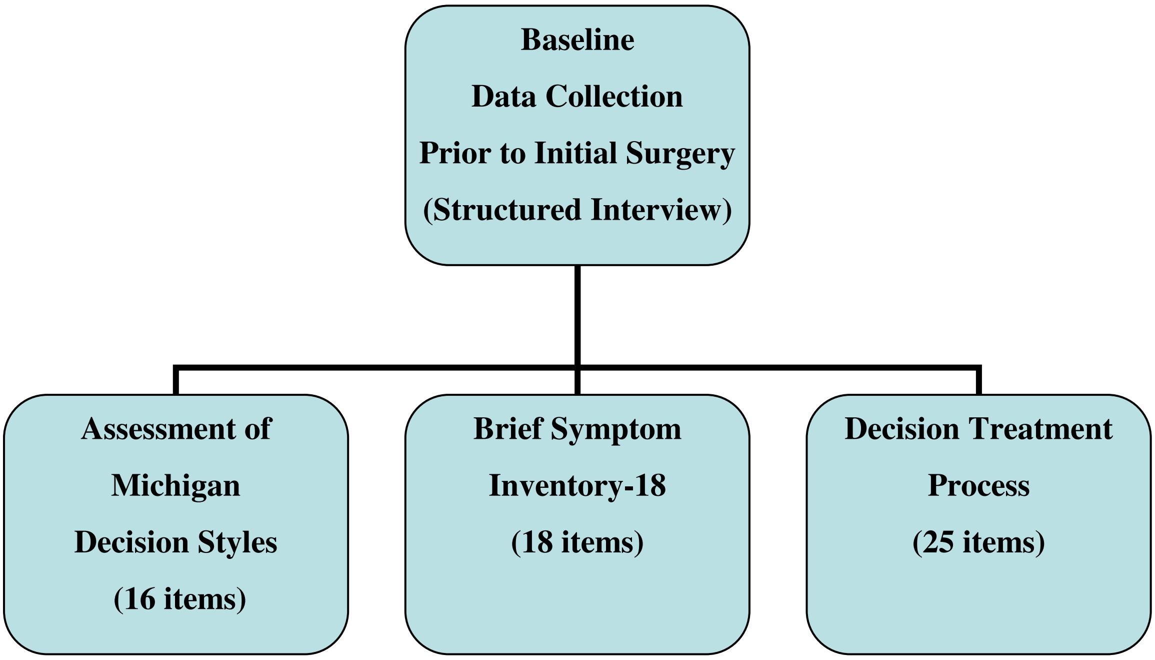
1. The consent forms and questionnaires were stored separately in a locked room and cupboard, to be stored for five years following National Health and Medical Research Committee (NHMRC) guidelines for research on human subjects;
2. The researcher was the only person who had access to the raw data in the locked cupboard.

Instruments - Baseline Data Collection

The Baseline Data Collection questionnaire collected socio-demographic information from the participants (see Appendix 4). Open-ended questions (age) and closed-ended questions were used to obtain this information. The socio-demographic variables included the following: age; education; marital status; postcode; religion (affiliation with religious denomination); occupation; employment status; income; private health insurance status; experience with breast cancer or cancer in the family and/or a close person; medical diagnosis; and significant support person. Two questions on ethnicity asked women if they identified themselves as an Aboriginal or Torres Strait Islander and these were obtained from the Australian Bureau of Statistics. This questionnaire also included two opened-ended questions asked women, "*What advice do you have for other women who are facing this decision*?" and "*What should nurses know about helping women make these decision*s?"

In addition, the baseline data collection questionnaire consisted of a structured questionnaire consisting of a group of instruments namely: *Michigan Assessment of Decision Styles* (*MADS*) 16 items (Pierce, 1995a); *Brief Symptom Inventory-18* (*BSI-18*) 18 items (Derogatis, 2000); and *Decision Treatment Process* 25 items (Pierce, 1995b). Figure 2 presents a diagrammatic representative of the instruments used in Baseline Data Collection.

Figure 2 Instruments contained in the baseline data collection.



Independent Variable: Decision Styles Instrument At Baseline (MADS)

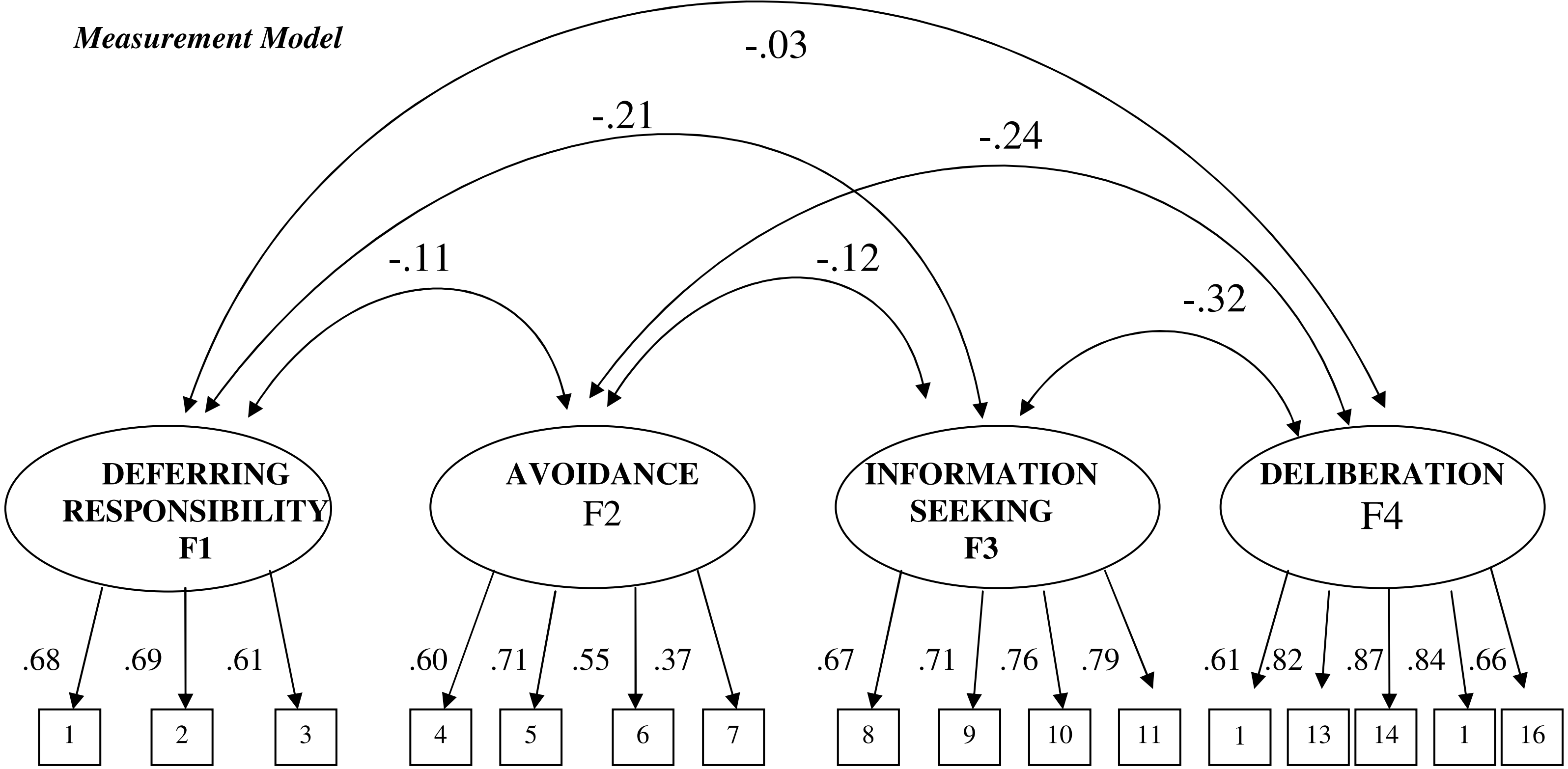
The women's decision styles were assessed using the *Michigan Assessment of Decision Style* (*MADS*) (Pierce, 1995a) instrument which includes 16 items relating to the decision style factors of *Avoidance* (4 items), *Deferring Responsibility* (3 items), *Information Seeking* (4 items), and *Deliberation* (5 items). The *MADS* is an instrument designed by Pierce (1995) to measure four key pre-decision behaviours on 5-point Likert scales ranging from "strongly disagree" to "strongly agree" (scored 1-5, respectively). Two factors, *Avoidance* (α= 0.63) and *Deferring Responsibility* (α= 0.76) indicate a tendency or preference to minimise personal involvement in the decision and defer the responsibility to another. The two remaining factors, *Information Seeking* (α= 0.80) and *Deliberation* (α= 0.85), indicate an inclination for involvement in the decision-making process.

MADS Instrument Original Development

The *MADS* factors model originated from an early qualitative Grounded Theory study by Pierce (1985) of 48 women (M = 49 years) diagnosed with early stage breast cancer. From this study a questionnaire was developed consisting of 46 items related to decision styles rated on a 9-point Likert scale where 1 indicated "No, definitely not", 5 indicated "Neutral" and 9 indicated "Yes, definitely". The decision styles fell into several categories including: information seeking behaviours; deliberation over treatment options and outcomes; trust in the physician's recommendation; avoidance or acceptance of responsibility for decision outcomes; fear; and risk taking. This instrument was used to survey 483 women who were either seeking breast care screening or evaluation for a perceived breast symptom at a large hospital in Michigan, USA. Analysis of the 46 items proceeded in steps. Firstly, an exploratory factor analysis was used to identify salient decision styles factors and then exploratory factors were applied. Confirmatory factor analysis using a structural equation modelling approach (EQS-Windows) identified four primary factors using 16 items. Higher Order Confirmatory Factor Analysis identified a four-factor model: *Deliberation*, *Information Seeking*, *Deferring Responsibility*, and *Avoidance*. This instrument was trialled in a reference group of six women in the local community to determine its suitability for Australian women prior to being used in a study of 377 women (Budden et al., 2003). The measurement model (Pierce, 1995a) for the *Michigan Assessment of Decision Styles* (*MADS*) is presented in Figure 3 and reproduced with permission from Pierce (Pierce, 1995a).

Figure 3 MADS

Measurement Model



X^2 (98) = 135.532, NFI = .918, NNFI = .970, CFI = .976, RMR = .154.

All paths are statistically significant (Pierce, 1995).

Psychological Distress at Baseline Data Collection (BSI-18)

The women's psychological distress levels were measured in the study using the *Brief Symptom Inventory-18* (*BSI-18*) (Derogatis, 2000) instrument. The level of distress experienced by the women was considered a potential confounding variable in the relationship between decision style and decision satisfaction. The *BSI-18* (Derogatis 2000) contains 18 questions scored on a 5-point Likert scale ranging from "strongly disagree" to "strongly agree" (scored 0-4, respectively). The instrument is a self-report symptom inventory designed to serve as a highly sensitive screen for psychological distress in medical and community populations and can be used as an outcome measure for the most prevalent manifestations of psychological disorders (Derogatis, 2000).

The *BSI-18* instrument was derived from the *Brief Symptom Inventory-53(BSI-53)* (Derogatis, 1993). The reduction of *BSI-53* items to form the *BSI-18* instrument was based on the prevalence of the symptom, item analysis characteristics and loading saturations in factor analyses. A Cronbach's Alpha measured the instrument's reliability (internal consistency) and these results are listed in Table 6. The inventory measures three symptom dimensions namely: *Somatization* (α=0.74); *Depression* (α=0.84); and *Anxiety* (α=0.79) and contains six items for each dimension (Derogatis, 2000).

1. *Somatization*- Six items on the *BSI-18* instrument, which reflect psychological distress reported by the women caused by the perception of bodily dysfunction, focussing on symptoms arising from cardiovascular, gastrointestinal, and other

physiological systems that have a powerful autonomic mediation (Derogatis, 2000).

2. *Depression*- Six items on the *BSI-18* instrument, which represent core symptoms of various symptoms of clinical depression and are identical to those found on the *Depression* dimension on the *BSI-53* instrument (Derogatis, 1993) Symptoms of disaffection and dysphoric mood are included as were those reflecting self-depreciation, anhedonia, and loss of hope (Derogatis, 2000).

3. *Anxiety*- Six items on the *BSI-18* instrument that is composed of symptoms that are prevalent in most major anxiety disorders and are identical to those found on the *Anxiety* dimension on the *BSI-53* instrument (Derogatis, 1993). Symptoms of nervousness, tension, motor restlessness, and apprehension are included, as are various symptoms that are indicative of panic states (Derogatis, 2000).

In addition, the *Global Severity Index* (*GSI*) can be calculated. The *GSI* represents the global or total score, which summarizes the respondent's overall level of psychological distress (Derogatis, 2000, pp. 5-6). Table 6 outlines the reliability testing of the *BSI-18* instrument.

Table 6 Reliability internal consistency coefficients for the BSI-18 instrument.

BSI -18 Dimension	Internal Consistency (α)
Somatization	0.74
Depression	0.84
Anxiety	0.79
Global Severity Index (*GSI*)	0.89

N = 1,134 community subjects
(Derogatis, 2000, p.11)

Decision Treatment Process

In addition, at baseline the questionnaire included items asking women to rate the importance of statements in describing their decision-making process. The *Decision Treatment Process* questionnaire (Pierce, 1995b) consisted of 25 items scored on a 5-point Likert scale ranging from “strongly disagree” to “strongly agree” (scored 1-5, respectively), and asks women to a rate the importance of items which describe the process for choosing a treatment for early breast cancer. The *Decision Treatment Process* (Pierce, 1995b) items were divided into the following five dimensions: *Doctor* (α= 0.82), *Information* (α= 0.75), *Support* (α= 0.48), *Control* (α= 0.64), and *Other* (α= 0.41). The reliability internal consistency for the total items in the *Decision Treatment Process* (Pierce, 1995b) questionnaire for the present study was strong (α = 0.87) .

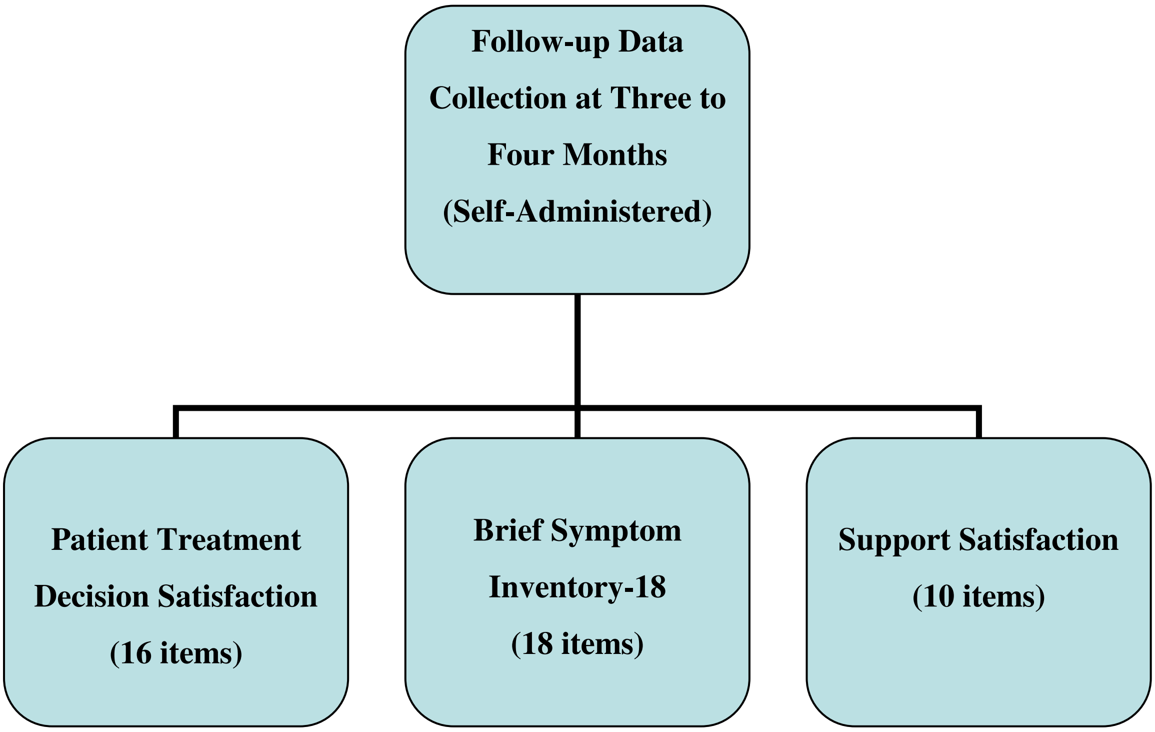
This *Decision Treatment Process* (Pierce, 1995b) questionnaire was pre-tested on a group of six women from the community (Budden et al., 2007; Budden et al., 2003) (as mentioned earlier relating to the *MADS* questionnaire). These women were selected through snowball sampling, to test the versatility and cultural sensitivity of applying this questionnaire in the Australian population. The feedback from the reference group related to some problems with the labelling of the socio-demographic questions such as "race" which was subsequently changed (consistent with the language used by the Australian Bureau of Statistics) to, "*Do you indentify as a Aboriginal*?" and "*Do you identify as a Torres Strait Islander*?" This questionnaire (as previously mentioned in the description of the *MADS* instrument) was used in a earlier study of 377 women (Budden et al., 2007; Budden et al., 2003) see Appendices 3 and 4. In addition, nurses from the Cancer Council Queensland were consulted about the items in the questionnaire to help determine its content validity. The protocols, recruitment of the women and structured interview technique of the study were evaluated for feasibility following its pilot testing on 20 women. No changes were required to the study and therefore these 20 women were included in the total sample for analyses.

Instruments-Follow-up Data Collection at Three to Four Months

The questionnaire for follow-up data collection at three to four months consisted of items relating to the participants treatment (see Appendix 5). This question was a closed ended question incorporating a number of common treatment options. The question specifically asked, "What treatment/s did you have following your diagnosis of early breast cancer?" This question also included an "other" response if the given answers did not address the women's treatment accurately. The women could have more than one response to this question, because women at 3 to 4 months after surgery may have started radiotherapy or some other type of adjunct treatment such as chemotherapy.

The follow-up data collection at three to four months questionnaire also contained group of instruments which consisted of the *Patient Treatment Decision Satisfaction* (*PTDS*) 16 items questionnaire (Budden & Pierce, 2001) and the *BSI-18* (Derogatis, 2000) 18 items and *Support Satisfaction* 10 items (developed by researcher). A summary of the instruments used in the Follow-up Data Collection questionnaire are presented in Figure 3.

Figure 3 Instruments contained in the follow-up data collection questionnaire at three to four months.



Dependent Variable: Decision Satisfaction At Three to Four Months (PTDS)

Decision satisfaction was measured using the *Patient Treatment Decision Satisfaction* (*PTDS*) questionnaire. The *Patient Treatment Decision Satisfaction* (*PTDS*) questionnaire was developed by the researcher (Budden & Pierce, 2001) modifying a previous questionnaire by Pierce (Pierce, 1993). The *PTDS* was developed by the researcher (Budden & Pierce, 2001) from a modified version of items from the *Women's Participation in Breast Cancer Treatment Decisions* questionnaire developed by Pierce (1993). The PTDS was modified from the original source by changing the questions used to statements, which were then scored on a 7-point Likert scale. A reference group of ten breast cancer survivors and recruited through the Cancer Council of Queensland (including two cancer council nurses) were used to assess the content validity and wording of the (*PTDS)* questionnaire.

This instrument contained 16 items scored on a 7-point Likert scale ranging from "strongly disagree" to "strongly agree" (scored 1-7, respectively). The 7-point Likert scale was chosen to increase the instrument's reliability (Streiner & Norman, 2000). The questions measured decision satisfaction, which were grouped by clinical judgement into two dimensions: *Decision Process Satisfaction* (6 items) and *Decision Outcome Satisfaction* (10 items). Reliability of the instrument was checked using Cronbach's alpha to test the internal consistency of the scales: *Decision Process Satisfaction* $\alpha = 0.91$, *Decision Satisfaction Outcome* $\alpha = 0.95$ and a total alpha for all 16 items was *Global Decision Satisfaction* $\alpha = 0.95$. The content of this questionnaire was further developed and validated using a reference group of 10 breast cancer survivors who were referred by Cancer Council Queensland. The *Patient Treatment Decision Satisfaction* questionnaire (*PTDS*) instrument was pilot tested on 20 participants in the present study to determine the feasibility of the data collection method and protocol. No changes were necessary to the data collection protocol.

Psychological Distress At Three to Four Months (BSI-18)

Psychological distress was once again measured using the *BSI-18* (Derogatis, 2000) questionnaire. The original instrument *Brief Symptom Inventory-18* (*BSI-18*) (as described in previous section in Baseline Data Collection) asked "the past 7 days including today" which was altered in Questionnaire 2 to, "in the last three months". The change was made due to the inconsistencies of the return date for the mailed questionnaires and caused limitations to the instrument. This change to the BSI-18 questions was a trade-off for feasibility in the study, although it may affect the construct validity of the instrument.

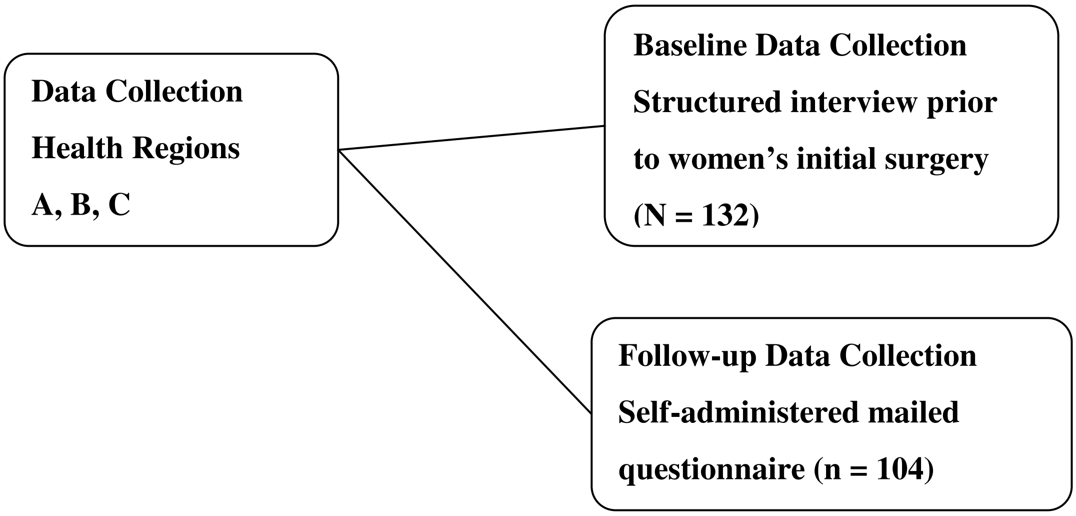
Support Satisfaction

These *Support Satisfaction* items were chosen from the literature and after discussion with nurses and surgeons. Support and *support satisfaction* were considered factors that may confound the study and influence the women's satisfaction scores. These 10 questions were scored on a 7-point Likert scale ranging from "strongly disagree" to "strongly agree" (scored 1-7, respectively). The questions asked women to rate their satisfaction with the support they received when making their treatment decisions namely: financial, family, social, psychological, emotional, nursing, informational, spiritual, and religious support. These Support and *support satisfaction* items were validated from the literature.

Data Collection Procedure

The data collection occurred on all sites and locations (Health Regions A, B and C) at two periods namely: 1) prior to participants’ initial surgery for early breast cancer; and 2) three to fours months following initial surgery. The data collection procedure is represented in Figure 4.

Figure 4 Outline of the data collection times.



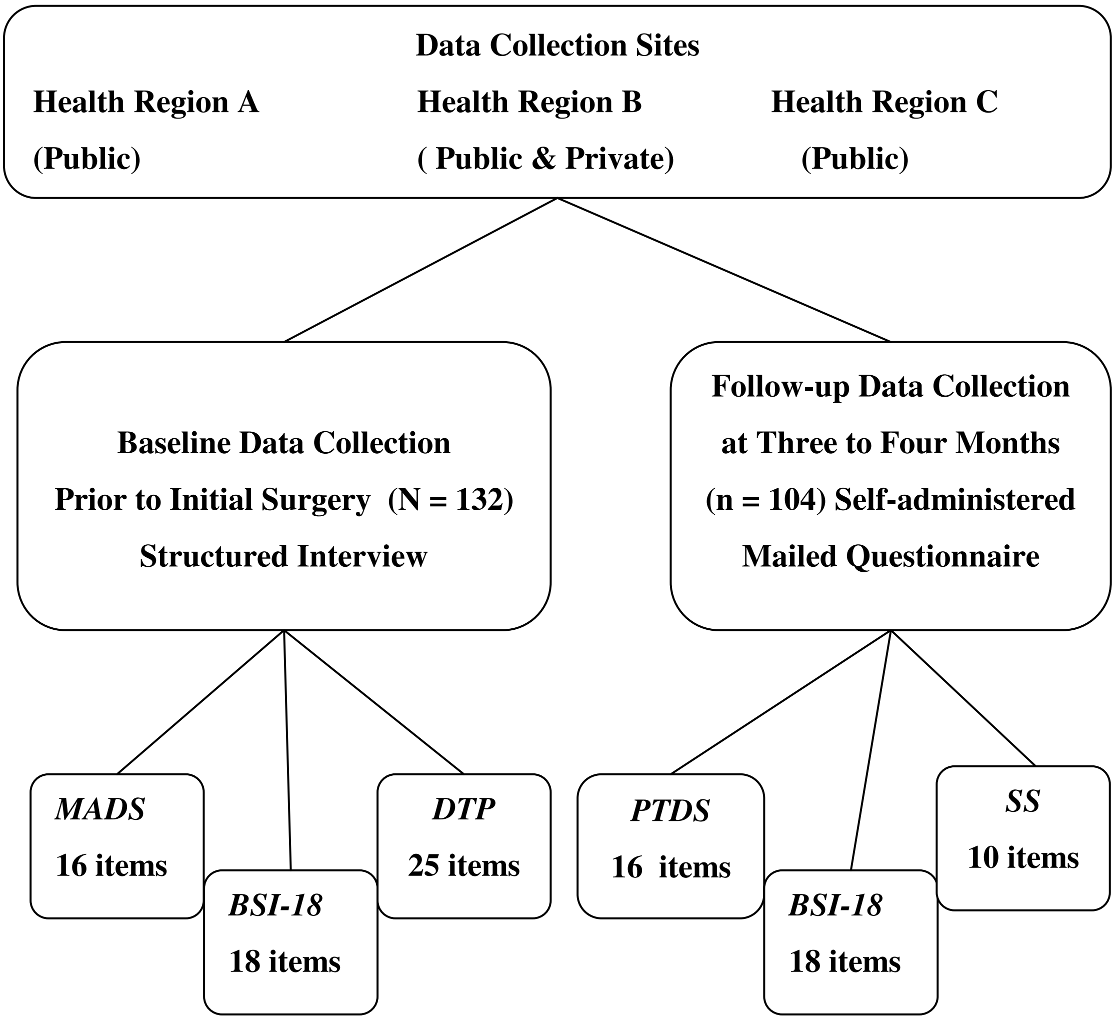
Public Health System

Women accessing the public health system who were eligible for the study were invited to participate in the study when they attended their surgical visit at the hospital clinic. The researcher or the research nurse (Health Regions A and C) attended each week's relevant breast clinic to identify (by consulting the treating doctors), provide information for and to recruit any eligible women into the study. Prior to inviting the eligible women into the study the doctor or the SBN gained permission form the women to be approached by the researcher or the research nurse.

Private Health System

The researcher and her supervisor Professor Barbara Hayes met with surgeons in Health Region B to explain in detail the study and to gain their support for referring women into the study. Each surgeon was given detailed information about the study and the eligibility criteria for participants into the study (see Appendix 9). At the surgeon's rooms eligible women were given information from their doctor that a study was being conducted. If the women indicated they would like to receive further information about the study and gave their permission to be contacted, the researcher was contacted by the doctor's office secretary and given eligible women's details. In addition, the researcher contacted the doctor's secretary each week for eligible women interested in the study. The researcher then contacted the women with further details and an invitation to join the study. The consenting women (none of the women contacted declined to be involved in the study) were then interviewed in exactly the same manner as the women in the public sector by the researcher. The interview was held in a setting to suit each woman's preference; usually this was in the women's home. Figure 5 provides a summary of the study.

Figure 5 Overview of study



Legend: *MADS = Michigan Assessment of Decision Styles*; *BSI-18 = Brief Symptom Inventory-18* ; *DTP = Decision Treatment Process*; *PTDS = Patient Treatment Decision Satisfaction;* and *SS = Support Satisfaction.*

Statistical Analysis

In meeting the study's overall aims, descriptive and inferential analyses of all the data were performed following the data cleaning process. Following the advice from my

Supervisor (a biostatistician), the following principles for statistical analysis of the data in the present study were used. The results were described using frequencies and percentages. Numerical variables (interval and ratio data) were described as mean values and standard deviations (SD) or median values and inter-quartile ranges (IQR) depending on the distribution of the variables.

To assess bivariate associations between: decision styles (*Michigan Assessment of Decision Styles- MADS*); decision satisfaction (*Patient Treatment Decision Satisfaction- PTDS*); socio-demographic characteristics; psychological distress (*BSI-18*) variables; and *Decision Treatment Process*; the following principles were used. For analysing two numerical variables, regression or correlation was used resulting in either Pearson's (parametric) or Spearman's (non-parametric) correlation coefficients; two categorical variables were analysed using Chi-squared tests classical; Fisher's exact test and Chi-square for trend (for unpaired data); and the McNemar test for paired data. When the two variables were numerical and categorical and the numerical data were approximately normally distributed, parametric tests for two groups using unpaired and paired *t*-tests for more than two groups ANOVA (unpaired) and ANOVA for repeated measurements (paired) was used. If the data were skewed, non-parametric tests for two groups were unpaired and paired Wilcoxon tests, and for more than two groups Kruskal-Wallis test (unpaired) and Friedman test (paired) were incorporated.

Hypothesis Testing

In further testing of the hypotheses (the influence of *MADS* as the independent variable on *PTDS* as the dependent variable), multivariate analysis principles used were as follows: if the outcome (*PTDS*- dependent variable) had numerical variability and was normally distributed then stepwise multiple linear regression modelling occurred; if the data were skewed, it was transformed so that approximate normality assumptions were given. The main parametric assumption for multiple regression is normality of the dependent variable. The main dependent variable (satisfaction score) was approximately normally distributed; other dependent variables investigated were logarithmic transformed to reach approximate normal distribution.

The resulting scores from the satisfaction questionnaire were approximately normally distributed. Hence, stepwise multiple linear regression analyses were used to assess the impacts of decision styles and women's level of psychological distress while adjusting for confounding variables. The main reason for using multiple stepwise regression was the type of the outcome variable (dependent variable). If the dependent variable is numerical, the only possible mainstream statistical approaches are multiple regression and ANOVA. The assumptions for ANOVA are much more rigorous (in particular regarding equal sample size and variance for each cell) and are usually only fulfilled with experimental designs.

Multiple stepwise regression was therefore seen as the method of choice, given that categorization of the dependent variable would have implied a loss of power. When necessary the dependent variable was transformed, to approach approximate normality (one of the assumptions of multiple regression). Stepwise backward and forward procedures were used to identify stable models.

All potential socio-demographic predictors were dummy coded for the multivariate analyses and stepwise forward and backward modelling processes were used. Models were accepted as stable if both forward and backward results were identical. Potential confounders such as psychological distress and socio-demographic characteristics were added to the model as independent variables and their effects were judged based on changes in the regression coefficients of the predictors in the model. The confounders such as age were adjusted by the process of entering the independent variables into the equation hierarchically following the procedure as detailed by Kleinbaum and Morgenstern (1982). Results of multiple linear regression analyses were presented as regression coefficients together with 95%-confidence intervals (95%-CI). Statistical analysis was performed using SPSS for Windows, release 11.0. Throughout the statistical analysis, on *a priori* significance level of 0.05 was assumed. Table 7 presents a summary of the statistical principles used during data analyses.

Table 7 Statistical data analysis principles.

Level of data	Normally Distributed	Statistical test	Paired data
Bivariate			
Two numerical variables (ratio)	Yes	(parametric) Pearson's Correlation Coefficient	Yes
	No	(nonparametric) Spearman's Correlation Coefficient	Yes
Two categorical (Nominal or interval)	Yes	Chi-square tests or Fishers exact test and trend (unpaired data) and paired	No No Yes
Numerical and categorical	Yes	(parametric for 2 groups) using unpaired	No
		paired t test	Yes
		(parametric for more than 2 groups) ANOVA (unpaired)	No
		ANOVA for repeated measures (paired)	Yes

Table 7 (continued). Statistical data analysis principles.

Level of data	Normally Distributed	Statistical test	Paired data
Bivariate			
Numerical and categorical	No	(Non-parametric test for 2 groups) paired	Yes
		unpaired Wilcoxon tests	No
		More than 2 groups	No
		Kruskal-Wallis test	
		(unpaired)	Yes
		Freidman test (paired)	
Multivariate Analysis (hypotheses)			
If outcome variables has numerical variability	Yes No (data re-coded for approximate normality assumptions)	Multiple linear regression	
If outcome variable is categorical with 2 categories	N/A	Logistic regression	

Baseline Data Collection Statistical Analyses

In the Baseline Data Collection, a descriptive analysis for all of the variables was conducted. The testing of bivariate associations was performed between the socio-demographic, decision styles (*MADS*), *Decision Treatment Process*, and psychological distress (*BSI-18*) variables.

Socio-Demographic Statistical Analyses

The numerical variable age (years) was re-coded and recoded for bivariate analyses into four groups namely: <50 years; 50-59 years; 60-69 years; and ≥ 70 years. To enable comparisons between location sites the region variable was recoded into the three Health regions (A, B, and C). Refer to Table 8.

Table 8 Re-coding of socio-demographic profile variables.

Variable	Original	Re-coded Final Categories
Age (years)	Numerical	< 50 years (n = 31) 50 – 59 years (n = 36) 60 – 69 years (n = 41) ≥ 70 years (n = 24)
Health region	Health Region A Health Region B Health Region C	Health region A (n = 66) Health region B (n = 48) Health region C (n = 18)
Marital status	De-facto Married Divorced Widowed Single	Living single: No (n = 89) Yes (n = 43)

Table 8 (continued). Re-coding of socio-demographic profile variables.

Variable	Original	Re-coded Final Categories
Highest level of education	0-7 grade	Up to grade 11 (n = 87)
	8-11 grade	
	High school graduate	≥Grade 12 (n = 45)
	TAFE graduate	
	University	
	Graduate	
Current employment status	Retired	No (n = 86)
	Homemaker	
	Disabled	
	Student	
	Unemployed	
	Full-time	Yes (n = 46)
	Part-time	
	Any employment	
Professional occupation	Categorical	No (n = 113)
		Yes (n = 17)
		Missing = 2
Total annual household income ($)	<6,000	≤$20,000 (n = 66)
	6,001-20,000	
	20,001-50,000	$20,001-50,000 (n = 43)
	50,001-60,000	>$50,000 (n = 20)
	≥60,001	Missing = 3
Number of people living in household	Numerical	1 (n = 25)
		2 (n = 66)
		≥3 (n = 41)

Table 8 (continued). Re-coding of socio-demographic profile variables.

Variable	Original	Re-coded Final Categories
Professional occupation	Categorical	No (n = 113) Yes (n = 17) Missing = 2
Private health insurance	No Yes	No (n = 103) Yes (n = 26) Missing = 3
Religion*	Categorical	No (n = 23) Yes (n = 109)
Personal history of breast cancer	No Yes	No (n = 130) Yes (n =2)
Family history of breast cancer	No Yes	No (n = 76) Yes (n = 56)
Personal history of cancer	No Yes	No (n = 103) Yes (n = 29)
Family history of cancer	No Yes	No (n = 39) Yes (n = 93)

* *Affiliation with religious congregation*

Decision Styles (MADS) Statistical Analyses

Percentages were used to describe each of the 16 items in the *MADS* instrument. The *MADS* items in each factor that is: *Avoidance* (4 items); *Deferring Responsibility* (3 items); *Information Seeking* (4 items); and *Deliberation* (5 items) were totalled and averaged, resulting in scores ranging from one (very low) to five (very high). Table 9 list the *MADS* items re-coded into the decision style factors.

***Table 9 MADS items recoded into decision style factors*.**

MADS items	**Re-coded MADS factors**
Deferring Responsibility* (3 items)	
"I will make a quick decision once I was told what my options were"	Deferring responsibility
" I will follow the recommendations of my doctor"	Deferring responsibility
"I will agree to the option that seemed the most reasonable to me at the time"	Deferring responsibility
Information Seeking (4 items)	
"I will develop a plan for gathering further information"	Information seeking
" I will read magazines and articles about breast cancer and different treatment"	Information seeking
"I will read scientific articles about the treatments that were being offered to me"	Information seeking
"I will spend as much time as I could gathering information"	Information seeking

* Deferring Responsibility relates to patients making the choice to the follow the doctors recommendation.

Table 9 (continued). MADS Original items and recoded decision style factors.

***MADS* factor items**	**Re-coded**
***Deliberation* (5 items)**	
"I will prefer to seek advice from specialists in breast cancer treatment"	Deliberation
'I will ask about the risks involved with each treatment alternate"	Deliberation
"I will carefully consider the risks of each option as I was making a choice"	Deliberation
"I will want to know the possible outcomes of each alternate that was being offered to me"	Deliberation
"I will ask a lot of questions concerning the treatment options"	Deliberation
Avoidance (4 items)	
"I want someone else to make the decision for me"	Avoidance
"I prefer in situations like these, that someone else tells me what to do"	Avoidance
"I prefer not knowing the possibility that unexpected things could happen to me"	Avoidance
"I believe that what will happen will happen and there is little I can do to change things"	Avoidance

The four *MADS* factors were skewed and analysed using median values and inter-quartile ranges. The Mann Whitney Wilcoxon test and the Kruskal-Wallis test were used to test the relationships between the *MADS* factors and socio-demographic variables. Spearman's rank correlations were calculated between the *MADS* factors and the *BSI-18* items.

Dependent Variable- Decision Satisfaction (PTDS) Statistical Analyses

The 16 items of the decision satisfaction variables were described as percentages and recoded as detailed in Table 10.

Table 10 Patient Treatment Decision Satisfaction items re-coded variables.

Decision Satisfaction	**Re-coded**
Decision Process (6 items)	
"I am very satisfied with the way nurses helped me to make my decision"	Decision Process Satisfaction
"I am very satisfied with the options that were offered to me"	Decision Process Satisfaction
"I am very satisfied with the way my options were offered to me"	Decision Process Satisfaction
"I am very satisfied with my participation in the decision"	Decision Process Satisfaction
"I am very satisfied that I had sufficient time to make my decision "	Decision Process Satisfaction Doctor

***Table 10 (continued). Patient Treatment Decision Satisfaction items re-coded* variables.**

Decision Satisfaction	**Re-coded**
Decision Process (6 items) (continued)	
"I am very satisfied with the information I used to make my choice"	Decision Process Satisfaction
Decision Outcome Satisfaction (10 items)	
"I am very confident that I made a satisfactory choice"	Decision Outcome Satisfaction
"I am satisfied with the choice I made"	Decision Outcome Satisfaction
"I am very satisfied with the quality of my decision-making activity "	Decision Outcome Satisfaction
"I am very satisfied with the outcome of the treatment "	Decision Outcome Satisfaction
"I am very satisfied that at the time, I was making a good decision"	Decision Outcome Satisfaction
"I am very satisfied with the outcome of my decision"	Decision Outcome Satisfaction

Table 10 (continued). Patient Treatment Decision Satisfaction items re-coded variables.

Decision Satisfaction	**Re-coded**
Decision Outcome Satisfaction (10 items) (continued)	
"I have no regrets about the treatment choice I made"	Decision Outcome Satisfaction
"I believe my decision will be very successful in the long run"	Decision Outcome Satisfaction
"I believe there is nothing I could have done differently at the time I was making my decision"	Decision Outcome Satisfaction

Psychological Distress (BSI-18) Statistical Analyses

Each of the *BSI-18* items was described as percentages. To investigate the relationship between each of the *BSI-18* dimensions (*Somatization*, *Depression*, *Anxiety*, and *Global Severity Index*) and the socio-demographic variables, non-parametric tests (e.g. Mann-Whitney-U test, Kruskal-Wallis test) were performed since the *BSI-18* scores were skewed. In the Baseline and Follow-up *BSI-18* instrument in the current study the 5-point Likert scale was scored from "strongly disagree" to "strongly agree" (score 1 to 5, respectively). For analysis in the study the *BSI-18* instrument's 5-point Likert score was changed from "strongly disagreed" to "strongly agreed (score 0 to 4, respectively) as outlined in the *BSI*-18 scoring manual (Derogatis, 2000). This change in the *BSI-18* scoring (0 to 4) method in the analysis allows comparison of the results with other studies. Table 11 details the recoding of the BSI-18 items into the dimensions of Somatization, Depression and Anxiety.

Table 11 BSI-18 dimension items re-coded variables.

BSI-18 Dimensions **Somatization (6 items)**	**Recoded Variable**
Faintness or dizziness	Somatization
Pain in the heart or chest	Somatization
Nausea or upset stomach	Somatization
Trouble getting your breath	Somatization
Numbness or tingling in parts of your body	Somatization
Feeling weak in parts of your body	Somatization
Depression (6 items)	
Feeling no interest in things	Depression
Feeling blue	Depression
Feelings of worthlessness	Depression
Feeling hopeless about the future	Depression
Thoughts of ending your life	Depression
Feeling lonely	Depression
Anxiety (6 items)	
Nervousness or shakiness inside	Anxiety
Feeling tense or keyed up	Anxiety
Suddenly scared for no reason	Anxiety
Spells of terror or panic	Anxiety
Feeling so restless, you couldn't sit still	Anxiety
Feeling fearful	Anxiety

To identify positive cases, the *BSI-18* items were analysed following the guidelines outlined in the *BSI-18* scoring manual (Derogatis, 2000). The *Global Severity Index* (*GSI*) score was calculated by the total sum of the items. Each dimension (*Somatization*, *Depression*, and *Anxiety*) was summed and converted to a T score using the norm for the female Oncology patients located in the *BSI-18* scoring manual (Derogatis, 2000). The cut-off score for each dimension was determined to be 63 when compared to the oncology female norm group (N = 741). The rule in *BSI-18* Manual stated, "that if a respondent has a *GSI* T score of 63 or higher (on the female oncology norm), or if any two dimensions T scores were 63 or higher the individual is considered a positive risk or a case" (Derogatis, 2000 p.23).

Decision Treatment Process

Each of the 25 items of the *Decision Treatment Process* was analysed using percentages. The items were then grouped by clinical judgement and recoded into four categories as follows: *Doctor* (11 items); *Information* (6 items); *Control* (2 items); *Support* (4 items); and Other (2 items) for bivariate analysis. The data were not normally distributed and therefore non-parametric statistical tests such as the Mann Whitney Wilcoxon Test and the Kruskal-Wallis test were used to test associations between the *Decision Treatment Process* and the socio-demographic variables. Table 12 outlines the re-coding of *the Decision Treatment Process* variables into categories based on clinical judgement.

Table 12 Decision Treatment Process items re-coded variables.

How important is it to you when making this decision that you…	**Re-coded**
Doctor (11 items)	
"Follow your doctor's advice"	Doctor
"Trust your doctor"	Doctor
"Have the advice of the best specialists"	Doctor
"Have a doctor who asks you what you want"	Doctor
"Have your doctor answer all your questions"	Doctor
"Have a woman doctor"	Doctor
"Have a doctor of the same cultural background as you"	Doctor
"Tell your doctor how you feel about treatment"	Doctor
"Have a doctor that cares about you"	Doctor
"Have a doctor who listens to you"	Doctor
"Have a doctor who tells you what to expect"	Doctor
Information (6 items)	
"Read a lot of information"	Information
"Get the treatment over with as soon as possible"	Information
"Ask questions"	Information
"Know if there are any side effects of the treatment"	Information
"Know if there might be unexpected problems with the treatment"	Information
"Know the chances that the cancer might return"	Information
Control (2 items)	
"Feel in control of choosing a treatment"	Control
"Participate in selecting a treatment"	Control

Table 12 (continued). Decision Treatment Process	
Control (2 items)	
How important is it to you when making this decision that you…	**Re-coded**
Support (4 items)	
"Have faith in God"	Support
"Have someone to talk to"	Support
"Talk to women who have had cancer"	Support
"Have friends and family come to the doctor's visits with you"	Support
Other (2 items)	
"Have a private room when you are in hospital"	Other
"Have your parking expenses paid for"	Other

Follow-up Data Collection

Dependent Variable- Patient Treatment Decision Satisfaction (PTDS)

The 16 items of the decision satisfaction variables were described as percentages. Scores of the decision satisfaction scale were transformed as case normality assumptions did not hold. The items were scored on a 7-point Likert scale from (strongly disagree = 1 to strongly agree = 7). The 16 items were categorised into two dimensions by clinical judgement of the researcher namely: *Decision Process Satisfaction* (6 items) and *Decision Outcome Satisfaction* (10 items). The items in each dimension were totalled and averaged to create a score called the *Global Decision Satisfaction*, and analysed using descriptive statistics such as median, ranges and inter-quartile range. Each of these dimensions of the *PTDS* scale was recoded to:

-3 to -1 for the disagree items; zero for neither disagree or agree; and to 1 to 3 for the agree items; and then they were totalled and averaged.

Bivariate analysis was used to test for associations between decision satisfaction scores and treatment received and socio-demographic variables were performed using non-parametric statistics of Wilcoxon-Mann-Whitney-U test and Spearman's rank correlation, and the Kruskal–Wallis test. Inferential analyses using Spearman's rank correlation coefficient were used to test the relationship between the decision satisfaction scores and psychological distress (*BSI-18*). Table 13 outlines the recoding of the decision satisfaction question.

Table 13 Patient Treatment Decision Satisfaction Items Re-coded.

Decision Satisfaction	**Re-coded**
Decision Process Satisfaction (6 items)	
"I am very satisfied with my decision-making experience"	Decision Process Satisfaction
"I am very satisfied with the options that were offered to me"	Decision Process Satisfaction
"I am very satisfied with the way my options were offered to me"	Decision Process Satisfaction

Table 13 (continued). Patient Treatment Decision Satisfaction items re-coded.

Decision Satisfaction (6 items) (continued)	
"I am very satisfied with my participation in the decision"	Decision Process Satisfaction
"I am very satisfied that I had sufficient time to make my decision "	Decision Process Satisfaction Doctor
"I am very satisfied with the information I used to make my choice"	Decision Process Satisfaction
Decision Outcome Satisfaction (10 items)	
"I am very satisfied with the way nurses helped me to make my decision"	Decision Outcome Satisfaction
"I am very confident that I made a satisfactory choice"	Decision Outcome Satisfaction
"I am satisfied with the choice I made"	Decision Outcome Satisfaction
"I am very satisfied with the quality of my decision-making activity "	Decision Outcome Satisfaction

Table 13 (continued). Patient Treatment Decision Satisfaction items re-coded.

Decision Outcome Satisfaction (10 items) (continued)	
"I am very satisfied with the outcome of the treatment "	Decision Outcome Satisfaction
“I am very satisfied that at the time, I was making a good decision”	Decision Outcome Satisfaction
“I am very satisfied with the outcome of my decision”	Decision Outcome Satisfaction
“I have no regrets about the treatment choice I made?	Decision Outcome Satisfaction
"I believe my decision will be very successful in the long run"	Decision Outcome Satisfaction
"I believe there is nothing I could have done differently at the time I was making my decision"	Decision Outcome Satisfaction

Support Satisfaction

Ten items scored on a 7-point Likert scale (from strongly disagree= 1 to strongly agree= 7) rated the women's satisfaction with the types of support received and were reported as percentages. Spearman's rank correlation coefficients were used to correlate between the *support satisfaction* and the decision satisfaction.

Hypotheses Testing

In further testing of the hypotheses (the influence of *MADS* as the independent variable on *PTDS* as the dependent variable), the multivariate analysis as described earlier were the principles used. The resulting scores from the satisfaction questionnaire were approximately normally distributed. Hence, stepwise multiple linear regression analyses were used to assess the impacts of decision styles and women's level of psychological distress while adjusting for confounding variables.

All potential socio-demographic predictors were dummy coded for the multivariate analyses and stepwise forward and backward modelling processes were used. Models were accepted as stable if both forward and backward results were identical. Potential confounders such as psychological distress and socio-demographic factors were added to the model as independent variables and their effects were judged based on changes in the regression coefficients of the predictors in the model. The confounders such as age were adjusted by the process of entering the independent variables into the equation hierarchically following the procedure as detailed by Kleinbaum and Morgenstern (1982). Results of multiple linear regression analyses were presented as regression coefficients together with 95%-confidence intervals (95%-CI). Statistical analysis was performed using SPSS for Windows, release 11.0. Throughout the statistical analysis, *a priori* significance level of 0.05 was assumed. In total, 16 models were created using forward and backward stepwise modelling procedures. Each socio-demographic variable, the psychological distress levels (BSI-18), and the satisfaction with support received was considered as potential confounders. Only six models were identified using this modelling process, which showed significant relationships between *MADS* and *PTDS*. A total of 12 models was investigated (4 *MADS* factors x 3 Satisfaction factors), however only six of these models showing significant relationships are described in detail in the next chapter (Chapter 4).

The current chapter presented the methodology of the research. Detailed information about the sampling and recruitment of the participants and the consequent ethical considerations were included. The instruments and data collection methods used in this research were outlined. Further, the statistical analysis and hypotheses testing for the study were discussed. The following chapter presents the findings of the analyses undertaken to test the hypotheses and central questions guiding the research.

CHAPTER 4- RESULTS

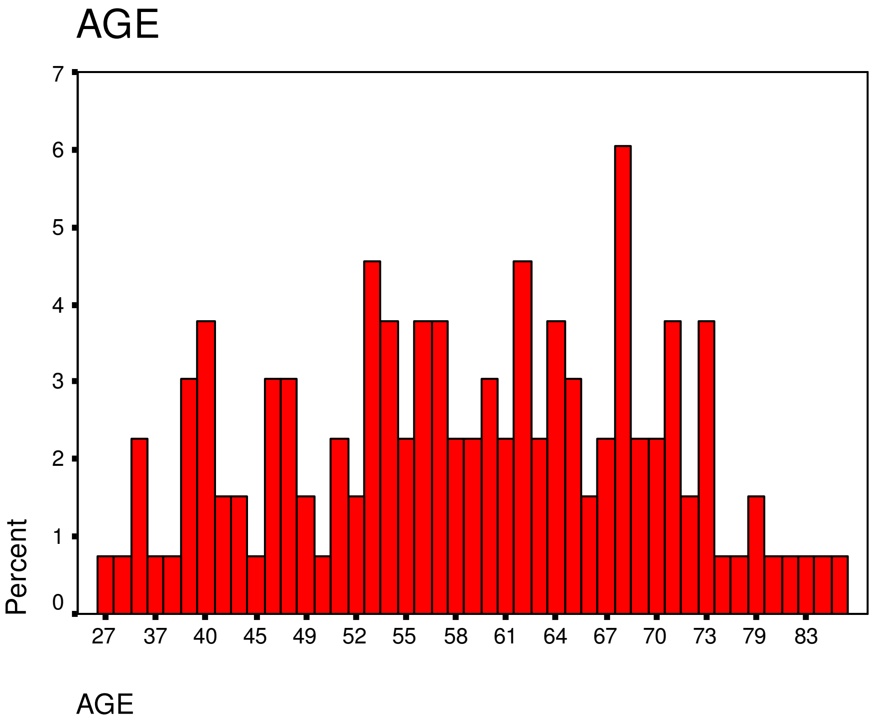
Introduction

The results of the statistical analyses are presented in the following sections: Description of sample; Baseline Data Collection; Follow-up at three to four months; and the comparison and testing of the main variables between each of the data collection times. Each section presents the descriptive statistics and bivariate analyses. Stepwise multiple regression was used for hypotheses testing and analysing the predictive ability of the independent variable of the *MADS* factors (*Michigan Assessment of Decision Styles*) on the dependent variable of decision satisfaction (*Patient Treatment Decision Satisfaction*) adjusted for confounding factors.

Description of Sample

A total of 132 women who were diagnosed with early breast cancer participated in the study (response rate = 96% of those invited into study). The mean age of the women was 58 years (SD ± 12.3) and age range was 27 to 86 years (Figure 6). Twenty three point five percent (23.5%) of women were aged in the youngest group (less than 50 years); 27.3% were aged between 50 and 59 years; 31.1% were in the 60 and 69 year group; and 18.2% were 70 years of age or older. The majority of women (59.8%) were married, 10 women (7.6%) lived in a de-facto relationship, and all other women (32.6%) identified that they currently lived without a partner (i.e. they were either single, divorced, widowed, or separated). Figure 6 details the ages of the participants.

Figure 6 Histogram (%) of age of participants (years) (N = 132).



Most of the women (65.9%) had completed Grade 11 or less in high school. The majority (65.1%) of women were not employed (i.e. they were retired, homemakers, disabled or unemployed). The women's highest level of education and employment status are presented in Table 14.

Table 14 Women's highest level (%) of completed education and employment status at baseline (N = 132).

Highest Level of Completed Education	**%**	**Employment Status**	**%**
Grade 11 or less	**65.9**	**Full-time**	20.5
High School	15.9	**Part-time**	14.4
TAFE College	10.6	**Retired**	**40.9**
University	7.6	**Homemakers**	17.4
		Disabled	4.5
		Unemployed	2.3

The median number of people in the household was 2 (IQR = 2-3) and one woman reported living in the house with nine other people. Almost a fifth of women indicated they were homemakers and the majority (56.6%) reported a household income less than $20,000 per year. Table 15 describes the occupation of the women and their total household income.

Table 15 Women's occupation and total annual household income (%) at baseline (N = 132).

Occupation	%	Total Yearly Household Income ($)	%
Homemaker	**21.5**	**< 6,000**	4.7
Clerical Work	6.9	**≤ 20,000**	**51.2**
Retail Work	5.4	**20,001-50,000**	33.3
Managerial Work	4.6	**> 50,000**	15.5
Primary School Teachers	4.6	Missing = 3	
Professional Job	13.1		
Other	43.9		
Missing = 2			

Less than a fifth (20.2%) of the women indicated being privately health insured. The majority (82.6%) of women reported believing in God. More than a fifth (22%) of women reported having a previous history of cancer, two indicated a previous history of breast cancer and 93 (70.5%) a family history of cancer. Over half of the women (56%) reported having a family member or close friend who had been diagnosed with breast cancer. Table 16 indicates the women's reported previous history or contact with cancer.

Table 16 Women's reported (%) previous history or contact with cancer at baseline (N =132).

Previous History of Types of Cancer	**%**
Any cancer	22.0
Breast Cancer	1.5
Skin Cancer	12.1
Cervical Cancer	4.5
Uterine Cancer	2.3
Kidney Cancer	0.8
Family history of cancer	**70.5**
Family history or close friend with Breast Cancer	42.4

Baseline Data Collection

Psychological Distress Levels (BSI-18)

Women's psychological distress levels at baseline were assessed using the *BSI-18*. Almost a third (31.8%) of women reported feeling a little bit of, "*nervousness or shakiness inside*" and over a quarter (26.5%) indicated moderately, "*feeling tense or keyed up*" since their diagnosis of breast cancer. The women's responses to the other *BSI-18* items are presented in Table 17.

***Table 17 Women's responses (%) to the baseline BSI-18 items at baseline* (N = 132).**

Since your diagnosis of breast cancer, how much have you been distressed by…?	**Not at all %**	**A little bit %**	**Moderately %**	**Quite a bit %**	**Extremely %**
Somatization					
Faintness or dizziness	**74.2**	20.5	3.8	0.8	0.8
Feeling no interest in things (n = 131)	**56.4**	23.7	9.2	8.4	2.3
Nausea or upset stomach	**67.4**	3.6	7.8	10.6	0.8
Numbness or tingling in parts of your body	**78.8**	13.6	3.8	1.5	2.3
Feeling weak in parts of your body	**77.3**	13.6	7.6	1.5	0
Pain in heart or chest	**75.8**	14.4	3.0	6.1	0.8
Trouble getting your breath	**90.2**	6.1	2.3	0.8	0.8

Table 17 (continued). **Women's responses (%) to the baseline BSI-18 items at baseline (N = 132).**

Since your diagnosis of breast cancer, how much have you been distressed by…?	**Not at all %**	**A little bit %**	**Moderately %**	**Quite a bit %**	**Extremely %**
Depression					
Feeling lonely	**60.5**	18.9	8.3	6.8	5.3
Feeling blue	**37.1**	28.8	15.2	13.6	5.3
Thoughts of ending your life	**95.5**	2.3	1.5	0	0.8
Feeling hopeless about the future	**62.1**	22.7	8.3	3.8	3.0
Feelings of worthlessness	**78.0**	13.6	3.8	3.0	1.5

Table 17 (continued). **Women's responses (%) to the baseline BSI-18 items at baseline (N = 132).**

Since your diagnosis of breast cancer, how much have you been distressed by…?	**Not at all** %	**A little bit** %	**Moderately** %	**Quite a bit** %	**Extremely** %
Anxiety					
Spells of terror or panic	**66.7**	16.7	9.1	5.3	2.3
Feeling tense or keyed up	22.7	20.5	22	**26.5**	8.3
Suddenly scared for no reason (n = 131)	**51.1**	19.8	11.5	14.5	3.1
Feeling so restless, you couldn't sit still	**65.2**	11.4	11.4	9.1	3.0
Feeling fearful	**42.4**	28	11.4	13.6	4.5
Nervousness or shakiness inside	27.3	**31.8**	15.2	15.2	10.6

Each dimension (i.e. *Somatization*, *Anxiety*, and *Depression*) was scored on a 5-point Likert scale and totalled for analysis. Following the scoring and analysis guidelines for *BSI-18* described by Derogatis (Derogatis, 2000) the scores were then converted to a T score using the Female Oncology Norm in the manual. The *GSI* score was the sum of all the dimensions. A woman was considered a positive risk or "case" if they received a Standardised T score of 63 or higher in any of the *BSI-18* dimensions (following the guidelines described by Derogatis, 2000) (see Methods section for more details). Seven of the women (5.3%) were identified as a positive case of *Somatization* and 31 (23.5%) with *Depression*. Thirty-eight (28.8%) women were found to be positive cases of *Anxiety*, with 29 (22.0%) women scoring as positive cases on the *GSI* (*Global Severity Index*) dimension. Nine (6.8%) women scored a zero in the *GSI* dimension, indicating they had not been feeling psychological distressed at all. Overall 29 (22.0%) of women scored as positive cases, this implies they either had scored 63 or above overall or a total of 63 or above in two dimensions of the *BSI-18*. The following table (Table 18) presents the *BSI-18* descriptive (univariate) analyses and psychological distress scores of the women.

Table 18 Positive cases and descriptive analyses of women on the BSI-18 at baseline (N = 132.).

Descriptive Analysis	Somatization	Depression	Anxiety	GSI
Number of Positive Cases	7	31	**38**	29
(%)	5.3	23.5	**28.8**	22.0
Median Raw Score	1	3	5.5	**11**
Interquartile Range (IQR)	(0, 3)	(0, 6)	(2, 10)	(4.25, 19)
Range	0-14	0-19	0-23	0-55
Median Standardised T score	46	55	**56**	55
(IQR)	(39, 53)	(40, 61)	(47 63)	(45.25, 61)
Range	39-73	40-81	36-79	31-79

The results of the analysis investigating the relationships between the *Somatization* scores and the women's socio-demographic variables are given in Table 19. Women who were younger were more likely to experience higher *Somatization* scores (p = 0.002). Women with a household income between AUD20, 001 and AUD50, 000 were more likely to experience higher *Somatization* scores (p = 0.01). No other statistically significant associations were identified during this analysis (see Table 19).

Table 19 BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline **(N = 132).**

Somatization	Median of standardised score on Somatization (IQR)	p-value	Positive cases of Somatization %	p-value
Age				
< 50years (n = 31)	53 (39-55)	**0.002****	3.2	1.0 ****
50 – 59 years (n = 36)	48 (46-56.5)		**8.3**	
60 – 69 years (n = 41)	46 (39-53)		7.3	
≥ 70 years (n = 24)	42.5 (39-46)		0	
Health region				
Health Region A (n = 66)	46 (39-53)	0.554**	4.6	0.567***
Health Region B (n = 48)	46 (39-55)		**8.3**	
Health Region C (n = 18)	46 (39-53.5)		0	

Table 19 (continued). BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline (*N = 132*).

Somatization	**Median of standardised score on Somatization (IQR)**	**p-value**	**Positive cases of Somatization %**	**p-value**
Living single				
No (n = 89)	46 (39-54)	0.940*	**5.6**	1.0***
Yes (n = 43)	46 (39-53)		4.7	
Education				
Up to grade 11 (n = 87)	46 (39-55)	0.756*	**5.7**	1***
≥Grade 12 (n = 45)	46 (39-52)		4.4	
Currently employed				
No (n = 86)	46 (39-53)	0.185*	**7.0**	0.420***
Yes (n = 46)	48 (39-55)		2.2	

Table 19 (continued). ***BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Somatization	**Median of standardised score on Somatization (IQR)**	**p-value**	**Positive cases of Somatization %**	**p-value**
Professional occupation				
No (n = 113)	46 (39-55)	0.176*	5.3	1***
Yes (n = 17)	46 (39-50.5)		**5.9**	
Missing = 2				
Household income				
≤$20,000 (n = 66)	46 (39-53)	**0.014****	4.5	0.790****
$20,001-50,000 (n = 43)	53 (46-57)		**9.3**	
>$50,000 (n = 20)	46 (39-53)		0	
Missing = 3				

Table 19 (continued). ***BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Somatization	Median of standardised score on Somatization (IQR)	p-value	Positive cases of Somatization %	p-value
Number of people in household				
1 (n = 25)	46 (39-54)	0.951**	**8.0**	0.113****
2 (n = 66)	46 (39-53.5)		7.6	
≥3 (n = 41)	46 (39-54)		0	
Private health insurance				
No (n = 103)	46 (39-53)	0.257*	3.9	0.145***
Yes (n = 26)	47 (39-55.5)		**11.5**	
Missing = 3				
Believers in God				
No (n = 23)	46 (39-53)	0.452*	4.3	1.0***
Yes (n = 109)	46 (39-55)		**5.5**	

***Table 19 (continued). BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Somatization	Median of standardised score on Somatization (IQR)	p-value	Positive cases of Somatization %	p-value
Personal history of breast cancer				
No (n = 130)	46 (39-53)	0.702*	4.6	0.103***
Yes (n = 2)	53.5 (39-68)		**50.0**	
Family history of breast cancer				
No (n = 76)	46 (39-54.5)	0.913*	**6.6**	0.698***
Yes (n = 56)	46 (39-53)		3.6	
Personal history of cancer				
No (n = 103)	46 (39-55)	0.108*	**5.8**	1.0***
Yes (n = 29)	46 (39-48)		3.4	

Table 19 (continued). ***BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Somatization	Median of standardised score on Somatization (IQR)	p-value	Positive cases of Somatization %	p-value
Family history of cancer				
No (n = 39)	46 (39-53)	0.687*	**7.7**	0.421***
Yes (n = 93)	46 (39-54)		4.3	

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

Women who were younger were more likely to score higher on the *BSI-18 Depression* symptoms items (p = 0.04) and almost a third (30.6%) of women in the 50-59 year age group were identified as positive cases of *Depression* symptoms. A quarter (25%) of the sample that lived in Health Region B region as well as almost a quarter (24.6%) of the women who lived in Health Region A scored as positive cases experiencing *Depression* symptoms. Women who lived alone were more likely (p = 0.047) to be identified as a positive case with *Depression* (34.9%) symptoms than those living with other people (18.0%). In Table 20, the women's *Depression* scores and their relationships with socio-demographic variables are described.

Table 20 BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline (N = 132).

Depression	Median of standardized score on Depression (IQR)	p-value	Positive cases of Depression %	p-value
Age				
< 50years (n = 31)	57 (48-63)	**0.0458****	29.0	0.0897****
50 – 59 years (n = 36)	57 (41.5-63)		**30.6**	
60 – 69 years (n = 41)	46 (40-58.5)		19.5	
≥ 70 years (n = 24)	46 (40-60.75)		12.5	
Health region				
Health Region A (n = 66)	48 (40-62)	0.305**	24.6	0.549***
Health Region B (n = 48)	56 (46-62.5)		**25.0**	
Health Region C (n = 18)	47 (44.5-55.5)		11.1	

Table 20 (continued). ***BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline (N = 132).***

Depression	Median of standardized score on Depression (IQR)	p-value	Positive cases of Depression %	p-value
Living single				
No (n = 89)	55(40-61)	0.2941*	18.0	0.0475***
Yes (n = 43)	55(46-64)		**34.9**	
Education				
Up to grade 11 (n = 87)	48 (40-61)	0.154*	20.7	0.386***
≥Grade 12 (n = 45)	57 (46-63)		**28.9**	
Currently employed				
No (n = 86)	48 (40-61)	0.156*	20.9	0.391***
Yes (n = 46)	57 (40-63.25)		**28.3**	

***Table 20 (continued). BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Depression	Median of standardized score on Depression (IQR)	p-value	Positive cases of Depression %	p-value
Professional occupation				
No (n = 113)	55 (40-61)	0.384*	**23.9**	1.0***
Yes (n = 17)	57 (43-63)		23.5	
Missing = 2				
Household income				
≤$20,000 (n = 66)	48 (40-61)	0.167**	21.2	0.791****
$20,001-50,000 (n = 43)	57 (40-65)		**34.9**	
>$50,000 (n = 20)	55 (48-60)		10.0	
Missing = 3				

***Table 20 (continued). BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Depression	Median of standardized score on Depression (IQR)	p-value	Positive cases of Depression %	p-value
Number of people in household				
1 (n = 25)	60 (43-65)	0.361**	**40.0**	0.047****
2 (n = 66)	48 (44.5-61)		21.2	
≥ 3 (n = 41)	55 (40-60)		17.1	
Private health insurance				
No (n = 103)	48 (40-61)	0.446*	**24.3**	0.795***
Yes (n = 26)	55 (46-61)		19.2	
Missing = 3				
Believers in God				
No (n = 23)	48 (46-60)	0.490*	21.7	1.0***
Yes (n = 109)	55 (40-61)		**23.9**	

***Table 20 (continued). BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Depression	**Median of standardized score on Depression (IQR)**	**p-value**	**Positive cases of Depression %**	**p-value**
Personal history of breast cancer				
No (n = 130)	55 (40-61)	0.985*	**23.8**	1.0***
Yes (n = 2)	53 (46-60)		0	
Family history of breast cancer				
No (n = 76)	51.5 (40-61)	0.460*	22.4	0.835***
Yes (n = 56)	55 (46-62.5)		**25.0**	
Personal history of cancer				
No (n = 103)	55 (46-61)	0.9401*	21.4	0.322***
Yes (n = 29)	55 (40-64)		**31.0**	

***Table 20 (continued). BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline* (N = 132).**

Depression	Median of standardized score of Depression (IQR)	p-value	Positive cases of Depression %	p-value
Family history of cancer				
No (n = 39)	55 (40-63)	0.8479*	**25.6**	0.822***
Yes (n = 93)	55 (40-61)		22.6	

*Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

Women who were younger were more likely (p = 0.0068) to be identified as a positive case for experiencing *Anxiety* (41.9%). The socio-demographic variable of women's age and the *Anxiety* score were found to be significantly correlated (p = 0.0480). The regional area where women lived and *Anxiety* scores were found to be significantly related (p = 0.015), with those who lived in Health Region B scoring the highest number of positive cases for experiencing *Anxiety* (37.5%). Those women with a family history of breast cancer scored a higher number of *Anxiety* positive cases (30.4%) than those without a family history of breast cancer (27.6%; p = 0.846). The women's *Anxiety* scores and socio-demographic profile analyses are further discussed in Table 21.

Table 21 BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline (N =132).

Anxiety	Median of standardized score on Anxiety (IQR)	p-value	Positive cases of Anxiety %	p-value
Age				
< 50years (n = 31)	59 (53-65)	**0.048****	**41.9**	**0.006******
50 – 59 years (n = 36)	58 (47-65.75)		36.1	
60 – 69 years (n = 41)	55 (43-61.5)		22.0	
≥ 70 years (n = 24)	50.5(43-59)		12.5	
Health region				
Health Region A (n = 66)	57 (47.5-63)	**0.015****	26.2	0.100***
Health Region B (n = 48)	59 (47.25-65)		**37.5**	
Health Region C (n =18)	47.5 (41.3-53)		11.1	

Table 21 (continued). ***BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

Anxiety	Median of standardized score on Anxiety (IQR)	p-value	Positive cases of Anxiety %	p-value
Living single				
No (n = 89)	55 (47-63)	0.949*	**29.2**	1.0***
Yes (n = 43)	57 (47-65)		27.9	
Education				
Up to grade 11 (n = 87)	55 (47-63)	0.661*	28.7	1.0***
≥ Grade 12 (n = 45)	57 (47-65)		**28.9**	
Currently employed				
No (n = 86)	55 (47-62.25)	0.358*	24.4	0.158***
Yes (n = 46)	57 (48-65)		**37.0**	

Table 21 (continued). ***BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

Anxiety	Median of standardized score on Anxiety (IQR)	p-value	Positive cases of Anxiety %	p-value
Professional occupation				
No (n = 113)	57 (47-65)	0.2970*	**30.1**	0.776***
Yes (n = 17)	53 (41.5-62.5)		23.5	
Missing = 2				
Household income				
≤ $20,000 (n = 66)	55 (47-61)	0.066**	18.2	0.025****
$20,001-50,000 (n = 43)	59 (47-66)		**44.2**	
> $50,000 (n = 20)	61 (53-65)		35.0	
Missing = 3				

***Table 21 (continued). BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

Anxiety	**Median of standardized score on Anxiety (IQR)**	**p-value**	**Positive cases of Anxiety %**	**p-value**
Number of people in household				
1 (n = 25)	55 (45-65)	0.894**	28.0	0.867****
2 (n = 66)	56 (47-63)		**30.3**	
≥ 3 (n = 41)	57 (47-64)		26.8	
Private health insurance				
No (n = 103)	55 (47-63)	0.186*	26.2	0.464***
Yes (n = 26)	59 (53-65)		**34.6**	
Missing = 3				

Table 21 (continued). ***BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

Anxiety	Median of standardized score on Anxiety (IQR)	p-value	Positive cases of Anxiety %	p-value
Believers in God				
No (n = 23)	53 (36-61)	0.058*	13.0	0.078***
Yes (n = 109)	57 (47-65)		**32.1**	
Personal history of breast cancer				
No (n = 130)	56 (47-63)	0.925*	28.5	0.494***
Yes (n = 2)	56 (47-65)		**50.0**	
Family history of breast cancer				
No (n = 76)	55 (47-63)	0.4869*	27.6	0.846***
Yes (n = 56)	59 (47.25-64.5)		**30.4**	

Table 21 (continued). ***BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics*** **(N = 132).**

Anxiety	Median of standardized score on Anxiety (IQR)	p-value	Positive cases of Anxiety %	p-value
Personal history of cancer				
No (n = 103)	57 (47-63)	0.912*	**30.1**	0.645***
Yes (n = 29)	55 (45-63.5)		24.1	
Family history of cancer				
No (n = 39)	55 (47-63)	0.8140*	25.6	0.6772***
Yes (n = 93)	57 (47-64)		**30.1**	

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

Women who were older were less likely (p = 0.009) to total a high score on the *BSI-18 Global Severity Index* (*GSI*). The highest rate of positive cases (36.1%) for *GSI* was found in the women who were aged between 50 and 59 years. Women's ages and the number of positive cases of *GSI* were identified as statistically significantly related (p = 0.018). Compared to Health Region A (20.0%) and Health Region C (5.6%) more women living in Health Region B (29.2%) were identified as a positive case for *GSI* (p = 0.102). Those women who indicated being employed scored a higher number of positive cases for GSI (30.4%) symptoms than those that were unemployed (17.4%; p = 0.121); however this difference was not statistically significant. Women with lower annual household income were less likely to be identified as a positive case of experiencing *GSI* than those receiving a higher income (p = 0.035). Annual household income of the women and scores for *GSI* were found to be similarly significantly related (p = 0.035). A slightly higher number of positive cases for *GSI* were identified in women living alone (23.3%) compared to those living with somebody else (21.3%; p = 0.824). Women who held private health insurance experienced a higher number of *GSI* positive cases (30.8% versus 19.4%; p = 0.285) as did those who believed in God (24.8% versus 8.7%; p = 0.104); however both those differences were not statistically significant. The women's *GSI* scores and socio-demographic profile analyses are further described in Table 22.

***Table 22 BSI-18 Global Severity Index (GSI) median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

GSI	Median of standardized score on GSI (IQR)	p-value	Positive cases of GSI %	p-value
Age				
< 50years (n = 31)	59 (50-62)	**0.009****	25.8	**0.018******
50 – 59 years (n = 36)	57 (48.63)		**36.1**	
60 – 69 years (n = 41)	48 (40-59.5)		17.1	
≥ 70 years (n = 24)	46.5 (40-57.75)		4.2	
Health region				
Health Region A (n = 66)	55 (41-61)	0.056**	20.0	0.102***
Health Region B (n = 48)	57 (47-62.8)		**29.2**	
Health Region C (n = 18)	47 (44.3-52)		5.6	

***Table 22 (continued). BSI-18 Global Severity Index (GSI) median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

GSI	Median of standardized score of GSI (IQR)	p-value	Positive cases of GSI %	p-value
Living single				
No (n = 89)	53 (45.5-61)	0.640*	21.3	0.824***
Yes (n = 43)	56 (42-61)		**23.3**	
Education				
Up to grade 11 (n = 87)	53 (45-61)	0.496*	18.4	0.187***
≥ Grade 12 (n = 45)	57 (46.5-61.5)		**28.9**	
Currently employed				
No (n = 86)	51 (42-61)	0.124*	17.4	0.121***
Yes (n = 46)	57 (47.5-62.25)		**30.4**	

Table 22 (continued). ***BSI-18 Global Severity Index (GSI) median standardised scores and positive cases of women correlated with their socio-demographic characteristics*** **(N = 132).**

GSI	Median of standardized score of GSI (IQR)	p-value	Positive cases of GSI %	p-value
Professional occupation				
No (n = 113)	55 (46-61)	0.690*	21.2	0.532***
Yes (n = 17)	56 (40-62.5)		**29.4**	
Missing = 2				
Household income				
≤ \$20,000 (n = 66)	50 (42-60)	**0.035****	12.1	**0.035******
\$20,001-50,000 (n = 43)	61 (46-64)		**37.2**	
≥ \$50,000 (n = 20)	56.5 (50-60.75)		25.0	
Missing = 3				
Number of people in household				
1 (n = 25)	58 (41-65)	0.752**	**32**	**0.097******
2 (n = 66)	53 (45-61)		22.7	
≥ 3 (n = 41)	55 (46-60.5)		14.6	

Table 22 (continued). ***BSI-18 Global Severity Index (GSI) median standardised scores and positive cases of women correlated with their socio-demographic characteristics*** **(N = 132).**

GSI	Median of standardized score on GSI (IQR)	p-value	Positive cases of GSI %	p-value
Private health insurance				
No (n = 103)	51 (45-61)	0.146*	19.4	0.285***
Yes (n = 26)	57.5 (45.75-61.75)		**30.8**	
Missing = 3				
Believers in God				
No (n = 23)	48 (40-58)	0.086*	8.7	0.104***
Yes (n = 109)	55 (46-61.5)		**24.8**	
Personal history of breast cancer				
No (n = 130)	55 (45.75-61)	0.744*	21.5	0.392***
Yes (n = 2)	54 (42-66)		**50**	
Family history of breast cancer				
No (n = 76)	51 (45.25-61)	0.656*	21.1	0.832***
Yes (n = 56)	56.5 (45.25-61)		**23.2**	

***Table 22 (continued). BSI-18 Global Severity Index (GSI) median standardised scores and positive cases of women correlated with their socio-demographic characteristics* (N = 132).**

GSI	Median of standardized score on GSI (IQR)	p-value	Positive cases of GSI %	p-value
Personal history of cancer				
No (n = 103)	55 (46-61)	0.702*	21.4	0.800***
Yes (n = 29)	50 (41-61.5)		**24.1**	
Family history of cancer				
No (n = 39)	51 (45-61)	0.774*	20.5	1.0***
Yes (n = 93)	56 (45.5-61)		**22.6**	

*Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

Decision Treatment Process

The majority of women rated the following *Decision Treatment Process* statements as important or critically important to: "*follow the doctor's advice*" (94.7%), "*have the advice of the best specialists*" (97.7%), "*have a doctor who asks you what you want*" (94%); and "*have a doctor that cares about you*" (97.7%) when making a treatment decision for early breast cancer. Other items the women indicated were important or critically important were to: *"know if there are any side effects of the treatment"* (98.5%), *"know if there might be unexpected problems with treatment"* (100%), "*get the treatment over as soon as possible*" (96.2%), *"know the chances that the cancer might return"* (98.5%) and "*participate in selecting a treatment*" (100%). The women's agreement to all *Decision Treatment Process* statements regarding the factors considered important when making the treatment decision are outlined in Table 23.

***Table 23 Women's responses (%) to the Decision Treatment Process statements regarding factors considered important when making the treatment decision* (N = 132).**

How important is it to you when making this decision that you…	**Not at all** *%*	**Unimportant** *%*	**Neither Important Nor Unimportant** *%*	**Important** *%*	**Critically Important** *%*
Doctor (11 items)					
"Follow your doctor's advice"	2.3	0	3	43.9	**50.8**
"Trust your doctor"	0	1.5	2.3	**57.6**	38.6
"Have the advice of the best specialists"	0	2.3	0	24.2	**73.5**
"Have a doctor who asks you what you want"	0.8	3.8	1.5	32.6	**61.4**
"Have an doctor that answers all your questions	**43.9**	19.7	31.1	4.5	0.8
"Have a woman doctor"	**43.2**	19.7	22.7	10.6	3.8
"Have a doctor the same race as you" (n = 130)	0	3.1	4.6	**66.9**	25.4
"Tell the doctor how you feel about the treatment"	0	0	10.6	**63.6**	25.8
"Have a doctor that cares about you"	0	0.8	1.5	38.6	**59.1**

Table 23 (continued). Women's agreement (%) to the Decision Treatment Process statements regarding factors considered important when making the treatment decision **(N = 132).**

How important is it to you when making this decision that you…	**Not at all** %	**Unimportant** %	**Neither Important Nor Unimportant** %	**Important** %	**Critically Important** %
Doctor (11 items) (continued)					
"Have a doctor who listens to you"(n =124)	**33.9**	12.9	18.5	23.4	11.3
"Have a doctor who tells you what to expect"	1.5	0.8	4.5	**56.8**	36.4
Information (6 items)					
"Read a lot of information"	0.8	0.8	15.2	**51.5**	31.8
"Get the treatment over with as soon as possible"	0	0	3.8	**50**	46.2
"Ask questions"	9.1	7.6	18.9	31.1	**33.3**
"Know if there are any side effects of the treatment"	0	0	1.5	31.1	**67.4**

***Table 23 (continued). Women's agreement (%) to the Decision Treatment Process statements regarding factors considered important when making the treatment decision* (N = 132).**

How important is it to you when making this decision that you…	**Not at all** %	**Unimportant** %	**Neither Important Nor Unimportant** %	**Important** %	**Critically Important** %
Information (6 items) (continued)					
"Know if there might be unexpected problems with the treatment"	0	0	0	34.8	**65.2**
"Know the chances that the cancer might return"	0	0	1.5	39.4	**59.1**
Control (2 items)					
"Feel in control of choosing a treatment"	0	1.5	2.3	44.7	**51.5**
"Participate in selecting a treatment"	0	0	0	25.8	**74.2**

Table 23 (continued). ***Women's agreement (%) to the Decision Treatment Process statements regarding factors considered important when making the treatment decision*** **(N = 132).**

How important is it to you when making this decision that you…	**Not at all** %	**Unimportant** %	**Neither Important Nor Unimportant** %	**Important** %	**Critically Important** %
Support (4 items)					
"Have faith in God"	0	1.5	1.5	**53.8**	43.2
"Have someone to talk to"	31.1	15.2	**31.8**	18.9	3.0
"Have friends and family come to the doctor's visits with you"	0	0	0.8	39.4	**59.8**
"Talk to other women who have had cancer" (Missing = 1)	3.1	5.3	21.4	**52.7**	17.6

Table 23 (continued). ***Women's agreement (%) to the Decision Treatment Process statements regarding factors considered important when making the treatment decision*** **(N = 132).**

How important is it to you when making this decision that you…	**Not at all** **%**	**Unimportant** **%**	**Neither Important Nor Unimportant** **%**	**Important** **%**	**Critically Important** **%**
Other (2 items)					
"Have a private room when you are in hospital"	0	0.8	0.8	34.1	**64.4**
"Have your parking expenses paid for"	5.3	10.6	20.5	31.1	**32.6**

The *Decision Treatment Process* items (overall Cronbach's Alpha α = 0.76) were grouped by clinical judgement and collapsed into five categories. All the items in each category were totalled and averaged. The categories contained the following number of items namely: *Doctor* (11 items); *Information* (6 items), *Cont*rol (2 items); *Support* (4 items); and *Other* (2 items). On average 66.7% of women rated the patient *Doctor* relationship as important or critically important (median = 4.1, IQR 3.8- 4.30, range = 3.2-4.8). A higher percentage of women (87.8%) rated on average, *Information* as important or critically important (median score = 4.4, IQR = 4.1- 4.6, range = 3.3-5). Ninety point eight percent of women rated the *Control* items as important or critically important (median score = 4, IQR = 4- 4.5, range = 2-5). Only over half (55.3%) of women rated on average that *Support* was important or critically important (median = 4, IQR = 3.3-4.6, range = 2-5).

In the bivariate analysis using non-parametric statistical tests, between the women's socio-demographic variables and their treatment *Decision Treatment Process* dimensions (*Doctor*, *Information*, *Control* and *Support*) only a few statistically significant relationships were found. Those women who were better educated (p = 0.019) or who were employed (p = 0.031) were more likely to value the importance of the *Doctor*'s role when making a treatment decision. *Information* was valued more in the treatment decision-making of women who did not have private insurance compared to those who did (p = 0.004). The *Control* dimension was more likely to be important to women who had a family history of cancer (p = 0.048) than those without a history. Women who believed in God were more likely to judge *Support* important when making a treatment decision for early breast cancer compared to women who did not believe in God ($p < 0.0001$). Women who received a yearly income over AUD20, 000 were more likely to identify the patient *Doctor* relationship, *Control* over treatment options and *Support* mechanism as more important than women in other income groups. Women who received an income between AUD20, 001 and AUD50, 000 perceived the quality and quantity of Information as more important than women in other income groups (see Table 24).

***Table 24 Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women* (N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N =132)**	**Median (IQR) (n =131)**	**Median (IQR) (n =130)**	**Median (IQR) (N =132)**
Age				
< 50years (n = 31)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4.5 (4-4.5)	4 (3.3-4.7)
50 – 59 years (n = 36)	4.2 (3.9- 4.5)	4.6 (4.1-4.7)	4.5 (4-4.5)	3.8 (3.4-4.3)
60 – 69 years (n =4 1)	4.1 (3.8-4.3)	4.3 (4-4.5)	4 (4-4.5)	4 (3.3-4.7)
≥70 years (n = 24)	4 (3.8-4.2)	4.4 (4.1-4.7)	4 (4-4.5)	3.8 (3.7-4.6)
	p = 0.111**	p =0.166**	p = 0.189**	p = 0.934**

Table 24 (continued). ***Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women*** **(N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Health region				
Region A (n = 66)	4 (3.8-4.3)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.3)
Region B (n = 48)	4.1 (3.8-4.4)	4.3 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.7)
Region C (n = 18)	4.2 (4-4.4)	4.4 (4.1-4.8)	4.5 (4-4.6)	4 (3.3-4.7)
	p = 0.338**	p = 0.851**	p = 0.547**	p = 0.546**

***Table 24 (continued). Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women* (N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Living single				
No (n = 89)	4.1 (3.8- 4.4)	4.4 (4.1-4.6)	4(4-4.5)	4 (3.3-4.7)
	4.1 (3.8-4.2)	4.3 (4-4.6)	4 (4-4.5)	3.7 (3.3-4).
Yes (n = 43)	p = 0.458*	p = 0.361*	p = 0.955*	p = 0.059*
Education				
Up to grade 11 (n = 87)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.3)
Grade 12 and more (n = 45)	4.2 (4-4.4)	4.4 (4-4.6)	4.5 (4-4.5)	4 (3.3-4.7)
	p = 0.019*	p = 0.996*	p = 0.100*	p = 0.612*

***Table 24 (continued). Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women* (N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Currently employed				
No (n = 86)	4.1 (3.8-4.3)	4.3 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.3)
Yes (n = 46)	4.2 (3.9-4.4)	4.4 (4.1-4.7)	4.5 (4-4.5)	4.3 (3.6-4.7)
	p = 0.031*	p = 0.251*	p = 0.021*	p = 0.208*
Professional occupation				
No (n = 113)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.5)
Yes (n = 17)	4.2 (4- 4.4)	4.4 (4.1- 4.6)	4.5 (4-4.5)	4.3 (3.3- 4.5)
Missing = 2	p = 0.147*	p = 0.896*	p = 0.842*	p =0.618*

Table 24 (continued). ***Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women* (N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Professional occupation				
No (n = 113)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.5)
Yes (n = 17)	4.2 (4- 4.4)	4.4 (4.1- 4.6)	4.5 (4-4.5)	4.3 (3.3- 4.5)
Missing = 2	p = 0.147*	p = 0.896*	p = 0.842*	p =0.618*
Household income				
≤$20,000 (n = 66)	4.0 (3.8-4.3)	4.3 (4.1-4.6)	4.0 (4.0-4.5)	3.7 (3.3-4.3)
$20,001-50,000 (n = 43)	4.2 (4.0-4.5)	4.4 (4.3-4.7)	4.5 (4.0-4.5)	4.3 (3.7-4.7)
≥$50,000 (n = 20)	4.2 (4.0-4.4)	4.3 (3.9-4.6)	4.5 (4.0-4.5)	4.3 (3.3-4.7)
Missing = 3	**p = 0.007****	**p = 0.036****	**p = 0.009****	**p = 0.046****

Table 24 (continued). ***Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women*** **(N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Number of people in household				
1 (n = 25)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4 (4-4.5)	3.7 (3.2-4.3)
2 (n = 66)	4.1 (3.8-4.3)	4.4 (4.1-4.7)	4 (4-4.5)	4 (3.7-4.7)
≥3 (n = 41)	4.1 (3.8-4.4)	4.3 (4-4.6)	4.3 (4-4.5)	4 (3.3-4.7)
	p = 0.568**	p = 0.215**	p = 0.842**	p = 0.180**
Private health insurance				
No (n = 103)	4.1 (3.8- 4.3)	4.4(4.1- 4.6)	4 (4-4.5)	4 (3.3-4.3)
Yes (n = 26)	4.1 (4-4.4)	4.1 (3.9-4.6)	4.3 (4- 4.5)	4.3 (3.3- 4.7)
Missing = 3	p = 0.652*	**p = 0.004***	p = 0.798*	p = 0.128*

Table 24 (continued). ***Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women*** **(N = 132).**

	Doctor	**Information**	**Control**	**Support**
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Believers in God				
No (n = 23)	4.1 (3.7-4.2)	4.3 (4-4.6)	4 (3.9-5)	3 (2.7-4)
Yes (n = 109)	4.1 (3.8-4.4)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.7-4.7)
	p = 0.191*	p = 0.190*	p = 0.566*	**p < 0.0001***
Personal history of breast cancer				
No (n = 130)	4.1 (3.8-4.4)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.3-4.7)
Yes (n = 2)	4.1 (4-4.2)	4.2 (4.1-4.3)	4 (4-4)	4 (4-4)

Table 24 (continued). ***Median of standardised scores of Decision Treatment Process dimensions relating to the patient-doctor relationship, the quality and quantity of information received, the control about treatment options, and the support mechanisms correlated with socio-demographic characteristics of the participating women*** **(N = 132).**

	Doctor	Information	Control	Support
Socio-demographic profile	**Median (IQR) (N = 132)**	**Median (IQR) (n = 131)**	**Median (IQR) (n = 130)**	**Median (IQR) (N = 132)**
Family history of breast cancer				
No (n = 76)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4 (4-4.5)	4 (3.7-4.3)
Yes (n = 56)	4.1 (3.8-4.3)	4.4 (4.1-4.6)	4.5 (4-4.5)	4 (3.3-3.7)
	p = 0.904*	p = 0.554*	p = 0.534*	p = 0.585*
Family history of cancer				
No (n = 39)	4.1 (3.8- 4.2)	4.3 (4.1-4.6)	4 (4-4.5)	4 (3.3-4)
Yes (n = 93)	4.1 (3.8- 4.4)	4.4 (4.1-4.6)	4.5 (4-4.5)	4 (3.3-4.7)
	p = 0.5546*	p = 0.9172*	p = 0.0480*	p = 0.7589*

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test

Michigan Assessment of Decision Styles (MADS)

More than ninety seven percent (97.7%) of the women agreed or strongly agreed that they would, *"follow the recommendations of my doctor"* for the treatment of early breast cancer. Most of the women agreed or strongly agreed to many of the statements related to their treatment decision-making such as, **"***I will agree to the option that seemed reasonable to me at the time (96.2%), "I would carefully consider the risks of each option as I was making a choice" (91.6%) and "I would want to know the possible outcomes of each alternate that was being offered to me"* (94%). Over eighty percent (84.4%) of women disagreed or strongly disagreed to the statement *"I want someone else to make the decision for me"*. The majority women disagreed or strongly disagreed to the statements *"I prefer not knowing the possibility that unexpected things could happen to me" (78.1%).* The women's agreement to all *MADS* items are detailed in Table 25.

Table 25 Women's agreement (%) to Michigan Assessment of Decision Styles (MADS) factor items **(N = 132).**

MADS factors	**Strongly Disagree** %	**Disagree** %	**Neither Agree Nor Disagree** %	**Agree** %	**Strongly Agree** %
Deferring Responsibility (3 items)					
"I will make a quick decision once I was told what my options were"	2.3	9.8	6.8	**50.8**	30.3
" I will follow the recommendations of my doctor"	0	0.8	1.5	43.9	**53.8**
"I will agree to the option that seemed the most reasonable to me at the time"	0	0.8	3.0	**55.3**	40.9
Information Seeking (4 items)					
"I will develop a plan for gathering further information"	0.8	10.6	25.0	**44.7**	18.9

Table 25 (continued). ***Women's agreement (%) to Michigan Assessment of Decision Styles (MADS) factor items (N = 132).***

MADS factors	**Strongly Disagree** %	**Disagree** %	**Neither Agree Nor Disagree** %	**Agree** %	**Strongly Agree** %
Information Seeking (4 items) (continued)					
" I will read magazines and articles about breast cancer and different treatment"	0.8	11.4	13.6	**45.5**	28.8
"I will read scientific articles about the treatments that were being offered to me"	2.3	25.8	24.2	**30.3**	17.4
"I will spend as much time as I could gathering information"	3.0	23.5	20.5	**37.1**	17.4
Deliberation (5 items)					
"I will prefer to seek advice from specialists in breast cancer treatment"	0	5.3	6.8	**49.2**	38.6

T*able 25 (continued).* ***Women's agreement (%) to Michigan Assessment of Decision Styles (MADS) factor items*** **(N = 132).**

MADS factors	Strongly Disagree %	Disagree %	Neither Agree Nor Disagree %	Agree %	Strongly Agree %
Deliberation (5 items) (continued)					
'I will ask about the risks with each treatment alternate"	0.8	2.3	9.1	**47.7**	40.2
"I will carefully consider the risks of each option as I was making a choice"	0	2.3	6.1	**54.5**	37.1
"I will want to know the possible outcomes of each alternate that was being offered to me"	0	3	3	**50.8**	43.2
"I will ask a lot of questions concerning the treatment options"	0	3.8	13.6	**50**	32.6

Table 25 (continued). ***Women's agreement (%) to Michigan Assessment of Decision Styles (MADS) factor items*** **(N = 132).**

MADS factors	**Strongly Disagree** %	**Disagree** %	**Neither Agree Nor Disagree** %	**Agree** %	**Strongly Agree** %
Avoidance (4 items)					
"I want someone else to make the decision for me" (n = 131)	**48.9**	35.5	5.3	8.4	1.5
"I prefer in situations like these, that someone else tells me what to do"	**44.7**	35.6	9.1	8.3	2.3
"I prefer not knowing the possibility that unexpected things could happen to me"	**45.5**	32.6	6.8	12.1	3.0
"I believe that what will happen will happen and there is little I can do to change things"	9.8	21.2	9.1	**34.8**	25

Scores from the 5-point Likert scale on each of the items creating the four *MADS* factors were summed and averaged. The four *MADS* factors (N =132) are described by median values and IQR, as their distributions were skewed, namely: *Deferring Responsibility* (median = 4.3, IQR = 4- 4.7); *Avoidance* (n = 131, median = 2.25, IQR = 1.75-2.75); *Information Seeking* (median = 3.75, IQR = 3-4); and *Deliberation* (median = 4.2, IQR = 4- 4.7).

Of the 132 women 16.7% strongly agreed to all three items of the *MADS* factor *Deferring Responsibility*. One participant (0.8%, n = 131) strongly agreed to all four factors of *Avoidance*. Seven point six per cent (7.6%) of the participating women strongly agreed with all four items of *Information Seeking*. For the *MADS* factor of *Deliberation* 12.9% of the participating women strongly agreed to all five items. Table 26 outlines the number of women who agreed or strongly agreed to all the items in each *MADS* factor.

***Table 26 Percentage of women who agreed or strongly agreed with all the items in each MADS factors* (N = 132).**

	Avoidance	**Deferring Responsibility**	**Information seeking**	**Deliberation**
	%	%	%	%
	2.3	84.8	37.8	75.1

No significant correlation was found between the women's age and the scoring on any of the four *MADS* factors (i.e. *Deferring Responsibility* r = 0.12, p = 0.169;

Information Seeking r = -0.10, p = 0.26; *Deliberation* r = -0.12, p = 0.158 and *Avoidance* r = 0.16, p = 0.077). Women who were older were more likely to have a high score in the *Avoidance* factor than younger women, however this result was again not significant (p = 0.149). The women's location was statistically significant for the *MADS* factors of *Information Seeking* (p = 0.009), *Deliberation* (p = 0.022) and *Avoidance* (p = 0.014). Women living in Health Region C were more likely to score high on *Deliberation* and low on *Avoidance*, whereas, those who lived in Health Region B scored higher for *Information Seeking*. Less educated women scored higher on *Avoidance* than those with more education (p = 0.032). Employed women were more likely to score highly on *Deliberation* (p = 0.015). A higher score for *Information Seeking* was more likely for women who received a higher annual household income (p = 0.007) and those without a personal history of cancer (p = 0.040). The complete bivariate analysis of the *MADS* factors with the women's socio-demographic profile is outlined in Table 27.

***Table 27 Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at baseline* (N = 132).**

Socio-demographic variables	**Deferring Responsibility Median (IQR) (N = 132)**	**Information Seeking Median (IQR) (N = 132)**	**Deliberation Median (IQR) (N = 132)**	**Avoidance Median (IQR) (n = 131)**
Age				
< 50years (n = 31)	4 (3.7-4.7)	3.8 (3-4.8)	4.4 (3.8-4.8)	1.8 (1.3-2.8)
50 – 59 years (n = 36)	4.3 (4-4.7)	3.9 (3-4.5)	4.4 (4-5)	2 (1.8-2.5)
60 – 69 years (n = 41)	4.3 (4-4.7)	3.8 (2.9-4)	4 (3.9-4.5)	2.3 (2-2.8)
≥ 70 years (n = 24)	4.3 (4-4.7)	3.5 (2.8-4)	4.2 (3.8-4.4)	2.5 (2-2.8)
	p = 0.263**	p = 0.563**	p = 0.210**	p = 0.149**

Table 27 (continued). ***Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at baseline*** **(N = 132).**

Socio-demographic variables	**Deferring Responsibility Median (IQR) (N = 132)**	**Information Seeking Median (IQR) (N = 132)**	**Deliberation Median (IQR) (N = 132)**	**Avoidance Median (IQR) (n = 131)**
Health region				
Brisbane (n = 66)	4.3 (4-4.7)	3.3 (2.8-4)	4.2 (3.8-4.4)	2.5 (2-2.8)
Townsville (n = 48)	4.3 (4-4.7)	4 (3.3-4.8)	4.2 (3.9-4.8)	2 (1.8-2.8)
Cairns (n = 18)	4.3 (4-5)	3.8 (3.3-4.5)	4.8 (4.2-5)	1.8 (1.3-2.3)
	p = 0.659**	**p = 0.009****	**p = 0.022****	**p = 0.014****
Living single				
No (n = 89)	4.3 (4-4.7)	3.8 (3-4.5)	4.4 (4-4.8)	2 (1.8-2.8)
Yes (n = 43)	4 (4-4.3)	3.5 (3-4)	4 (3.8-4.6)	2.4 (1.8-2.8)
	p = 0.015*	p = 0.090*	p = 0.125*	p = 0.614*

Table 27 (continued). ***Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at*** **baseline (N = 132).**

Socio-demographic variables	Deferring Responsibility Median (IQR) (N = 132)	Information Seeking Median (IQR) (N = 132)	Deliberation Median (IQR) (N = 132)	Avoidance Median (IQR) (n = 131)
Education				
Up to grade 11 (n = 87)	4.3 (4-4.7)	3.5 (3-4)	4.2 (3.8-4.6)	2.3 (2-2.8)
≥Grade 12 (n = 45)	4 (4-4.8)	3.8 (2.9-4.5)	4.2 (4-4.8)	2 (1.5-2.5)
	p = 0.408*	p = 0.316*	p = 0.258*	**p = 0.032**
Currently employed				
No (n = 86)	4.3 (4-4.7)	3.5 (3-4)	4.2 (3.8-4.4)	2.3 (2-2.8)
Yes (n = 46)	4.3 (3.7-4.7)	3.8 (3-4.6)	4.5 (4-4.8)	2 (1.5-2.9)
	p = 0.390*	p = 0.227*	**p = 0.015***	p = 0.055*
Professional occupation				
No (n =113)	4.3 (4-4.7)	3.8 (3-4)	4.2 (3.9-4.7)	2.3 (1.8-2.8)
Yes (n = 17)	4.3 (3.8-4.7)	3.8 (2.9-4.8)	4.4 (3.8-4.8)	1.8 (1.5-2.8)
Missing = 2	p = 0.724*	p = 0.835*	p = 0.764*	p = 0.173*

***Table 27 (continued). Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at baseline* (N = 132).**

Socio-demographic variables	**Deferring Responsibility Median (IQR) (N = 132)**	**Information Seeking Median (IQR) (N = 132)**	**Deliberation Median (IQR) (N = 132)**	**Avoidance Median (IQR) (n = 131)**
Household income				
≤ \$20,000 (n = 66)	4.3 (4-4.7)	3.3 (2.8-4)	4.2 (3.8-4.4)	2.4 (2-2.8)
\$20,001-50,000 (n = 43)	4.3 (4-4.7)	3.8 (3.3-4.8)	4.4 (4-4.8)	2 (1.7-2.8)
> \$50,000 (n = 20)	4.5 (3.8-4.7)	3.8 (3-4.5)	4.2 (3.9-4.8)	1.6 (1.3-2.9)
Missing = 3	p = 0.970**	**p = 0.007****	**p = 0.047****	p = 0.141**
Number of people in household				
1 (n = 25)	4.3 (4-4.7)	3.3 (3-4)	4.2 (3.9-4.5)	2.5 (1.8-2.8)
2 (n = 66)	4.4 (4-4.7)	3.8 (3-4.3)	4.2 (4-4.8)	2.3 (2-2.5)
≥3 (n = 41)	4.3 (4-4.7)	3.5 (2.9-4.6)	4.4 (3.8-4.8)	2 (1.5-3)
	p = 0.502**	p = 0.434**	p = 0.686**	p = 0.773**

Table 27 (continued). Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at baseline **(N = 132).**

Socio-demographic variables	Deferring Responsibility Median (IQR) (N = 132)	Information Seeking Median (IQR) (N = 132)	Deliberation Median (IQR) (N = 132)	Avoidance Median (IQR) (n = 131)
Private health insurance				
No (n = 103)	4.3 (4-4.7)	3.5 (2.8-4)	4.2 (3.8-4.8)	2.1 (1.8-2.8)
Yes (n = 26)	4.3 (3.7-4.7)	3.8 (3-4.1)	4.1 (4-4.4)	2 (1.7-2.8)
Missing = 3	p = 0.428*	p = 0.368*	p = 0.270*	p = 0.795*
Believers in God				
No (n = 23)	4 (4-4.7)	3.8 (2.8-4.3)	4 (3.8-4.8)	2 (1.3-2.8)
Yes (n = 109)	4.3 (4-4.7)	3.8 (3-4)	4.2 (4-4.7)	2.3 (1.8-2.8)
	p = 0.284*	p = 0.636*	p = 0.567*	p = 0.159*
Personal history of breast cancer				
No (n = 130)	4.3 (4-4.7)	3.8 (3-4.1)	4.2 (3.8-4.8)	2.3 (1.8-2.8)
Yes (n = 2)	4.5 (4.3-4.7)	3.4 (3-3.8)	4.3 (4-4.6)	2 (1.3-2.8)
	p = 0.523*	p = 0.653*	p = 0.902*	p = 0.691*

***Table 27 (continued). Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at baseline* (N = 132).**

Socio-demographic variables	Deferring Responsibility Median (IQR) (N = 132)	Information Seeking Median (IQR) (N = 132)	Deliberation Median (IQR) (N = 132)	Avoidance Median (IQR) (n = 131)
Family history of breast cancer				
No (n = 76)	4.3 (4-4.7)	3.6 (3-4)	4.3(4-4.8)	2 (1.8-2.8)
Yes (n = 56)	4.3 (4-4.7)	3.8 (3-4.5)	4.2 (3.8-4.6)	2.3 (1.8-2.8)
	p = 0.505*	p = 0.496*	p = 0.387*	p = 0.884*
Personal history of cancer				
No (n = 103)	4.3 (4-4.7)	3.8 (3-4.5)	4.2 (3.8-4.8)	2 (1.8-2.8)
Yes (n = 29)	4.3 (4-4.7)	3.3 (2.8-3.9)	4.2 (4-4.7)	2.3 (1.8-2.8)
	p = 0.172*	**p = 0.040***	p = 0.991*	p = 0.838*

Table 27 (continued). Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women's socio-demographic characteristics at baseline (N = 132).

Socio-demographic variables	**Deferring Responsibility Median (IQR) (N = 132)**	**Information Seeking Median (IQR) (N = 132)**	**Deliberation Median (IQR) (N = 132)**	**Avoidance Median (IQR) (n = 131)**
Family history of cancer				
No (n = 39)	4 (4-4.7)	3.8 (3-4)	4.2 (4-4.8)	2 (1.8-2.8)
Yes (n = 93)	4.3 (4-4.7)	3.8 (3-4.5)	4.2 (3.8-4.7)	2.3 (1.8-2.8)
	p = 0.391*	p = 0.605*	p = 0.503*	p = 0.395*

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test

Using Spearman rank correlation coefficients to judge correlations between psychological distress levels as measured with *BSI-18* and decision measured by *MADS*, only the *Avoidance* factor was positively correlated and significant with *Anxiety* (r = 0.22, p = 0.010) and *GSI* (r = 0.18, p = 0.037). In a further multiple linear regression analysis the significant relationship between the levels of *Avoidance* and *Anxiety* was adjusted for the confounding effect of age (adjusted p = 0.012; Age: regression coefficient ß = -0.019, p = 0.004). Similarly, the significant relationship between the levels of *Avoidance* and *GSI* were adjusted for the confounding effect of age using multiple liner regression (adjusted p = 0.018; Age: regression coefficient ß = -0.023, p = 0.001).

Women who received a high score in any of the *BSI-18* dimensions were more likely to achieve a low score on *Deferring Responsibility*. Those women who had high score on *Information Seeking* were also likely to achieve high scores on the *BSI-18* dimensions. *Deliberation* was negatively correlated with *Depression*, *Anxiety*, and *GSI symptoms*. However, none of those relationships was statistically significant. The correlations between the women's psychological distress levels (*BSI-18*) and decision styles (*MADS*) are outlines in Table 28.

Table 28 Spearman rank correlation coefficients and p-values for correlations between women's psychological distress levels as measured with BSI-18 and women's decision styles as assessed by MADS scores at baseline (N = 132).

BSI-18	**Deferring Responsibility**	**Avoidance**	**Information Seeking**	**Deliberation**
Somatization	r = -0.03	r = 0.05	r = 0.08	r = 0.07
	p = 0.741	p = 0.570	p = 0.380	p = 0.431
Depression	r = -0.08	r = 0.07	r = 0.04	r = -0.03
	p = 0.361	p = 0.445	p = 0.678	p = 0.760
Anxiety	r = -0.04	r = 0.22	r = 0.04	r = -0.09
	p = 0.631	**p = 0.010**	p = 0.646	p = 0.325
GSI	r = -0.07	r = 0.18	r = 0.04	r = -0.05
	p = 0.413	**p = 0.037**	p = 0.0640	p = 0.566

Qualitative Dimensions at Baseline

The women's response to the opened ended questions *"What nurses should know to help women make decisions?"* after recoding from content analysis are listed in Table 29. The answers to the open-ended qualitative questions were subjected to simple content analysis. Identification of patterns and early themes emerged; the researcher then categorised the patterns and themes to determine their frequencies and reported them as such.

Table 29 ***Women's responses after recoding from content analysis to the question "What nurses should know to help women make decisions***?"

"What nurses should know to help women make decisions?"	**At baseline (n=132) %**
Post-operative complications and management	19.7
Provide emotional & psychological support	24.2
Not much / Don't know	0.8
To Individualise care	6.1
Nurses are already well educated	4.5
Treatment Options	6.8
Did not see a nurse	3.8
To involve the family	0
To maintain a positive outlook	3.0
Have good communication skills	3.0
Provide honest answers to questions	1.5
Provide practical and informational support	4.5
Know what information women need to make decisions	18.2
Understand the psychological and emotional impact of breast cancer	25.0

The women's responses to the opened ended questions *"What advice do you have for other women who are facing this decision?"* are listed in Table 30.

Table 30 Women's responses to the questions "What advice do you have for other women who are facing this decision?"

"What advice do you have for other women who are facing this decision?"	**At baseline (n=132) %**
To be positive	20.5
Search for as much information as possible	6.8
Talk and listen to other women who have had breast cancer	4.5
To follow your doctor's advice	15.2
Take your time to decide	0.8
Ask and write questions	8.3
To involve family and friends	3.8
Have your treatment as soon as possible	6.1
Have faith and pray in God	3.8
Trust in your doctor	3.0
Look at all treatment options and consequences	3.0
Read all information you are given	5.3
Seek support	2.3
Have a mammogram and regular breast checks	9.8
Seek the best medical advice	5.3
Make your own decision	2.3
Talk to your doctor	6.1
Trust your instincts	2.3

Follow-up at Three to Four months

One hundred and four (78.8%; 28 missing) women were successfully followed up 3 to 4 months after the initial surgery of breast cancer and completed the second questionnaire. There was an attrition loss of 28 women (n = 104) women in the follow-up data collection at three to four months. The attrition of these women, in part, can be attributed to 10 questionnaires being returned indicating that there was no one with that name living at that address (moved houses) and one woman who withdrew from the study. Of the 104 women, 62.1% indicated receiving breast conservation surgery (BCS) (lumpectomy) and 41.7% mastectomy surgery. The distribution of the other treatments the women reported receiving over the three to fours months are listed in Table 31.

Table 31 Type of treatment received (%) by women at 3 to 4 months (n = 103).

Types of Treatment	Prevalence of Treatment* %
Mastectomy	41.7
Lumpectomy	62.1
Axillary Clearance	24.1
Radiation	51.5
Chemotherapy	33.0
Hormonal Therapy	49.5
Complementary	0.9
Breast Reconstruction	1.0
Other	2.9

* Each woman may have had more than one treatment.

The types of treatment received by women varied across Health Regions. More women in Region A and Region B received breast conservation surgery (BCS-lumpectomy) than mastectomy surgery. Whereas, more women in Region C received mastectomy surgery than Breast Conservation Surgery. The details of women's treatment for early breast cancer across the Health Regions at 3 to 4 months are stated in Table 32.

Table 32 Percentage of treatment across each Health Region at 3 to 4 months (n = 104).

Types of Treatment	Health Region A %	Health Region B %	Health Region C %
Mastectomy	37.7	40.0	**70.0**
Lumpectomy	64.2	**65.0**	40.0
Axillary Clearance	15.1	25.0	**40.0**
Radiation	**60.4**	50.0	10.0
Chemotherapy	28.3	35.0	**50.0**
Hormonal Therapy	49.1	**50.0**	**50.0**
Complementary Therapy	1.9	**2.5**	0
Breast Reconstruction	0	**2.5**	0
Other	**3.8**	2.5	0

A majority of the women (69.3%, n = 101) indicated being offered treatment choices by their doctor. Less than half of the women (44.6%) reported they had been actively involved in the treatment decision-making, 36.6% were involved; however, the doctor recommended the treatment plan and 18.8% reported not being involved in the treatment decision-making.

Of the women that indicated they had received help from nurses (n = 55) 100% obtained informational support, 9.1% spiritual support, 45.5% emotional support, 9.1% received financial advice, 20% psychological support and 1.8% other support. Over half of these women (52.7%) reported the help they received by nurses was very helpful, 41.8% helpful and 5.5% slightly helpful.

Psychological Distress at Three to Four Months (BSI-18)

The women's psychological distress levels were again measured using the *BSI-18* (Derogatis, 2000) instrument. In the 3 to 4 months follow-up phase many women felt relatively low levels of psychological distress. However, 19.3% of women reported "*feeling tense or keyed up"*; 16.3% "*nervousness or shakiness inside"*; 19.2% *feeling lonely"*; 20.2% "*feeling nausea or upset stomach"*; 16.4% "*feeling blue"*; and 15.4% "*Feeling weak in parts of your body"* quite a bit or extremely during the previous three months. The women's responses to all *BSI-18* items at three to four months after initial surgical treatment for early breast cancer are listed in Table 33.

***Table 33 Women's levels of psychological distress (%) as measured by BS1-18 scores (%) at 3 to 4 months after initial surgery* (n = 104).**

In the last three months, how much have you been distressed by…?	**Not at all %**	**A little bit %**	**Moderately %**	**Quite a bit %**	**Extremely %**
Somatization (6 items)					
Faintness or dizziness	**54.8**	31.1	8.7	1.9	2.9
Pain and in the heart or chest	**66.7**	26.0	4.8	1.9	1.0
Nausea or upset stomach	**50.0**	21.2	8.7	13.5	6.7
Trouble getting your breath (n =103)	**66.0**	23.3	4.9	3.9	1.9
Numbness or tingling in parts of your body	**46.2**	26.0	16.3	10.6	1.0
Feeling weak in parts of your body	**39.4**	26.9	18.3	12.5	2.9

Table 33 (continued). ***Women's levels of psychological distress (%) as measured by BS1-18 scores (%) at 3 to 4 months after initial surgery*** **(n = 104).**

In the last three months, how much have you been distressed by…?	**Not at all %**	**A little bit %**	**Moderately %**	**Quite a bit %**	**Extremely %**
Depression (6 items)					
Feeling hopeless about the future	**62.5**	25.0	6.7	2.9	2.9
Feeling no interest in things	**48.1**	23.1	16.3	8.7	3.8
Thoughts of ending your life	**91.3**	6.7	0	1.0	1.0
Feeling lonely	**46.2**	22.1	12.5	11.5	7.7
Feelings of worthlessness	**64.4**	18.3	12.5	2.9	1.9
Feeling blue	**38.5**	29.8	15.4	10.6	5.8

Table 33 (continued). Women's levels of psychological distress (%) as measured by BS1-18 scores (%) at 3 to 4 months after initial surgery (n = 104).

In the last three months, how much have you been distressed by…?	**Not at all** %	**A little bit** %	**Moderately** %	**Quite a bit** %	**Extremely** %
Anxiety (6 items)					
Suddenly scared for no reason	**64.4**	18.3	7.7	6.7	2.9
Feeling tense or keyed up	25.0	**37.5**	18.3	13.5	5.8
Nervousness or shakiness inside	**47.1**	25.0	11.5	14.4	1.9
Spells of terror or panic	**74.0**	13.5	5.8	5.8	1.0
Feeling so restless, you couldn't sit still	**51.0**	24.0	12.5	9.6	2.9
Feeling fearful	**53.8**	29.9	7.7	5.8	2.9

The summarised positive cases of women on the BSI-18 scores at three to fours months after initial surgery for early breast cancer are list in Table 34.

***Table 34 Positive cases of women on the BSI-18 scores at follow-up 3 to 4 months after initial surgery* (n=104).**

Positive Cases	Somatization	Depression	Anxiety	GSI
Number of Positive Cases #	20	**29**	19	**27**
(%)	19.2	27.9	18.3	26.0
Median Raw Score	3	3	3.5	10.5
Interquartile Range (IQR)	(1, 7)	(1, 7)	(1, 7)	(5, 22.5)
Range	0-22	0-20	0-23	0-65
Median Standardised T score	53	55	50.5	54
(IQR)	(46, 61)	(46, 63)	(43, 59)	(46, 62.8)
Range	39-81	40-81	36-79	31-80

#scored a positive case this implies they either had 63 or above or a total of 63 or above in two dimension.

The number of women identified as positive cases for somatisation increased significantly between baseline assessment and follow-up (p = 0.001) while positive cases of anxiety decreased (p=0.024). The number of positive cases of depression (p =

0.541) and of the total GSI score (p = 0.690) remained unchanged. Of the 98 women who were initially negative cases for somatization, 15.3% were positive at follow-up; while of the 32 women who were initially positive cases for anxiety, 65.6% were negative at follow-up.

Three to four months after initial surgery, those who lived alone were more likely to experience higher Somatization scores (p= 0.037) than those women who were living with other people. The higher educated women had a significantly higher level of Somatization symptoms (p= 0.010). No other statistically significant findings were identified between the socio-demographic characteristics of women and their Somatization scores at follow-up (see Table 35).

Table 35 Relationships between women's BSI-18 Somatization scores at 3 to 4 months after initial surgery and their socio-demographic characteristics **(n = 104).**

Somatization	Median of standardised score of Somatization [IQR]	p-value	% Positive cases of Somatization	p-value
Age				
<50years (n= 22)	57 (47.5, 65.3)	0.597**	31.8	0.065***
50 – 59 years (n= 27)	55 (48, 59)		22.	
60 – 69 years (n= 37)	53 (46, 59)		13.5	
≥ 70 years (n= 18)	53 (46, 59.8)		11.1	
Health region				
Health Region A (n= 53)	53 (46, 65)	0.258**	26.4	0.102***
Health Region B (n= 40)	53 (46, 59)		15.0	
Health Region C (n= 11)	55 (53, 57)		0	
Living single				
No (n= 70)	53 (46, 59)	**0.037***	18.6	**0.797*****
Yes (n= 34)	57 (53, 62)		20.6	

***Table 35 (continued). Relationships between women's BSI-18 Somatization scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Somatization	Median of standardised score of Somatization [IQR]	p-value	% Positive cases of Somatization	p-value
Education				
Up to grade 11 (n= 67)	53 (46, 59)	**0.010***	14.9%	**0.193*****
≥Grade 12 (n= 37)	57 (53, 65)		27.0%	
Currently employed				
No (n= 71)	53 (46, 61)	0.803*	16.9%	0.427***
Yes (n= 33)	53 (46, 63)		24.2%	
Professional occupation				
No (n= 88)	53 (46, 59)	0.333*	17.0%	0.162***
Yes (n= 15)	57 (46, 66)		33.3%	
Missing= 1				

Table 35 (continued). ***Relationships between women's BSI-18 Somatization scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Somatization	Median of standardised score of Somatization [IQR]	p-value	% Positive cases of Somatization	p-value
Household income				
≤$20,000 (n= 53)	53 (46, 61)	0.988**	18.9	1.0****
$20,001-50,000 (n= 34)	55 (46, 61)		20.6	
>$50,000 (n= 15)	53 (48, 62)		20.0	
Missing= 2				
Number of people in household				
1 (n= 21)	53 (50.5, 70)	0.753**	19.0	0.859****
2 (n= 53)	53 (46, 72)		20.8	
≥ 3 (n= 30)	55 (47.5, 70)		16.7	
Private health insurance				
No (n= 76)	54 (46, 61)	0.421*	18.4	1.0***
Yes (n= 25)	53 (46, 59)		20.0	
Missing= 3				

Table 35 (continued). Relationships between women's BSI-18 Somatization scores at 3 to 4 months after initial surgery and their socio-demographic characteristics (n = 104).

Somatization	Median of standardised score of Somatization [IQR]	p-value	% Positive cases of Somatization	p-value
Believers in God				
No (n= 19)	55 (46, 61)	0.892*	15.8	1.0***
Yes (n= 85)	53 (46, 61)		20.0	
Personal history of breast cancer				
No (n= 102)	53 (46, 61)	0.600*	19.6	1.0***
Yes (n= 2)	57 (53, 61)		0	
Family history of breast cancer				
No (n= 62)	53 (46, 59.5)	0.643*	16.1	0.447***
Yes (n= 42)	55 (46, 62.8)		23.8	
Personal history of cancer				
No (n= 80)	53 (46, 59)	0.442*	18.8	0.776***
Yes (n= 24)	55 (48, 62)		20.8	

***Table 35 (continued). Relationships between women's BSI-18 Somatization scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Somatization	Median of standardised score of Somatization [IQR]	p-value	% Positive cases of Somatization	p-value
Family history of cancer				
No (n= 30)	53 (46, 61.3)	0.905*	16.7	0.788***
Yes (n= 74)	53 (46, 59.5)		20.3	

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis test, *** Fisher's Exact test, **** Chi-square Trend Test

The relationships between BS1-18 Depression scores and the women's socio-demographic characteristics at follow-up are outlined in Table 36. Women's age was found to be significantly (p= 0.024) related with the Depression score; those women less than 60 years of age experienced higher scores. Thirty-seven per cent (37.0%) of women aged between 50 and 59 years were positive cases of Depression. The higher educated women were more likely to score higher on the Depression dimension than those less educated, although this was not found to be significant (p= 0.162) (see Table 36).

***Table 36 Relationships between women's BSI-18 Depression scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Depression	Median of standardized score of Depression [IQR]	p-value	Positive cases of Depression %	p-value
Age				
<50years (n= 22)	58.5 (44.5, 63.3)	**0.024****	36.4	0.230****
50 – 59 years (n= 27)	60 (48, 65)		37.0	
60 – 69 years (n= 37)	46 (40, 56)		16.2	
≥ 70 years (n= 18)	48 (40, 63.8)		27.8	
			p = 0.197****	
Health region				
Health Region A (n=53)	57 (46, 64)	0.146**	32.1	0.118***
Health Region B (n= 40)	48 (40, 63)		27.5	
Health Region C (n= 11)	48 (40, 60)		9.1	
			p = 0.342***	

Table 36 (continued). **Relationships between women's BSI-18 Depression scores at 3 to 4 months after initial surgery and their socio-demographic characteristics (n = 104).**

Depression	Median of standardized score of Depression [IQR]	p-value	Positive cases of Depression %	p-value
Living single				
No (n= 70)	55 (40, 63.3)	0.756*	28.6	1.0***
Yes (n= 34)	56 (46, 63)		26.5	
Education				
Up to grade 11 (n= 67)	48 (40, 63)	0.162*	25.4	0.497***
≥Grade 12 (n= 37)	57 (47, 63.5)		32.4	
Currently employed				
No (n= 71)	48 (46, 64)	0.846*	29.6	0.644***
Yes (n= 33)	57 (43, 62)		24.2	

***Table 36 (continued). Relationships between women's BSI-18 Depression scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Depression	Median of standardized score of Depression [IQR]	p-value	Positive cases of Depression %	p-value
Professional occupation				
No (n=88)	55 (46, 63)	0.537*	27.3%	0.757***
Yes (n=15) Missing= 1	57 (46, 66)		33.3%	
Household income				
≤$20,000 (n= 53)	48 (46, 64)	0.733**	28.3%	1.0****
$20,001-50,000 (n= 34)	57 (46, 63.3)		29.4%	
>$50,000 (n= 15)	57 (46, 63)		26.7%	
Missing= 2				
Number of people in household				
1 (n= 21)	55 (46, 64.5)	0.974**	28.6%	0.643****
2 (n= 53)	55 (43, 63.5)		30.2%	
≥3 (n=30)	52.5 (44.5, 61.5)		23.3%	

Table 36 (continued). Relationships between women's BSI-18 Depression scores at 3 to 4 months after initial surgery and their socio-demographic characteristics **(n = 104).**

Depression	Median of standardized score of Depression [IQR]	p-value	Positive cases of Depression %	p-value
Private health insurance				
No (n= 76)	55 (46, 63.8)	0.465*	28.9	0.798***
Yes (n= 25)	48 (43, 62)		24.0	
Missing= 3				
Believers in God				
No (n= 19)	57 (40, 63)	0.558*	26.3	1.0***
Yes (n= 85)	55 (46, 63.5)		28.2	
Personal history of breast cancer				
No (n= 102)	55 (46, 63)	0.467*	28.4	1.0***
Yes (n= 2)	47 (46, 48)		0	

***Table 36 (continued). Relationships between women's BSI-18 Depression scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Depression	Median of standardized score of Depression [IQR]	p-value	Positive cases of Depression %	p-value
Family history of breast cancer				
No (n= 62)	48 (46, 63)	0.602*	25.8	0.657***
Yes (n= 42)	57 (40, 64)		31.0	
Personal history of cancer				
No (n= 80)	51.5 (41.5, 61)	0.205*	23.8	0.119***
Yes (n= 24)	58.5 (46, 65)		41.7	
Family history of cancer				
No (n= 30)	55 (46, 63.3)	0.974*	30.0%	0.811***
Yes (n=74)	56 (40, 63)		27.0%	

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

At follow-up, women who were aged less than 60 years scored higher Anxiety scores (although not significant; p= 0.076) than older women. Similarly, the trend between increasing age and fewer positive cases of Anxiety was not significant (p= 0.079). Twenty-nine point seven per cent (29.7%) of women with education of grade 12 or higher were identified as positive case of Anxiety compared to 11.9% of women with less education (p= 0.034). The complete socio-demographic profile of the women and the analysis with the BSI-18 Anxiety scores are displayed in Table 37.

Table 37 Relationships between women's BSI-18 Anxiety scores at 3 to 4 months after initial surgery and their socio-demographic characteristics **(n = 104).**

Anxiety	Median of standardized score of Anxiety [IQR]	p-value	% Positive cases of Anxiety	p-value
Age				
<50years (n= 22)	54 (43, 65.3)	0.076**	27.3	p=0.079****
50 – 59 years (n= 27)	55 (47, 63)		25.9	
60 – 69 years (n= 37)	47 (43, 55)		10.8	
≥ 70 years (n= 18)	47.5 (36, 57)		11.1	
Health region				
Health Region A (n= 53)	53 (43, 62)	0.595 **	24.5	0.135***
Health Region B (n= 40)	53 (43, 59)		15.0	
Health Region C (n= 11)	48 (43, 55)		0	
Living single				
No (n= 70)	53 (43, 59)	0.992*	18.6	1.0***
Yes (n=34)	48 (43, 59.5)		17.6	

***Table 37 (continued). Relationships between women's BSI-18 Anxiety scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Anxiety	Median of standardized score of Anxiety [IQR]	p-value	% Positive cases of Anxiety	p-value
Education				
Up to grade 11 (n= 67)	48 (43, 59)	0.307*	11.9	**0.034*****
≥Grade 12 (n= 37)	53 (43, 64)		29.7	
Currently employed				
No (n= 71)	48 (43, 59)	0.885*	18.3	1.0***
Yes (n= 33)	53 (43, 60)		18.2	
Professional occupation				
No (n= 88)	53 (43, 59)	0.818*	17.0	0.470***
Yes (n= 15)	47 (36, 66)		26.7	
Missing= 1				

Table 37 (continued). Relationships between women's BSI-18 Anxiety scores at 3 to 4 months after initial surgery and their socio-demographic characteristics **(n = 104).**

Anxiety	Median of standardized score of Anxiety [IQR]	p-value	% Positive cases of Anxiety	p-value
Household income				
≤$20,000 (n= 53)	48 (43, 59)	0.499**	17.0	0.730****
$20,001-50,000 (n= 34)	54 (43, 59.8)		20.6	
>$50,000 (n= 15)	48 (43, 61)		20.0	
Missing= 2				
Number of people in household				
1 (n= 21)	48 (43, 60.5)	0.929**	19.0	0.857****
2 (n= 53)	53 (43, 59)		18.9	
≥3 (n= 30)	48 (43, 59.5)		16.7	
Private health insurance				
No (n= 76)	50.5 (43, 59)	0.840*	18.4	1 ***
Yes (n= 25)	48 (43, 62)		20.0	
Missing= 3				

Table 37 (continued). ***Relationships between women's BSI-18 Anxiety scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Anxiety	**Median of standardized score of Anxiety [IQR]**	**p-value**	**% Positive cases of Anxiety**	**p-value**
Believers in God				
No (n= 19)	48 (43, 55)	0.558*	26.3	1.0***
Yes (n= 85)	53 (43, 61)		28.2	
Personal history of breast cancer				
No (n= 102)	53 (43, 59)	0.830*	18.6	1.0***
Yes (n= 2)	48 (48, 48)		0	
Family history of breast cancer				
No (n=62)	47.5 (43, 57.5)	0.066*	14.5	0.302***
Yes (n= 42)	55 (43, 62.8)		23.8	
Personal history of cancer				
No (n= 80)	50.5 (43, 59)	0.429*	17.5	0.765***
Yes (n= 24)	50.5 (47, 61)		20.8	

***Table 37 (continued). Relationships between women's BSI-18 Anxiety scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104).**

Anxiety	Median of standardized score of Anxiety [IQR]	p-value	% Positive cases of Anxiety	p-value
Family history of cancer				
No (n= 30)	47 (43, 58)	0.423*	16.7	1.0***
Yes (n= 74)	53 (43, 59)		18.9	

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

No significant relationships were found between the women's BSI Global Severity Index (GSI) scores and their socio-demographic characteristics at follow-up (see Table 4.23). The trend between increasing age and fewer positive GSI cases was not significant (p= 0.078). Those women living in Health Region A scored the highest percentage (32.1%) of positive case for GSI, while there were none in Health Region C (p= 0.071). Thirty seven point eight percent (37.8%) of women who had an education background of at least completing Year 12 were identified as positive cases for GSI compared with 19.4% of women with less education (p = 0.061). See Table 38 for the relationships between the BSI-18 scores at three to four months.

***Table 38 Relationships between women's BSI-18 Global Severity Index (GSI) scores at 3 to 4 months after initial surgery and their socio-demographic characteristics* (n = 104)**

GSI	Median of standardized score of GSI [IQR]	p-value	% Positive cases of GSI	p-value
Age				
<50years (n= 22)	58 (46, 66)	0.094**	36.4	0.078***
50 – 59 years (n= 27)	57 (50, 65)		37.0	
60 – 69 years (n= 37)	47 (43.5, 56.5)		13.5	
≥70 years (n= 18)	52 (42, 61.5)		22.2	
Health region				
Health Region A (n= 53)	55 (46, 65)	0.429**	32.1	0.071***
Health Region B (n= 40)	51 (42, 62.5)		25.0	
Health Region C (n= 11)	55 (42, 56)		0	

Table 38 (continued). ***Relationships between women's BSI-18 Global Severity Index (GSI) scores at 3 to 4 months after initial surgery and their socio-demographic characteristics*** **(n = 104).**

GSI	Median of standardized score of GSI [IQR]	p-value	% Positive cases of GSI	p-value
Living single				
No (n= 70)	51 (44.3, 62.3)	0.289*	25.7	1.0***
Yes (n= 34)	56 (47, 63)		26.5	
Education				
Up to grade 11 (n= 67)	51 (45, 58)	0.089*	19.4	0.061***
≥Grade 12 (n= 37)	58 (46.5, 64.5)		37.8	
Currently employed				
No (n= 71)	53 (46, 62)	0.858*	25.4	0.815***
Yes (n= 33)	56 (45, 63.5)		27.3	

Table 38 (continued). ***Relationships between women's BSI-18 Global Severity Index (GSI) scores at 3 to 4 months after initial surgery and their socio-demographic characteristics (n = 104).***

GSI	Median of standardized score of GSI [IQR]	p-value	% Positive cases of GSI	p-value
Professional occupation				
No (n= 88)	54 (46, 61.8)	0.733*	23.9	0.212***
Yes (n= 15)	56 (45, 66)		40.0	
Missing= 1				
Household income				
≤$20,000 (n= 53)	51 (46, 62.5)	0.758**	24.5	0.760****
$20,001-50,000 (n= 34)	56 (46, 63.3)		29.4	
>$50,000 (n= 15)	56 (45, 64)		26.7	
Missing= 2				
Number of people in household				
1 (n= 21)	55 (47, 63.5)	0.873**	23.8	0.914****
2 (n= 53)	53 (45.5, 63)		28.3	
≥ 3 (n= 30)	53 (45.8, 62.5)		23.3	

Table 38 (continued). **Relationships between women's BSI-18 Global Severity Index (GSI) scores at 3 to 4 months after initial surgery and their socio-demographic characteristics (n = 104).**

GSI	Median of standardized score of GSI [IQR]	p-value	% Positive cases of GSI	p-value
Private health insurance				
No (n= 76)	55 (46, 62.8)	0.483*	26.3	1.0***
Yes (n= 25)	50 (42, 62)		24.0	
Missing= 3				
Believers in God				
No (n= 19)	56 (42, 58)	0.668*	15.8	0.387***
Yes (n= 85)	51 (46, 63.5)		28.2	
Personal history of breast cancer				
No (n= 102)	54 (46, 63)	0.878*	26.5	1.0***
Yes (n= 2)	52.5 (50, 55)		0	
Family history of breast cancer				
No (n= 62)	51 (46, 58.3)	0.304*	19.4	0.072***
Yes (n= 42)	57 (45, 65)		35.7	

Table 38 (continued). ***Relationships between women's BSI-18 Global Severity Index (GSI) scores at 3 to 4 months after initial surgery and their socio-demographic characteristics (n = 104).***

GSI	Median of standardized score of GSI [IQR]	p-value	% Positive cases of GSI	p-value
Personal history of cancer				
No (n= 80)	51 (45.3, 61)	0.308*	23.8	0.427***
Yes (n= 24)	57 (46, 63)		33.3	
Family history of cancer				
No (n= 30)	52 (46, 59)	0.777*	20.0	0.464***
Yes (n= 74)	55 (45, 63.3)		28.4	

* Mann Whitney Wilcoxon Test, ** Kruskal Wallis Test, *** Fisher's Exact Test, **** Chi-square Trend Test

Qualitative Dimensions

The women's responses to the opened ended questions "*What nurses should know to help women make decisions?*" at the follow-up at three to four months. Almost a fifth of women (19.2%) indicated it was important for nurses to know the postoperative management of breast cancer treatment; the psychological and emotional effects (22.1%) and provide emotional and psychological support to women (see Table 39).

Table 39 Women's responses (%) to the question" What nurses should know to help women make decisions?"

What nurses should know to help women mak decisions?"	**At 3 to 4 months follow-up (n=104)** **%**
Post-operative complications and management	12.5
Provide emotional & psychological support	19.2
Not much/Don't Know	1.9
Individualise care	1.9
Nurses are well educated	7.7
Treatment Options	5.8
Did not see a nurse	3.8
Involve family	1.9
Maintain Positive Outlook	4.8
Good communication skills	3.8
Honest answers	1.9

Practical and informational support	6.7
Know what information women need to make decisions	11.5
Psychological and Emotional Impact of breast cancer	22.1

The women’s responses to the opened ended questions “ “*What advice do you have for other women who are facing this decision*?” at the three to four months Follow-up are presented in Table 40. Over a fifth (23.1%) of women indicated they would advise women to think positively (see Table 40).

Table 40 Women's responses (%) to "What advice do you have for other women who are facing this decision?"

"What advice do you have for other women who are facing this decision?"	**At 3 to 4 months follow-up (n=104) %**
Positive thinking	23.1
Search as much information as possible	9.6
Talk and listen to other women who have had breast cancer	5.8
Follow doctors advice	12.5
Take your time to decide	4.8
Ask and write questions	13.5
Involve family and friends	6.7
Have treatment as soon as possible	1.9
Faith and pray in God	4.8
Trust in doctor	4.8
Look at all options and consequences	5.8
Read all information	1.0
Seek support	1.9
Have mammogram and regular breast checks	2.9
Seek the best medical advice	2.9
Make your own decision	3.8
Talk to doctor	2.9
Trust your instincts	4.8

Decision Satisfaction (PTDS)

The majority of the women agreed or strongly agreed with the decision satisfaction (*PTDS*) statements: "*I am very satisfied with my decision-making experience"* (79.8%); *"I am very satisfied with my participation in the decision"* (79.8%); *"I am very satisfied that I had sufficient time to make my choice"*(70.2%). Thirty four point six percent (34.6%) of the women indicated they neither agreed nor disagreed with the statement, "*I am very satisfied with the way nurses helped me make my decision"*.

For the *PTDS Decision Outcome Satisfaction* items, 83.6 % of women agreed or strongly agreed with the following statement, *"I am very satisfied with the choice I made"*, *"I am very satisfied that at the time I was making a good decision"* (84.6%), and *"I have no regrets about the treatment choice I made"* (85.3%). Table 41 outlines the percentage of agreement to the decision satisfaction items.

***Table 41 Women's agreement (%) with Patient Treatment Decision Satisfaction (PTDS) items 3 to 4 months after initial surgery* (n =104).**

Treatment Decision Satisfaction	Strongly Disagree %	Disagree %	Slightly Disagree %	Neither Agree Nor Disagree %	Slightly Agree %	Agree %	Strongly Agree %
Decision Process Satisfaction (6 items)							
" I am very satisfied with my decision-making experience"	1.9	1.9	1.0	10.6	4.8	**40.4**	39.4
" I am very satisfied with the options that were offered to me"	3.8	2.9	1.0	14.4	4.8	**39.4**	33.7
" I am very satisfied with the way the options were offered to me"	1.9	3.8	2.9	14.4	5.8	**38.5**	32.7
" I am very satisfied with my participation in the decision"	1.0	1.9	1.9	11.5	3.8	**41.3**	38.5
" I am very satisfied that I had sufficient time to make my choice"	2.9	1.9	1.9	16.3	6.7	**40.4**	29.8

Table 41 (continued). ***Women's agreement with Patient Treatment Decision Satisfaction (PTDS) items 3 to 4 months after initial surgery*** **(n =104).**

Treatment Decision Satisfaction	Strongly Disagree %	Disagree %	Slightly Disagree %	Neither Agree Nor Disagree %	Slightly Agree %	Agree %	Strongly Agree %
Decision Process Satisfaction (6 items) (continued)							
" I am very satisfied with the information I used to make my choice"	1.9	1.0	1.9	11.5	5.8	**40.4**	37.5
Decision Outcome Satisfaction (10 items)							
" I am very satisfied with the way nurses helped me to make my decision"	2.9	3.8	1.9	34.6	2.9	**28.8**	25.0
" I am very confident that I made a satisfactory choice"	0	1.0	1.9	10.6	1.9	**38.5**	46.2

***Table 41 (continued). Women's agreement with Patient Treatment Decision Satisfaction (PTDS) items 3 to 4 months after initial surgery* (n =104).**

Treatment Decision Satisfaction	**Strongly Disagree %**	**Disagree %**	**Slightly Disagree %**	**Neither Agree Nor Disagree %**	**Slightly Agree %**	**Agree %**	**Strongly Agree %**
Decision Outcome Satisfaction (10 items) (continued)							
" I am very satisfied with the choice I made"	0	1.0	2.9	11.5	1.0	**42.3**	41.3
" I am very satisfied with the quality of my decision-making activity"	0	1.0	1.9	13.5	4.8	**39.4**	**39.4**
" I am very satisfied with the outcome of the treatment"(n = 103)	0	3.9	0	13.6	5.8	35.9	**40.8**
" I am very satisfied that at the time I was making a good decision"	0	0	1.0	9.6	4.8	**44.2**	40.4
" I am very satisfied with the outcome of the decision"	0	1.9	1.9	12.5	4.8	36.5	**42.3**

***Table 41 (continued). Women's agreement with Patient Treatment Decision Satisfaction (PTDS) items 3 to 4 months after initial surgery* (n =104).**

Treatment Decision Satisfaction	**Strongly Disagree %**	**Disagree %**	**Slightly Disagree %**	**Neither Agree Nor Disagree %**	**Slightly Agree %**	**Agree %**	**Strongly Agree %**
Decision Outcome Satisfaction (10 items) (continued)							
" I have no regrets about the treatment choice I made"(n = 102)	0	2.9	2.0	8.8	1.0	41.2	**44.1**
" I believe my decision will be very successful in the long run"	0	1.0	0	13.5	2.9	36.5	**46.2**
" I believe there is nothing I could have done differently at the time I was making my decision"	1.0	2.9	1.0	11.5	2.9	31.7	**49.0**

Sixteen (15.4%, n = 104) of the women strongly agreed to all the seven questions of the *PTDS* scale for the *Decision Process Satisfaction* dimension, five (4.8%) women were on average not satisfied and another five (4.8%) averaged overall a zero, so neither agreed nor disagreed with the items. Overall, three (2.9%) women were mostly dissatisfied with their *Decision Outcome Satisfaction*, three (2.9%) women averaged zero, so neither agreed nor disagreed with the items, and 27 (26.5%) women strongly agreed to all *Decision Outcome Satisfaction* questions. See Table 42 for the percentage of women who agreed or strongly agree with all the dimension of the decision satisfaction items.

Table 42 Percentage of women who agreed or strongly agreed with all the items of decision satisfaction (PTDS) dimensions at 3-4 months (n = 104).

Decision Satisfaction (*PTDS*)	**Agreed or Strongly Agreed %**
Decision Process	53.7
Decision Outcome	67.8

The *Global Decision Satisfaction* (GDS) score was calculated by totalling all the *PTDS* items and dividing by all the 16 items. In relation to the *Global Decision Satisfaction* (GDS) four (3.9%) women were on average dissatisfied with their decision process or outcome and two (2.0%) women averaged zero, so neither agreed nor disagreed with the items, and 14 (13.7%) women strongly agreed to all satisfaction questions. The descriptive statistics for the *PTDS* dimensions are presented in Table 43.

***Table 43 Descriptive statistics of women's Patient Treatment Decision Satisfaction (PTDS) scores at 3 to 4 months after initial surgery* (n = 104).**

	Decision Process Satisfaction (n = 104)	**Decision Outcome Satisfaction (n = 102)**	**Global Decision Satisfaction (n = 102)**
Median*	2	2.1	2
IQR	(1.2 to 2.6)	(1.8 to 3)	(1.5 to 2.7)
Range	-2.7 to 3	1.6 to 3	-1.4 to 3

*2 implies on average agreement with statements.

No significant relationships were found between the women's treatments and their decision satisfaction scores. Women's relationship between their received treatment and their decision satisfaction at three to four months are described in Table 44.

***Table 44 Relationships between women's decision satisfaction (PTDS) scores at 3 to 4 months after initial surgery and their breast cancer treatment* (n = 103).**

Treatment	Decision Process Satisfaction	Decision Outcome Satisfaction	Global Decision Satisfaction
	Median (IQR) **p-value***	**Median (IQR)** **p-value***	**Median (IQR)** **p-value***
Mastectomy			
No (n = 60)	2.0 (0.8, 2.6)	2.1 (1.7, 3.0)	2.0 (1.5, 2.7)
Yes (n = 43)	2.0 (1.4, 2.6)	2.1 (1.8, 3.0)	2.0 (1.7, 2.7)
	p = 0.933	p = 0.735	p = 0.688
Lumpectomy			
No (n = 39)	2.0 (1.3, 2.4)	2.1 (1.7, 2.9)	2.0 (1.5, 2.6)
Yes (n = 64)	2.0 (1.0, 2.6)	2.1 (1.8, 3.0)	2.0 (1.5, 2.8)
	p = 0.956	p = 0.806	p = 0.902
Axillary clearance			
No (n = 81)	2.0 (1.3, 2.6)	2.3 (1.8, 3.0)	2.1 (1.6, 2.7)
Yes (n = 22)	1.8 (0.9, 2.6)	2.0 (1.4, 2.9)	1.9 (1.3, 2.8)
	p = 0.338	p = 0.268	p = 0.219
Radiation therapy			
No (n = 50)	2.0 (1.1, 2.6)	2.1 (1.6, 3.0)	2.0 (1.5, 2.8)
Yes (n = 53)	2.0 (1.3, 2.3)	2.2 (1.8, 3.0)	2.0 (1.5, 2.6)
	p = 0.573	p = 0.994	p = 0.746
Chemotherapy			
No (n = 69)	2.0 (1.1, 2.6)	2.4 (1.7, 3.0)	2.1 (1.5, 2.8)
Yes (n = 34)	1.9 (1.4, 2.4)	2.0 (1.8, 2.6)	2.0 (1.5, 2.4)
	p = 0.575	p = 0.200	p = 0.369

Table 44 (continued). ***Relationships between women's decision satisfaction (PTDS) scores at 3 to 4 months after initial surgery and their breast cancer treatment*** **(n = 103).**

Treatment	Decision Process Satisfaction	Decision Outcome Satisfaction	Global Decision Satisfaction
	Median (IQR) **p-value***	**Median (IQR)** **p-value***	**Median (IQR)** **p-value***
Hormone therapy			
No (n = 52)	2.0 (1.3, 2.6)	2.3 (1.8, 3.0)	2.0 (1.5, 2.8)
Yes (n = 51)	1.9 (0.9, 2.4)	2.0 (1.6, 3.0)	2.0 (1.5, 2.6)
	p = 0.733	p = 0.534	p = 0.485
Alternative therapy**			
No (n =101)	2.0 (1.4, 2.6)	2.1 (1.8, 3.0)	2.0 (1.5, 2.7)
Yes (n =2)	0.1 (-0.3, 0.6)	1.6 (1.4, 1.8)	1.0 (0.7, 1.3)

*Non-parametric Wilcoxon-Mann-Whitney-U test; **No statistical test conducted because of small sample size.

Only one woman had breast re-construction hence it was impossible to calculate comparative statistics.

No significant associations were found between the women's age and their *Decision Process Satisfaction* (Spearman rank correlation: satisfaction with process r = -0.15, p = 0.126; *Decision Outcome Satisfaction* r = 0.01, p = 0.946; *Global Decision Satisfaction* r = -0.08, p = 0.397). The negative correlation coefficients imply that younger women were less likely to be satisfied with their decision process and globally; however these relationships were not significant statistically. A positive relationship (although not significant) was found between the age of the women and their decision satisfaction outcome although again not significant. Those women who were living alone were less likely to be satisfied with their decision process ($p = 0.012$) than those living with other people. Lower educated women were found to be more satisfied with their decision outcome ($p = 0.005$) and globally ($p = 0.014$) than those with a higher education. Non-professional women were also found to be more satisfied with their decision outcome ($p = 0.0004$) and globally ($p = 0.002$) than those in professional occupations. Less decision process ($p = 0.038$) and global satisfaction ($p = 0.044$) was found for women who received a higher annual household income. No other significant results were identified between the women's decision satisfaction and their socio-demographic background. The bivariate analysis of women's decision satisfaction and their socio-demographic profile are listed in Table 45.

***Table 45 Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months* (n = 104).**

Socio-demographic variables	Decision Process Satisfaction Median, (IQR) (n = 104)	Decision Outcome Satisfaction Median, (IQR) (n = 102)	Global Decision Satisfaction Median, (IQR) (n = 102)
Age			
<50years (n = 22)	2.1 (1.6, 2.6)	2.0 (1.7, 2.8)	2.0 (1.5, 2.6)
50 – 59 years (n = 27)	2.0 (1.6, 2.8)	2.0 (2.0, 3.0)	2.0 (1.7, 2.8)
60 – 69 years (n = 37)	2.0 (1.4, 2.6)	2.3 (1.8, 3.0)	2.1 (1.7, 2.8)
≥ 70 years (n = 18)	1.5 (0.9, 2.1)	2.2 (1.1, 2.8)	1.7 (1.3, 2.4)
	p = 0.332**	p = 0.441**	p = 0.383**
Health region			
Health Region A (n = 53)	1.7 (0.9, 2.4)	2.1 (1.5, 3.0)	2.0 (1.4, 2.6)
Health Region B (n = 40)	2.0 (1.6, 2.6)	2.2 (1.8, 3.0)	2.0 (1.7, 2.8)
Health Region C (n = 11)	2.1 (1.7, 2.6)	2.7 (1.7, 2.9)	2.4 (1.8, 2.7)
	p = 0.163**	p = 0.795**	p = 0.462**

Table 45 (continued). Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months (n = 104).

Socio-demographic variables	**Decision Process Satisfaction Median, (IQR) (n = 104)**	**Decision Outcome Satisfaction Median, (IQR) (n = 102)**	**Global Decision Satisfaction Median, (IQR) (n = 102)**
Living single			
No (n = 70)	2.0 (1.6, 2.7)	2.3 (1.8, 3.0)	2.1 (1.5, 2.8)
Yes (n = 34)	1.7 (0.9, 2.3)	2.0 (1.4, 2.8)	1.9 (1.5, 2.4)
	p = 0.012*	p = 0.180*	p = 0.052*
Education			
Up to grade 11 (n = 67)	2.0 (1.4, 2.6)	2.4 (2.0, 3.0)	2.3 (1.8, 2.8)
≥Grade 12 (n = 37)	1.7 (0.9, 2.3)	1.8 (1.3, 2.4)	1.9 (1.3, 2.3)
	p = 0.126*	**p = 0.005***	**p = 0.014**
Currently employed			
No (n = 71)	2.0 (1.3, 2.4)	2.3 (1.8, 3.0)	2.0 (1.5, 2.7)
Yes (n = 33)	2.0 (1.4, 2.6)	2.0 (1.6, 2.9)	2.0 (1.4, 2.6)
	p = 0.544*	p = 0.294*	p = 0.826*

Table 45 (continued). Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months (n = 104).

Socio-demographic variables	**Decision Process Satisfaction Median, (IQR) (n = 104)**	**Decision Outcome Satisfaction Median, (IQR) (n = 102)**	**Global Decision Satisfaction Process Median, (IQR) (n = 102)**
Professional occupation			
No (n = 88)	2.0 (1.4, 2.6)	2.4 (2.0, 3.0)	2.1 (1.7, 2.8)
Yes (n = 15)	1.4 (0.6, 2.0)	1.4 (1.1, 1.8)	1.5 (1.1, 1.8)
Missing = 1	p = 0.059*	**p = 0.0004***	**p = 0.002***
Household income			
≤$20,000 (n = 53)	2.0 (1.0, 2.4)	2.2 (1.7, 2.9)	2.0 (1.5, 2.6)
$20,001-50,000 (n = 34)	2.3 (1.7, 3.0)	2.3 (2.0, 3.0)	2.4 (1.9, 2.9)
>$50,000 (n = 15)	1.7 (0.6, 2.1)	1.7 (1.3, 2.3)	1.6 (1.1, 2.2)
Missing = 2	**p = 0.038****	p = 0.060**	**p = 0.044****

***Table 45 (continued). Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months* (n = 104).**

Socio-demographic variables	Decision Process Satisfaction Median, (IQR) (n = 104)	Decision Outcome Satisfaction Median, (IQR) (n = 102)	Global Decision Satisfaction Process Median, (IQR) (n = 102)
Number of people in household			
1 (n = 21)			
2 (n = 53)	5 (0.9, 2.0)	2.0 (1.7, 2.9)	1.8 (1.6, 2.1)
≥ 3 (n = 30)	2.0 (1.1, 2.9)	2.4 (1.4, 3.0)	2.2 (1.4, 2.9)
	2.1 (1.6, 2.6)	2.1 (1.8, 2.9)	2.1 (1.7, 2.6)
	p = 0.053**	p = 0.682**	p = 0.225**
Private health insurance			
No (n = 76)	2.0 (1.4, 2.6)	2.1 (1.8, 3.0)	2.0 (1.5, 2.7)
Yes (n = 25)	2.0 (0.9, 2.6)	2.4 (1.6, 3.0)	2.2 (1.4, 2.8)
Missing = 3	p = 0.896*	p = 0.934*	p = 0.793*

***Table 45 (continued). Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months* (n = 104).**

Socio-demographic variables	Decision Process Satisfaction Median, (IQR) (n = 104)	Decision Outcome Satisfaction Median, (IQR) (n = 102)	Global Decision Satisfaction Process Median, (IQR) (n = 102)
Believers in God			
No (n = 19)	1.7 (0.9, 2.0)	2.0 (1.3, 2.9)	1.9 (1.5, 2.4)
Yes (n = 85)	2.0 (1.3, 2.6)	2.2 (1.8, 3.0)	2.0 (1.6, 2.8)
	p = 0.163*	p = 0.232*	p = 0.197*
Personal history of breast cancer			
No (n = 102)			
Yes (n = 2)	2.0 (1.2, 2.6)	2.1 (1.7, 3.0)	2.0 (1.5, 2.7)
	2.1 (1.7, 2.6)	2.9 (2.9, 3.0)	2.6 (2.4, 2.8)
	p = 0.694*	p = 0.153*	p = 0.292*

Table 45 (continued). Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months **(n = 104).**

Socio-demographic variables	Decision Process Satisfaction Median, (IQR) (n = 104)	Decision Outcome Satisfaction Median, (IQR) (n = 102)	Global Decision Satisfaction Process Median, (IQR) (n = 102)
Family history of breast cancer			
No (n = 62)			
Yes (n = 42)	2.0 (1.4, 2.6)	2.1 (1.8, 3.0)	2.1 (1.6, 2.8)
	2.0 (0.6, 2.6)	2.0 (1.7, 2.9)	1.9 (1.5, 2.6)
	p = 0.458*	p = 0.538*	p = 0.429*
Personal history of cancer			
No (n = 80)			
Yes (n = 24)	2.0 (1.4, 2.6)	2.1 (1.8, 3.0)	2.0 (1.5, 2.8)
	1.8 (0.9, 2.4)	2.2 (1.4, 2.9)	2.0 (1.3, 2.6)
	p = 0.402*	p = 0.637*	p = 0.563*

Table 45 (continued). Median values and interquartile ranges of Patient Treatment Decision Satisfaction (PTDS) (process, outcome, and global satisfaction) scores and relationships with women's socio-demographic characteristics at 3 to 4 months **(n = 104).**

Socio-demographic variables	**Decision Process Satisfaction Median, (IQR) (n = 104)**	**Decision Outcome Satisfaction Median, (IQR) (n = 102)**	**Global Decision Satisfaction Process Median, (IQR) (n = 102)**
Family history of cancer			
No (n = 30)	1.8 (1.1, 2.3)	2.1 (1.8, 3.0)	2.0 (1.5, 2.6)
Yes (n = 74)	2.0 (1.4, 2.6)	2.2 (1.7, 3.0)	2.0 (1.5, 2.8)
	p = 0.477*	p = 0.943*	p = 0.788*

* Mann Whitney Wilcoxon Test

Significant relationships were identified between decision satisfaction (*PTDS*) and *Somatization* and the *GSI* (*BSI-18*). The women's satisfaction with their decision process, outcome, and global satisfaction were negatively correlated with *Somatization* symptoms and their *GSI* score. Those women who experienced higher distress levels with their *Somatization* symptoms were less likely to be satisfied with the decision process (p= 0.008), outcome (p= 0.004) and global satisfaction (p= 0.003) than other women with less symptoms. Similarly, women who experienced overall distress levels measured by means of *GSI* scores were less likely to be satisfied with the decision process (p= 0.028), outcome (p= 0.029) and with global satisfaction (p= 0.020) than other women with less distress. The relationship between women's distress levels (*BSI-18*) and their decision satisfaction (*PTDS*) are given in Table 46.

Table 46 Relationships between women's psychological distress levels as assessed with BSI-18 and their satisfaction as assessed with the Patient Treatment Decision Satisfaction (PTDS) score 3 to 4 months after initial surgery (n =104).

Decision Satisfaction	Somatization	Depression	Anxiety	GSI
Decision Process Satisfaction (n = 104)	r = -0.26* **p = 0.008**	r = -0.16* p = 0.108	r = -0.13* p = 0.202	r = -0.22* **p = 0.028**
Decision Outcome Satisfaction (n = 102)	r = -0.28* **p = 0.004**	r = -0.16* p = 0.103	r = -0.10* p = 0.337	r = -0.21* **p = 0.029**
Global Decision Satisfaction (n = 102)	r = -0.29* **p = 0.003**	r = -0.17* p = 0.084	r = -0.12* p = 0.223	r = -0.23* **p = 0.020**

*r = Spearman rank correlation coefficient.

Overall, the majority of the sample were satisfied with the support (such as: financial, family, social, psychological, emotional, nursing, informational, spiritual, religious and physical support) they received during the time they were making their treatment decision. The majority of women reported they were "satisfied" or "very satisfied" with the family (82.7%), social (70.2%), nursing (68.9%) and informational (80.8%) support they received. Table 47 describes women's satisfaction

at three to four months with the types of support they received. Women's satisfaction with the types of support they received is presented in Table 47.

Table 47 Women's reported satisfaction (%) with the types of support they received (%) 3 to 4 months after the initial surgery (n =104).

Overall, how would you rate your satisfaction with the support you received when making your decision?	**Very Unsatisfied %**	**Unsatisfied %**	**Slightly Unsatisfied %**	**Neither Satisfied Nor Unsatisfied %**	**Slightly Satisfied %**	**Satisfied %**	**Very Satisfied %**
Financial Support	3.8	1.9	3.8	41.3	1.9	22.1	**25.0**
Family Support	1.0	1.0	1.9	6.7	6.7	18.3	**64.4**
Social Support	1.9	0	3.8	18.3	5.8	34.6	**35.6**
Psychological Support	1.0	3.8	1.9	31.7	5.8	**38.5**	17.3
Emotional Support	1.0	1.0	4.8	21.2	6.7	**33.7**	31.7
Nursing Support (n = 103)	1.9	1.9	1.0	20.4	5.8	32.0	**36.9**
Informational Support	0	1.9	1.9	7.7	**7.7**	29.8	**51.0**
Spiritual Support	1.9	1.9	2.9	**45.2**	1.0	23.1	24.0

Table 47 (continued). ***Women's reported satisfaction (%) with the types of support they received (%) 3 to 4 months after the initial surgery*** **(n = 104).**

Overall, how would you rate your satisfaction with the support you received when making your decision?	Very Unsatisfied %	Unsatisfied %	Slightly Unsatisfied %	Neither Satisfied Nor Unsatisfied %	Slightly Satisfied %	Satisfied %	Very Satisfied %
Religious Support	1.9	2.9	1.9	**55.8**	0	19.2	18.3
Physical Support	1.9	3.8	2.9	28.8	3.8	22.1	**36.5**

Most variables that measured the perceived support that the women had received were statistically significantly positively related to their satisfaction with their treatment decision. Table 48 details the relationship between women’s decision satisfaction at three to fours months and the types of support they received.

Table 48 Correlations between women's perceived satisfaction with the support they received and their Patient Treatment Decision Perceived satisfaction (PTDS) score assessed 3 to 4 months after initial surgery **(n = 104).**

Types of Support	**Decision Process Satisfaction (n = 104)**	**Decision Outcome Satisfaction (n = 102)**	**Global Decision Satisfaction (n = 102)**
Financial	r = 0.17*	r = 0.29*	r = 0.25*
	p = 0.091	**p = 0.003**	**p = 0.010**
Family	r = 0.44*	r = 0.33*	r = 0.40*
	p < 0.001	**p = 0.001**	**p < 0.001**
Social	r = 0.49*	r = 0.35*	r = 0.45*
	p < 0.001	**p < 0.001**	**p < 0.001**
Psychological	r = 0.47*	r = 0.39*	r = 0.47*
	p < 0.001	**p < 0.001**	**p < 0.001**
Emotional	r = 0.52*	r = 0.40*	r = 0.48*
	p < 0.001	**p < 0.001**	**p < 0.001**
Nursing	**r = 0.53***	**r = 0.44***	**r = 0.52***
	p < 0.001	**p < 0.001**	**p < 0.001**
Informational	r = 0.35*	r = 0.39*	r = 0.38*
	p < 0.001	**p < 0.001**	**p < 0.001**
Spiritual	r = 0.31*	r = 0.29*	r = 0.32*
	p = 0.002	**p = 0.003**	**p = 0.001**
Religious	r = 0.28*	r = 0.26*	r = 0.29*
	p = 0.004	**p = 0.009**	**p = 0.003**
Physical	r = 0.45*	r = 0.37*	r = 0.44*
	p < 0.001	**p < 0.001**	**p < 0.001**

*r = Spearman rank correlation coefficient.

Comparison across Pre- and Post- Treatment

Michigan Assessment of Decision Styles

No statistically significant relationships were identified using Spearman rank correlation coefficients between the *MADS* factors scores as assessed at baseline and the women's distress levels *(BSI-18* dimension scores) assessed at 3 to 4 months after initial surgery. Those women who received low scores on *Deferring Responsibility* were more likely to obtain higher scores on the BSI-18 dimensions namely: *Somatization* (r= -0.16), *Depression* (r= -0.14), *Anxiety* (r= -0.16), and *GSI* (r= -0.15). In contrast, only positive correlations were identified between Information Seeking and *Somatization* (r= 0.10), *Depression* (r= 0.05), *Anxiety* (r= 0.10) and *GSI* (r= 0.10). None of these relationships were however significant (refer to Table 49).

Table 49 Correlations between women's decision styles (MADS) scores (as assessed at baseline) and their standardized psychological distress scores (BSI–18) assessed at 3 to 4 months after initial surgery (n = 104).

BSI-18	Deferring Responsibility	Avoidance	Information Seeking	Deliberation
Somatization	r = -0.15*	r = 0.01*	r = 0.10*	r = -0.02*
	p = 0.12	p = 0.93	p = 0.31	p = 0.81
Depression	r = -0.14*	r = -0.01*	r = 0.05*	r = -0.06*
	p = 0.16	p = 0.95	p = 0.64	p = 0.52
Anxiety	r = -0.16*	r = -0.07*	r = 0.10*	r = 0.05*
	p = 0.10	p = 0.47	p = 0.30	p = 0.58
GSI	r = -0.16*	r = -0.02*	r = 0.10*	r = -0.01*
	p = 0.11	p = 0.84	p = 0.33	p = 0.94

*r = Spearman rank correlation coefficient.

The decision styles (*MADS*) average scores were correlated against the satisfaction scores for the types of support received by women using a Spearman rank correlation coefficients (refer to Table 4.33). A significant positive relationship was found between the decision styles *Deferring Responsibility* and the perceived satisfaction with Nursing Support received (r = 0.24, p = 0.013) and the perceived satisfaction with Physical Support (r = 0.24, p = 0.013) received. Those women who received a high score for the decision styles *Avoidance* were more likely to be satisfied with the Spiritual Support they received (r = 0.24, p = 0.015). Table 50 provides the relationship between women's decision styles (*MADS*) and their types of support.

Table 50 Correlations between perceived satisfaction with types of support received assessed at 3 to 4 months after initial surgery and decision styles (MADS) scores as assessed at baseline (n = 104).

Types of support	**Deferring Responsibility**	**Avoidance**	**Information Seeking**	**Deliberation**
Financial	r = 0.09*	r = 0.08*	r = -0.14*	r = -0.14*
	p = 0.368	p = 0.395	p = 0.147	p = 0.162
Family	r = 0.13	r = -0.03*	r = 0.07*	r = 0.14*
	p = 0.174	p = 0.792	p = 0.477	p = 0.144
Social	r = 0.03*	r = -0.03*	r = - 0.03*	r = 0.01*
	p = 0.745	p = 0.747	p = 0.779	p = 0.933
Psychological	r = 0.13*	r = 0.06*	r = -0.10*	r = -0.04*
	p = 0.188	p = 0.543	p = 0.315	p = 0.707
Emotional	r = 0.13*	r = 0.09*	r = -0.11*	r = -0.04*
	p = 0.195	p = 0.341	p = 0.259	p = 0.678
Nursing	r = 0.24*	r = 0.06*	r = -0.11*	r = -0.02*
	p = 0.013	p = 0.578	p = 0.282	p = 0.818
Informational	r = 0.15*	r = 0.01*	r = -0.09*	r = 0.07*
	p = 0.138	p = 0.894	p = 0.346	p = 0.454
Spiritual	r = 0.08*	r = 0.24*	r = 0.005*	r = 0.11*
	p = 0.433	**p = 0.015**	p = 0.962	p = 0.275
Religious	r = -0.04*	r = 0.16*	r = -0.09*	r = 0.04*
	p = 0.692	p = 0.115	p = 0.388	p = 0.683
Physical	r = 0.24*	r = 0.14*	r = 0.05*	r = 0.09*
	p = 0.013	p = 0.149	p = 0.642	p = 0.350

*r = Spearman rank correlation coefficient.

BSI comparisons between baseline and 3 to 4 months follow-up values showed a significant increase for somatisation (p<0.001) and a significant decrease for anxiety (p=0.024), while cases of depression (p=0.541) and global severity index (p=0.690) did not change. Table 51 details the BSI-18 dimension at baseline and 3 to 4 months after initial surgery.

Table 51 Percentage of women identified as positive cases for BSI at baseline and 3-4 months.

Time	**Depression % Cases**	**Anxiety % Cases**	**Somatization % Cases**	**Global Severity Index % Cases**
Baseline prior to surgery (N = 132)	23.5	**28.8**	5.3	17.4
3-4 months post-surgery (n = 104)	**27.9**	18.3	19.2	26.0

Decision Satisfaction

Women's satisfaction (*PTDS*) with their decision process (Data Collection Stage 2) was found to be significantly correlated (r = -0.26, n=104, p=0.008) as was satisfaction with decision outcome (r= -0.28, n=102, p=0.004) with somatization (BSI-18) at 3 to 4 months. At 3 to 4 months women's Decision Process Satisfaction was significantly correlated with the distress GSI at 3 to 4 months (r = -0.22, n=104, p=0.028). A significant negative relationship was identified between women's

Decision Outcome Satisfaction at 3 to 4 months and GSI at 3 to 4 months (r= -0.22, n=102, p=0.029). Women's Global Decision Satisfaction at 3 to 4 months follow-up was found to be significantly correlated with the BSI-18 dimensions of Somatization (r = -0.29, n=102, p=0.003), GSI (r = -0.23, n=102, p=0.020) at follow-up.

Using Spearman Rank Correlation Coefficients, no significant relationship was identified between the baseline *BSI-18* variables and women's decision satisfaction (*PTDS*) at 3 to 4 months. Those women who experienced higher Somatization distress scores were more satisfied with their decision process, outcome, and global satisfaction (*PTDS*). Women who were less satisfied with their decision (process, outcome and global- *PTDS*) experienced higher scores of Depression (*BSI-18*). Whereas, women with lower *Anxiety* scores were more satisfied with their decision process and global satisfaction, but less satisfied with their decisions outcome. Those women with a higher *GSI* score were less satisfied with their decisions outcome and global satisfaction and more satisfied with their decision process (PTDS). However, none of these relationships was statistically significant. Table 52 describes the *BSI-18* baseline scores with women's decision satisfaction (*PTDS*) at 3 to 4 months.

Table 52 Women's BSI-18 scores at baseline with PTDS at 3 to 4 months after initial treatment. Spearman rank correlation coefficients of standardized BSI scores at baseline with decision satisfaction scores at 3 to 4 months.

Decision Satisfaction	Somatization	Depression	Anxiety	GSI
Decision Process Satisfaction (n = 104)	r = 0.13 p = 0.194	r = -0.02 p = 0.860	r = -0.01 p = 0.918	r = 0.02 p = 0.812
Decision Outcome Satisfaction (n = 102)	r = 0.03 p = 0.798	r = -0.06 p = 0.571	r = 0.01 p = 0.984	r = -0.001 p = 0.995
Global Decision Satisfaction (n = 102)	r = 0.08 p = 0.425	r = -0.05 p = 0.589	r = -0.02 p = 0.881	r = -0.001 p = 0.993

Hypotheses Testing

In testing the study's hypotheses the association between the decision styles *MADS* factors (*Deferring Responsibility*, *Avoidance*, *Information* and *Deliberation*) as assessed at baseline and the *Patient Treatment Decision Satisfaction* (*PTDS*; decision satisfaction process, outcome and global) as assessed 3 to 4 months after initial surgery were measured, initially bivariately. Due to the data being skewed, non-parametric Spearman rank correlation coefficients were used to test these relationships. The only significant relationships identified bivariately were between the decision styles *Deferring Responsibility* and the *Decision Process Satisfaction* (r = 0.20, p = 0.045), *Decision Outcome Satisfaction* (r = 0.21, p = 0.038), and *Global Decision Satisfaction* (r = 0.21, p = 0.032). Women who had a higher score for *Deferring Responsibility* were more satisfied with their decision process, outcome, and *Global Decision Satisfaction*.

Those who had higher scores on *Information Seeking* were more likely to be satisfied with their process (r = 0.14) and global (r = 0.03) of decision-making, but less satisfied with their decision outcome (r = -0.01). Women who score high on the *MADS* factor of *Deliberation* were more likely satisfied with their decision process (r = 0.19), outcome (r = 0.10) and global (r = 0.13) although these relationships were all not significant. However those who received high scores on *Avoidance* were less likely to be satisfied with their decision process (r = -0.08), outcome (r = -0.13) and global (r = -0.10). However, none of those relationships were statistically significant. Table 53 outlines the correlation between women's decision styles (*MADS*) and women's decision satisfaction (*PTDS*).

Table 53 Correlations between women's decisions styles (MADS) at baseline and their decision satisfaction (PTDS) scores at 3 to 4 months after initial surgery (n = 104).

	Deferring Responsibility	**Information Seeking**	**Deliberation**	**Avoidance**
Decision Process Satisfaction	r = 0.20* **p = 0.045**	r = 0.14* p = 0.147	r = 0.19* p = 0.06	r = -0.08* p = 0.404
Decision Outcome Satisfaction	r = 0.21* **p = 0.038**	r = -0.01* p = 0.893	r = 0.10* p = 0.30	r = -0.13* p = 0.199
Global Decision Satisfaction	r = 0.21* **p = 0.032**	r = 0.03* p = 0.736	r = 0.13* p = 0.20	r = -0.10* p = 0.299

*r = Spearman rank correlation coefficient.

In further testing of the hypotheses of the study, modelling of the decision styles (*MADS*) scores (as the independent variable) with *Patient Treatment Decision Satisfaction* (*PTDS*) variables (as the dependent variables) were undertaken using Stepwise Multiple Linear Regression analyses. A total of 12 models were investigated (4 *MADS* factors x 3 Satisfaction factors), however only six of these models showing significant relationships are described in detail.

In Model 1 the *MADS* factor of *Deferring Responsibility* and the *Decision Outcome Satisfaction* (*PTDS*) were found to be significantly related (p = 0.031). In addition, the predictors for *Decision Outcome Satisfaction* in the model were if women were professionals (p = 0.002) and their satisfaction with the psychological support (p = 0.003) they received. Those women who were more satisfied with the psychological support they received were more satisfied with their decision outcome (regression coefficient ß = 0.041). Whereas, professional women were less satisfied with the outcome of their decision (regression coefficient ß = -0.069) at 3 to 4 months. Model 1 (see Table 54) details the multivariate analysis of the *MADS* decision style *Deferring Responsibility* and women's *Decision Outcome Satisfaction* at three to four months.

Table 54 Model 1: Deferring Responsibility (MADS) and women's Decision Outcome Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months (n = 104).

Influencing variable	Regression coefficient (β)	95%-confidence interval	p-value
Deferring Responsibility	0.034	(0.004, 0.063)	**p = 0.025**
Satisfied with psychological support	0.041	(0.016, 0.066)	**p = 0.018**
Being a professional	-0.069	(-0.116, -0.023)	**p = 0.004**

Multiple *R* = 0.52; adjusted for the confounding effects of age and household income per person in household

In Model 2 the *Deferring Responsibility* decision styles was significantly related with the global satisfaction (p = 0.011). The satisfaction with the emotional (regression β= 0.039, p = 0.011) and informational support (regression coefficient β= 0.046, p = 0.013) received, was positively related to the *Global Decision Satisfaction* of the women and acted as statistically significant predictor. Women who were professionals (see Table 55) were less satisfied with their global decision (regression coefficient β= -0.057, p = 0.010). Table 55 provides details of the *Deferring Responsibility* decision style (*MADS*) and women's overall *Global Decision Satisfaction* at three to four months.

Table 55 Model 2: Deferring Responsibility (MADS) and women's Global Decision Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months (n = 104).

Influencing variables	**Regression coefficient (β)**	**95%-confidence interval**	**p-value**
Deferring Responsibility	0.037	(0.009, 0.065)	**p = 0.011**
Satisfied with emotional support	0.039	(0.011, 0.067)	**p = 0.008**
Satisfied with informational support	0.046	(0.010, 0.081)	**p = 0.013**
Being a professional	-0.057	(-0.100, -0.014)	**p = 0.010**

Multiple *R* = 0.56; adjusted for the confounding effects of age.

The *MADS* factor *Avoidance* was a significant influencing variable for the women's global satisfaction (p = 0.007). Women more satisfied with their global decision were more likely to score lower on *Avoidance* (regression coefficient ß = -0.030). Satisfaction with the emotional support (p = 0.005) and the information received (p = 0.005) were significantly related variables with *Global Decision Satisfaction*. *Global Decision Satisfaction* was negatively related to education (regression coefficient ß = -

0.051). Those who were more educated were less satisfied with their global decision (p = 0.003). Table 56 outlines Model 3 results of multiple linear regression analysis between the decision style factor of *Avoidance* (*MADS*) and women's *Global Decision Satisfaction* (*PTDS*) at three to four months.

Table 56 Model 3: Avoidance (MADS) and women's Global Decision Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to months (n = 104).

Influencing variables	**Regression coefficient (β)**	**95%-confidence interval**	**p-value**
Avoidance	-0.030	(-0.051, -0.008)	**p = 0.007**
Satisfied with emotional support	0.041	(0.013, 0.070)	**p = 0.005**
Satisfied with informational support	0.051	(0.016, 0.086)	**p = 0.005**
Education: Grade 12 or higher	-0.051	(-0.084, -0.018)	**p = 0.003**

Multiple $R = 0.58$; adjusted for the confounding effects of marital status, religion, and chemotherapy.

The decision style of *Information Seeking* was identified as a significant predictor for women's satisfaction with their decision process (p = 0.011). Higher *Decision Process*

Satisfaction was identified in those women with higher *Information Seeking* scores (regression coefficient ß = 0.030). Other relationships revealed in the regression analysis, were that those women who were satisfied with the emotional (regression coefficient ß = 0.048, p = 0.014) and physical support (regression coefficient ß = 0.039, p = 0.021) they received were more satisfied with their process of treatment decision-making. Model 4 (see Table 57) details the multiple linear regression analysis between the decision style factor of *Information Seeking* (*MADS*) and women's *Decision Process Satisfaction* (*PTDS*) at three to four months.

Table 57 Model 4: Information Seeking (MADS) and women's Decision Process Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months (n = 104).

Influencing variables	**Regression coefficient (β)**	**95%-confidence interval**	**p-value**
Information Seeking	0.030	(0.007, 0.053)	**p = 0.011**
Satisfied with emotional support	0.048	(0.010, 0.085)	**p = 0.014**
Satisfied with physical support	0.039	(0.006, 0.073)	**p = 0.021**

Multiple *R* = 0.55; adjusted for the confounding effects of educational level, chemotherapy, and global psychological distress score at 3-4 months.

Deliberation was identified as a significant predictor for women's satisfaction with their decision outcome (p = 0.019). Those women satisfied with their decision outcome were more likely to achieve a higher *Deliberation* score (regression coefficient ß = 0.036). More satisfaction with informational support was positively related to women satisfaction with decision outcome (regression coefficient ß = 0.063, p <0.001). Higher educated women were less satisfied with their decision outcome (regression coefficient ß = -0.049, p = 0.003). Table 58 outlines the regression analysis for Model 5 between decision style factor *Deliberation* and women's *Decision Outcome Satisfaction* at three to four months.

Table 58 Model 5: Deliberation (MADS) and women's Decision Outcome Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months (n = 104).

Influencing variables	Regression coefficient (β)	95%-confidence Interval	p-value
Deliberation	0.036	(0.006, 0.065)	**p = 0.019**
Satisfied with informational support	0.063	(0.029, 0.096)	**P < 0.001**
Education: Grade 12 or more	-0.049	(-0.081, -0.017)	**p = 0.003**

Multiple *R* = 0.51; adjusted for the confounding effects of psychological distress score *Somatization* at 3-4 months follow-up.

Avoidance was identified as a significant predictor for women's satisfaction with their decision outcome (p = 0.001). A higher satisfaction with decision outcome occurred when women received a lower *Avoidance* score (regression coefficient ß = -0.034). Significant positive relationships were found between women's satisfaction with their decision outcome and their satisfaction with the informational (regression coefficient ß = 0.048, p = 0.008) and physical support (regression coefficient ß = 0.033, p = 0.010) they received. Those women with less education had higher satisfaction with their decision outcome (regression ß = -0.053, p = 0.001). The details of the multiple linear regression analysis between the *MADS* decision style factor of *Avoidance* and women's *Decision Outcome Satisfaction* at three to four months are presented in Table 59.

***Table 59 Model 6: Avoidance (MADS) and women's Decision Outcome Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months* (n = 104).**

Influencing variables	Regression coefficient β	95%-confidence Interval	p-value
Avoidance	-0.034	(-0.054, -0.014)	**p = 0.001**
Satisfied with informational support	0.048	(0.013, 0.082)	**p = 0.008**
Satisfied with physical support	0.033	(0.008, 0.058)	**p = 0.010**
Education: Grade 12 or more	-0.053	(-0.085, -0.021)	**p = 0.001**

Multiple $R = 0.58$; adjusted for the confounding effects of psychological distress score *Somatization* at 3-4 months follow-up and whether or not the woman believed in God.

Based on the results of the modelling process it was concluded that the women's decision styles (*MADS*) were related to their decision satisfaction (*PTDS*) for surgical treatment selection for early breast cancer. A relationship was found between women's decision styles and their decision satisfaction. Therefore, the null hypothesis was rejected and the alternative hypothesis was accepted.

In summary the most important finding in this research was demonstration of a relationship between women's decision styles (*MADS*) and decision satisfaction

(*PTDS*) at three to four months following early breast cancer treatment. Women who received a high score in the *MADS* factor *Avoidance* were more likely to experience increased *Anxiety and Global Distress (GSI)* than other women prior to initial treatment. More than 50% of women indicated they were satisfied with their treatment decision. Women who experienced increased *Somatization* distress post-treatment were less likely to be satisfied with their treatment decision-making. The next chapter discusses the interpretation of these analyses; recommendations for further research; and clinical implications for the discipline of nursing science.

CHAPTER 5-DISCUSSION

Introduction

Integrating previous chapters, this final chapter presents a synthesis and discussion of the findings and an analysis of the contribution of the study to nursing science, and recommendations for practice and for further research. This Australian research is the first internationally to examine the relationship between women's decision styles and decision satisfaction when they are faced with choosing a treatment option for early breast cancer. This research is important and has critical implications for the development of evidence-based decision support interventions given to women by nurses. The understanding of this relationship is paramount in determining the utility of the Michigan Assessment of Decision styles (*MADS*) (Pierce, 1995a) instrument in indentifying those women at risk of experiencing post-decision dissatisfaction following treatment for early breast cancer. Post-decision dissatisfaction can ultimately lead to post-decision regret and varying degrees of physical and psychological morbidity and psychological distress.

To date, there are no published studies using the *MADS* instrument. From personal discussion with Pierce (personal communication, October 11, 2000), this is the first study to use the *MADS* instrument in a prospective design in a sample of women with breast cancer. As no other appropriate instrument was available to measure post-decision satisfaction the researcher developed the Patients' Treatment Decision Satisfaction (*PTDS*) questionnaire for this study. Preliminary reliability measurement (Cronbach's alpha $\alpha = 0.95$) was strong; however, further psychometric testing is needed in a larger sample to confirm the instrument's reliability and validity.

The unique, major finding of this study is evidence for statistically significant relationships between Queensland women's decision style (*MADS* factors: *Information Seeking*; *Deliberation*; *Avoidance*; and *Deferring Responsibility*) and their decision satisfaction (*Patient Treatment Decision Satisfaction*) following early breast cancer diagnosis. The *Patient Treatment Decision Satisfaction (PTDS) questionnaire* is comprised of the following dimensions: *Decision Process Satisfaction* and *Decision Outcome Satisfaction* with a *Global Decision Satisfaction* score. The *MADS* was assessed at baseline and the *PTDS* 3 to 4 months after initial surgical treatment for early breast cancer. The discussion of the present study exclusively focuses on the results relating to the independent and dependent variables of the hypotheses, namely: women's decision styles (*MADS*) and decision satisfaction (*PTDS*).

The chapter plan is organised under seven section headings. Initially the sections examined are: *Michigan Assessment of Decision Styles*; and the individual *MADS* factors of 1) *Avoidance*; 2) *Deferring Responsibility*; 3) *Information Seeking;* 4) and *Deliberation*. A section on Decision Satisfaction is then presented followed with Research Limitations. This final chapter then leads to its closure with sections on Clinical Implications; Further Research; Contribution to the Discipline of Nursing; and, finally, the Conclusions.

Michigan Assessment of Decision Styles (MADS)

A thorough examination of the existing literature, did not identify any published studies using the *MADS* instrument, and therefore direct comparisons with the current study will relate to the researcher's previous study in a sample of 377 Australian women undergoing routine mammography screening (Budden et al., 2007; Budden et al., 2003). Surprisingly, in contrast to the previous findings, age was not found to be correlated with any of the *MADS* factors in the present study. Instead, the results suggest that, when women are diagnosed, their decision styles, psychological response, and preferences for early breast cancer treatment may be very similar regardless of their age. Thus, when women are choosing a treatment, the treatment selected may be more related to their perception of the best surgical option or the option they believe is more likely to lead to a cure and a good quality of life. This conclusion is further supported in the present study, where the majority of women indicated it was critically important to know if the cancer would return; a finding that has been similarly reported in other studies (Budden et al., 2007; Meyer, Talbot, & Ranalli, 2007).

Interestingly, significant correlations were identified between the women's treatment location and *MADS* factors. Women living in smaller regional centres indicated that they required more information and generally scored higher in the decision style factor *Deliberation*. A plausible explanation is that one of the two smaller regions contains a radiation oncology unit, and thus allows women to choose surgical treatment without travelling excessive distances. However, in the other smaller regions without facilities to provide radiation oncology, women carefully deliberated the trade-offs and consequences for each option, in terms of cost, time and travel required away from home. Subsequently, most of these women chose mastectomy surgery, which may not have been their original preferred option.

Referring again to the distinction between decision support interventions and decision aids. The current models of generic decision aids have been found to help patients' involvement in treatment decisions but they have little effect on their decision and satisfaction (O'Connor et al., 2001). Therefore, the development of customised decision support interventions is imperative and these are now only in early evolution in nursing science from generic decision aids. Decision support interventions are designed to be patient and condition specific and facilitate treatment decisions linked with post-treatment decision satisfaction.

MADS Factors

Avoidance

This research found only a small proportion of women scored high on the decision style factor of *Avoidance* which was only slightly lower than in the sample of women undergoing routine mammography screening (Budden et al., 2007). Women who scored high on this factor had an interesting socio-demographic profile: in general having a lower education level. It is proposed that these women may have felt overwhelmed by the diagnosis and medical language and preferred not to engage in the decision-making process with their doctor.

More importantly, these women also experienced high levels of psychological distress following their breast cancer diagnosis, as measured by the *Brief Symptom Inventory-18* (*BSI-18*) at baseline. Women who indicated they used this decision style (*MADS* factor of *Avoidance*) seemed to be very anxious *(Anxiety* and *GSI BSI-18*) and overwhelmed with the impact of the diagnosis and preferred not to participate in the treatment decision process. The feelings of uncertainty and emotional stress seemed almost to evoke a panic response (Pierce, 1988; Pierce, 1993) where these women desired to escape the treatment choice dilemma. These women's *Avoidance* behaviour may have helped them to cope shortly after diagnosis. However, previous breast cancer studies suggest that this generalised avoidance coping behaviour by women may be a predictor for maladjustment through the cancer trajectory (Stanton et al., 2000; Stanton, Danoff-Burg, & Huggins, 2002).

Furthermore, a negative relationship was found between the *MADS* factor *Avoidance* and women's Decision Satisfaction (*Decision Outcome Satisfaction* and *Global*

Decision Satisfaction). Therefore, the women who obtained high scores of the *MADS* factor *Avoidance* were more likely to be dissatisfied with the treatment decision and consequently experience post-decision regret. This decision dissatisfaction and post-decision regret could increase women's distress levels and their propensity to develop long-term psychological illnesses such as anxiety and depression.

The psychological responses of women who scored high on the *Avoidance* decision style factor are similar to that which has been described by Janis and Mann (1977) as the, "Defensive Avoidance" coping pattern, or as documented in the stress and coping literature as, "Denial or Avoidance" behaviour (Lazarus & Folkman, 1984). The psychological distress and severe emotional impact experienced by these women (high score in *MADS* factor *Avoidance*), coupled with the uncertainty of treatment outcomes, may induce a subconscious psychological shutdown mechanism, to avoid any further threatening stimuli (Janis & Mann, 1977; Lazarus & Folkman, 1984). Consequently, findings suggest these women do not engage in the decision-making process by using problem-focused coping methods but use emotion-focused coping strategies instead (Lazarus & Folkman, 1984).

It is well documented that women, following the penetrating shock of a breast cancer diagnosis and the subsequent cognitive overload, women often experience attention fatigue (Cimprich, 1999; Cimprich et al., 2005). For these women, after a diagnosis of breast cancer the inability to process and remember information, can lead to further psychological distress (Cimprich, 1999; Cimprich et al., 2005). In addition, these women prefer not to know about the possibility of unexpected consequences and feel they do not have control over future events related to treatment outcomes (Pierce, 1993; Reaby, 1998a).

Based on the findings of this research it is, therefore, useful for nurses, when caring for women in the cohort scoring higher in the *Avoidance* factor, to implement emotional psychological distress-reducing interventions, prior to attempting to engage these women in the decision-making process with their doctor. Furthermore, the development of rapport or close professional relationship between nurses and women is of primary relevance to help women dispel any misconceptions about the aetiology and treatment of breast cancer, which are often expressed by women (Arman, Backman, Carlsson, & Hamrin, 2006).

Given the relationship between *Avoidance* as a decision style (*MADS* factor) and psychological distress, it is proposed that women who score on the decision styles factor require a complete psychological assessment, to identify those women ‘at risk’ of developing other disorders (such as anxiety and/or depression). Other measurements such as instruments assessing fatigue, (which often remains undetected) are also important. Fatigue can be closely associated with depression and anxiety and is reported in many other cancer studies (Bender, Ergyn, Rosenzweig, Cohen, & Sereika, 2005; Tchekmedyian et al., 2003). Thus, fatigue can be a compounding factor but, whatever the source of the fatigue; nurses need to address this issue with women. Developing evidence suggests women’s pre-surgical psychological state predicts those women at risk of developing psychological morbidity and psychiatric disorders (Dean & Surtees, 1989), up to 12 months following surgery (Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Stanton et al., 2002). Nurses can use the *MADS* (Pierce, 1995a) instrument to identify women who score high on the *Avoidance* decision style factor and refer them if appropriate, for pre- and post-operative psychological screening assessment and management.

In decision science, it is generally accepted that a pre-requisite to achieve quality decisions is that individuals to carefully consider and evaluate each alternate choice (Baron, 2000; Janis & Mann, 1977). Women who prefer not to be involved in the choice dilemma of treatment do not comprehensively appraise the possible risks and outcomes of each option and thus are frequently dissatisfied with the consequences of treatment (Pierce, 1993). Although, only a few women in this research obtained high scores on the *Avoidance* decision style factor, a larger sample (increase in statistical power) may confirm the strength of the trends in pre-identified in pre-decision behaviour in future studies.

Deferring Responsibility

The majority of the women in the study obtained a high score in the decision style factor *Deferring Responsibility*. Most of these women wanted to make a decision and have treatment as soon as they understood their options. In contrast to previous research examining women who were screened for breast cancer (Budden et al., 2003), participants' socio-demographic profiles were not found to be associated with this decision style factor. Consequently, it can be argued that, following diagnosis, most women in this high scoring cohort prefer to play a passive role in treatment decision-making; such an argument is supported in studies of other breast cancer women (Degner et al., 1997; Degner & Sloan, 1992). A possible explanation for this finding is that when women are confronted with the psychological assault of a life threatening illness in an effort to conserve their cognitive resources they rely on the doctor as the perceived expert to guide their treatment decisions. This process has been described by Simon (1957) in his seminal theory of "bounded rationality" as "satisficing", where decision makers accept the first choice which meets most of their expectations (Newell & Simon, 1972).

Women obtaining a higher score on the *Deferring Responsibility* factor usually experience less psychological distress, compared to women scoring high on the other *MADS* factors. These findings are consistent with the original Grounded Theory analysis by Pierce (1985) of the Deferrer decision style. This efficient heuristic process seems to shortcut the decision-making experiences, decreases women's cognitive load and aids their emotional adjustment (Pierce, 1985, 1988; Pierce, 1993). However, it has been documented that adopting these mental shortcuts can ultimately lead to errors in decision-making (Thomas, Wearing, & Bennett, 1991; Tversky & Kaheman, 1974).

Women who make the decision to give treatment responsibility (*Deferring Responsibility*) to the doctor allow themselves to avoid decisional conflict, and conserve their time and cognitive energy, to focus on emotionally coping with the illness. This response is similar to the coping pattern called "Unconflicted Adherence" (Janis & Mann, 1977). It seems for many of these women; it is deemed not important to perform thorough information searches about each treatment option, as these women may actually prefer to have limited information. Most of these women perceived not being involved in the treatment decision; this perception is reported also in international (Pierce, 1985, 1988; Pierce, 1993) and Australian studies of women after a diagnosis of breast cancer (Reaby, 1998a). The women in this group seldom remember the first consultation with their doctor/surgeon because of their emotional overload which affects their cognitive information processing system and memory (attention overload) (Cimprich, 1999; Pierce, 1988).

Internationally, it remains unknown how patients choose between equally effective medical treatments. This discrepancy may relate to lack of experience and knowledge by the women in choosing between equally effective medical treatment (such as mastectomy and breast conservation surgery). Furthermore, each of the treatments has some predictable, but also uncertain undesired outcomes, and women may subconsciously reduce their decision conflict by preferring to make a decision collaboratively with their doctor.

The relationship with their doctor is critically important to the cohort of women who obtain a high score on the decision style factor *Deferring Responsibility*. Women overwhelmingly supported the importance of trust in the relationship with their doctors (Henman, Butow, Brown, Boyle, & Tattersall, 2002; Kraetschmer, Sharpe, Urowitz, & Deber, 2004). In addition, the support role of nurses following women's diagnosis and treatment for early breast cancer cannot be overstated. Women who prefer limited information are often those who intuitively choose the most salient or attractive treatment without consideration of other options (Pierce, 1988; Pierce, 1993). This finding was supported in this research, where women who scored high on the *Deferring Responsibility* factor (as assessed by *MADS*) were also found to have lower levels of psychological distress (as assessed by the *BSI-18*) at baseline; a result which is consistent with the findings of Pierce (1988) in respect to the Deferrer decision style.

Women who made the decision to give the doctor the treatment responsibility and follow their recommendation (high scores in the *Deferring Responsibility* factor) require nurses to assist them to verbalise their fears and feelings about breast cancer, and clarify their values related to treatment options. This decision support facilitates the information processing of these women and allows them to access their ability to cognitively attend to crucial information, such as the consequences of each treatment offered (Pierce, 1988; Pierce, 1993). The emotional support received from nurses and the physical support provided by others, throughout the breast cancer trajectory, plays a pivotal role for these women and influences their levels of decision satisfaction.

Women's decision satisfaction was found to be positively correlated with the *Deferring Responsibility* factor. Two of the regression models indicated the cohort of women who scored high on the *MADS* factor *Deferring Responsibility* were more satisfied (*Decision Outcome Satisfaction* and *Global Decision Satisfaction*) than other women with the treatment decision. The majority of the women in the study were high scorers in the *Deferring Responsibility MADS* factor and indicated it was important to trust their doctor. Therefore, these women probably felt they were inexperienced in this area of treatment decision-making would have better outcomes if they followed their doctor's advice (perceived expert). The women's faith in their doctor's knowledge and experience may have lead them to be satisfied with the outcome of the treatment decision, as they may believe their own decision may have had worse consequences.

Women who preferred to defer the decision responsibility and accept the treatment recommendation from their doctor were more satisfied with their decision-making. These results support the argument that once women choose to hand over the control of the decision-making to the expertise of the doctor, they accept the consequences of their treatment decision in the short term. However, doctors may have different values to women at the time of decision-making, and the treatment choice may not serve the women's needs in the long-term (Pierce, 1993).

Information Seeking

Women who scored high on the decision style factor of *Information Seeking* were evenly distributed between the surgical treatments. Many women who chose mastectomy surgery believed that removing the breast is more likely to lead to a cure for breast cancer, and this belief has been reflected in other Australian studies (Reaby, 1996, 1998a). The reasons women in the present study chose their initial treatment was not the focus of the study, and therefore specific data were not collected about the reasons for their decision, but about the relationship between decision style and decision satisfaction.

Well-educated women, those who were employed, and those with a higher household income were vigilant in finding information and took active control of the treatment decision with their doctor. These women are usually familiar with accessing information from various sources such as the internet, as well as reading and understanding detailed medical information. These women need guidance from nurses to identify the locations of accurate and comprehensive treatment information.

When women were surveyed in this study, they had received various types of information given to them by their doctors. The public hospital sites were serviced by a part-time Specialist Breast Care Nurse (SBN) using the protocol devised by the National Breast Cancer Centre (NBCC) and women received the recommended information book from the NBCC (National Breast Cancer Centre, 1996, 2003b). Women, who had elected treatment as private patients, may or may not have received the NBCC book (National Breast Cancer Centre, 1996, 2003b), depending on the surgeon they consulted. Many women in the private system were not referred or given information about Specialist Breast Nurses until the researcher provided support contacts (including the Cancer Council of Queensland) following the baseline-structured interview. Therefore, these women, when first recruited into the study, usually had fragmented pieces of information about treatment options for their cancer. Australian research has demonstrated a disparity currently exists between the type and amount of information needed by individual women and the education they receive from doctors and nurses (Steginga et al., 1998; Wilkes, White, Beale, Cole, & Tracy, 1999; Williams et al., 2002).

Nurses play a key role in information brokering by providing women with further explanation about the outcomes and possible consequences of breast cancer treatment, after they have consulted doctors. This role is emphasised in the professional nursing standards from the international body, International Council of Nurses (ICN) (International Council of Nurses, 2004) and the Australian Nurses and Midwifery Council (ANMC) (Australian Nursing and Midwifery Council, 2003). Women have a preferred style and differences in respect to the type and amount of information they want in order to choose a medical treatment option. There is strong evidence, however, that effective communication impacts on patients' decision-making, psychological adjustment and satisfaction in the treatment trajectory (Devine & Westlake, 1995; Hathaway, 1986; Johnston & Voegele, 1993).

Women diagnosed with breast cancer cite a preference for communication that is conveyed in an individual, positive, and accurate way. It is also important to women they are informed about the emotional aspects of the disease and its treatment (National Health and Medical Research Council National Breast Cancer Centre, 2000; Women's perspectives sub-group NHMRC Working Party, 1994) and nurses can provide informational, emotional and practical support to these women. If women have problems communicating with their doctor and other team members they may have difficulty understanding the information and this could also contribute to their anxiety and depression (Lerman et al., 1993), coping and psychological adjustment (McWilliam, Brown, & Stewart, 2000). Most women, not all, ask for compact information about breast cancer treatment, which is accurate and comprehensive. This finding was also indentified in a previous study of women undergoing routine mammography screening where only a third of women strongly agreed to all the *Information Seeking* items (Budden et al., 2003). These findings reinforce the importance of nurses' assessment of the amount and type of information women prefer before the provision of copious amounts of indiscriminate treatment material. In addition, it is necessary for the nurses to assess women's understanding of the treatment options and related consequences.

Women in the current study identified the importance of support, which was positively related to their decision satisfaction. Women's psychological adjustment is improved when they feel well supported (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Davis, Williams, Parle, Redman, & Turner, 2004). Special Breast Care Nurses help women recall information and help reduce their psychological morbidity (P. Maguire, Tait, Brooke, Thomas, & Sellwood, 1980; McArdle, 1996; Watson, Denton, & Baum, 1998). Unfortunately, in Australia at the current time the small numbers of Specialist Breast Nurses (employed nationwide) translates to many women being unable to benefit from accessing the valuable resources provided by these nurses (Campbell, Khan, Rankin, Williams, & Redman, 2006).

Women who made the decision to give the doctor the treatment responsibility and follow their recommendation (high scores in the *Deferring Responsibility* factor) were on average satisfied with their decision process. These data suggest if women feel they have received the information they required to make a treatment decision, they are satisfied they have made an informed decision. This result may explain why many of the women were satisfied with the information they received when deciding on treatment and these women did not have post-decision regrets. Unfortunately, due to the dearth of studies investigating the phenomenon of patient decision satisfaction, comparisons with other literature is difficult. Clearly, further research is needed to address this important, neglected aspect of the cancer patient experience.

Women in higher socio-economic groups and without a personal history of cancer were high in *Information Seeking*. Many of these women are well educated and familiar with accessing and reading technical and scientific information. Whereas, women without a personal history of cancer and are inexperienced in making these types of treatment decisions and require accurate information about each option to make an informed decision. It is recommended by the National Medical and Research Council (NHMRC) that doctors need to provide the following information to achieve informed consent for patients having medical treatment namely: to fully inform patients about their diagnosis, prognosis and treatment options, and to provide accurate (National Health and Medical Research Council, 1993) clinical information about the consequences of treatment.

Women in the high scoring cohort of *Information Seeking* prefer to develop a plan for finding more information as well as reading magazines and scientific articles (Pierce, 1995b). The decision hazard for these women is they can become confused, exhausted and overwhelmed by the process of gathering and confirming treatment information (Pierce, 1993). A key decision support role for nurses is to help women develop and plan a strategy for finding further information, which helps to reduce their decision conflict and aids their decision-making. Nurses can primarily intervene to assist women to verbalise and identify the type of information they require by referring them to the best support agencies and websites (such as the National Breast Cancer Centre and the Australian Cancer Society). As well as determining information preferences, nurses need to assess a woman's understanding of information provided to discriminate between treatment options, and their ability to problem solve before a treatment action plan is developed.

There is mounting literature about the differences presentation and framing of medical treatment outcomes can make to women (Siminoff & Fetting, 1989;

Zimmermann, Baldo, & Molino, 2000); as patients (Llewellyn-Thomas, McGreal, & Thiel, 1995; O'Connor, 1989), when they are making choice decisions. Some women may prefer information presented in quantitative statistical terms (such as probabilities), while others prefer non-probabilistic and qualitative information (Man-Son-Hing et al., 2002; O'Connor, 1989) about treatment options. Nurses need to assess women's understanding and preference for the amount and type of information and their ability to problem solve before an action plan is developed. Subsequently, the action plan by nurses needs to be developed in collaboration with women to facilitate their informed treatment decision-making.

Deliberation

A small proportion of women received a high score in the decision style factor of *Deliberation* and this fraction was lower than the results found in the previous study of women undergoing routine mammography screening (Budden et al., 2003). Previous research using different instruments to measure women's preferences for involvement in breast cancer decision-making have also found that only a small number of women wanted an active role in decision-making (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner et al., 1997). This cohort of women wants to take full responsibility and seem to operate from an internal locus of control. This decision-making style *Deliberation* resembles the coping pattern described in the literature as “Vigilance” (Janis & Mann, 1977). A ‘Vigilant’ decision maker engages in a systematic information search to make a quality decision and reduce their decision conflict. The cohort of women who scored higher on this decision style factor of *Deliberation* thoroughly examines each option treatment and possible consequences with their personal value system. These women collect exhaustive amounts of information regarding the possible risks and adverse reactions for each treatment (Pierce, 1988).

The cohort of women who score higher on the *Deliberation* factor tend to be younger (although not statistically significant in this sample) and active in the treatment decision-making. Other studies of cancer patients have confirmed this trend (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Degner & Russell, 1988; Pierce, 1988; Pierce, 1993) which describes changes in societal demographics and attitudes, where younger people are generally more educated and informed, and want more control in medical care decisions. This higher scoring cohort of women in the decision style factor *Deliberation* also require frequent access to their doctor and permission to take their time to read scientific information to inform their decision-making and make a quality decision (Pierce, 1988). Women who score higher in respect to this decision style factor (*Deliberation*) need to evaluate each option and its uncertainty with their family to reduce the degree of decision conflict. Women who score high in respect to the *Deliberation* factor were usually more satisfied with the outcome of their decision. Further, women who score high in respect to the *Deliberation* factor were usually more satisfied with the outcome (*Decision Outcome Satisfaction*) of their decision. This cohort of women probably felt they had been able to obtain the information and their preferred level of control to make an informed treatment decision.

Based on the findings on this research nurses may provide women (who score high on *Deliberation*) with instrumental and emotional support, as these women can be the most complicated in planning structured decision support interventions. The *MADS* instrument can be used to assess women's decision styles and their required decision support interventions. Nurses can also help women develop a plan for finding information about the risks and possible outcomes in respect to each treatment option (Pierce, 1988). Women who are in the cohort of high scores on the *Deliberation* decision style factor often want to meet and talk to breast cancer survivors before choosing a treatment. Nurses need to refer these women to the Breast Cancer volunteers available through the Australian Cancer Councils and State Cancer Councils.

Decision Satisfaction

Just over half of the women reported being very satisfied with their process, outcome, and global satisfaction for decision-making and perceived they had sufficient time to make their decision. This result is consistent with other findings (Degner et al., 1997; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002) where approximately half of women's involvement matched their desired participation in the decision-making process. Interestingly, no significant relationships were found between treatments and decision satisfaction scores. However, the majority of women at least agreed to being satisfied with their decision. Women's perception of satisfaction may be influenced by a psychological process described by Festinger (1957) as "cognitive dissonance". After a decision is made, the decision maker can experience dissonance. In an effort to reduce cognitive dissonance, an individual (or decision maker/s) subjectively evaluates their decision in a biased manner to support their action and regain internal psychological equilibrium.

Decision Process Satisfaction was found to be significantly positively associated with the support received by these women. In the literature the support received by women is frequently cited by women as important (Thewes, Butow, Girgis, & Pendlebury, 2004; Turner, Hayes, & Reul-Hirche, 2004; Turner, Kelly, Swanson, Allison, & Wetzig, 2005; Turner, Zapart et al., 2005; Wilkes et al., 2002). However, the measurement of the phenomenon of decision satisfaction is difficult, complex, and affected by other factors such as the outcomes and unexpected consequences of treatment. Such as, women indicating they were not affiliated with any religious congregation but thought is was important to believe in God in guiding the treatment decision. Other mediating factors on decision satisfaction may be women's personality factors or alternatively dispositional optimism (Carver et al., 2005; Johnson et al., 1996) emotional support received (P. N. Butow et al., 2000); relationship with their doctor (McWilliam et al., 2000); personal history and experience (Pierce, 1988; Pierce, 1993); and quality of life concerns (Sammarco, 2001a, 2001b, 2003). The measurements of these other mediating variables were outside the confines of the research, and therefore discussion of these factors is only speculative, at best, and not included. Such as women indicating they were not affiliated with any religious denomination but thought it was important to believe in God in guiding the treatment decision. Given the lack of systematic research that focuses beyond the initial treatment period, more longitudinal studies are needed in an effort to gain a better understanding of the long-term consequences and satisfaction levels of these women with respect to their treatment decision for early breast cancer.

Decision styles (*MADS*) in this study were identified to be important factors related to women's decision satisfaction. All the decision style factors were found to be related to some aspect of the dimensions of women's satisfaction. Specifically, a positive relationship was identified between women's *Information Seeking* and *Decision Process Satisfaction; Deliberation* and *Decision Outcome Satisfaction; Deferring Responsibility* and *Decision Outcome Satisfaction;* and *Deferring Responsibility* and *Global Decision Satisfaction*. In contrast, a significant negative relationship was found between women's *Avoidance* and *Global Decision Satisfaction*. Therefore, a relationship has been found between the *MADS* factors and women's decision satisfaction which supports the use of the instrument to aid the development of evidence-based nursing interventions.

Women who experienced psychological distress symptoms (*Somatization* and *GSI*) following treatment were less satisfied with their process of decision-making. The timing of data collection occurred when many women would be still recovering from their initial surgery and may still be undergoing adjunctive treatment, and associated adverse reactions. Consequently, a "hindsight bias" (Fischhoff, 1975, 1982) may occur for women evaluating their choice at this time. The suffering of the consequences of their treatment by women may overshadow and influence their satisfaction perception.

However, the impact of the type of breast surgery on women's psychological state is less clear. There are inconsistent findings in the literature related to the psychological effects of mastectomy surgery and breast conservation surgery. Some studies have indicated that women who have chosen breast conservation surgery have a better quality of life (Al-Ghazal et al., 2000); and that breast reconstruction had psychological benefits for women (Al-Ghazal, Fallowfield, & Blamey, 1999a, 1999b).

Other studies have reported no psychological differences between treatments (Maunsell, Brisson, & Deschenes, 1989; Wolberg, 1990). More longitudinal research examining the long-term effects of treatment would provide more data about the needs of women through out their treatment trajectory.

Limitations

Several research limitations deserve mention. These limitations relate to the power of the study (sample size); selection bias; and measurement bias. Firstly, the sample size was relatively small and many non-significant statistical results were identified. No attempt was made to adjust for multiple testing. The statistical power of the study was low because of the relatively small sample size. Using a larger sample size would permit more meaningful comparison among variables and confirm the significance of identified trends. Initially, a sample size of 400 women was calculated using power analysis to detect small differences between variables; however the difficulties with recruitment and time restraints limited the sample size. Thus, the statistical power was lowered and allows only detection of relatively large differences in the data. Also the statistical test results (other than the main hypothesis for which the study was planned) might have been compromised by the issue of multiple testing and lack of power. Caution should be taken when interpreting these results.

Three limitations relating to sample bias exist. The first is the sample was selected using a non-probability method. Therefore, the generalisability of the findings is limited and difficult to extrapolate to the target population of all Australian women with early breast cancer. Furthermore, the women in the study were recruited from three coastal areas of Queensland and may not reflect the decision style and decision satisfaction of women living in rural and remote areas. Many of these women had a high previous history of personal or family cancer. Thus, the second bias in the study flows directly from the cancer history of these women; that is, the incidence of previous cancer reported is likely to be higher than in other populations.

The third is that further selection bias may have occurred related to the referral method of women into the study by surgeons. For instance, on few occasions, women were not referred into the study because the surgeon believed they were too psychologically distressed or too old to be involved in the study. In reality, these women may be those most at risk for psychological morbidity post-treatment and might have had many difficulties engaging in the treatment decision process. Their input in this research may have increased the number of women in the *Avoidance MADS* factor.

When the researcher was meeting with surgeons and seeking their support for referral of eligible women in the study, it became apparent that some did not agree with the National Breast Cancer Centre's definition of early breast cancer. Some surgeons did not agree that a 5cm breast lump was early breast cancer and would consider it as advanced breast cancer. Thus, some women who would have been eligible in terms of the inclusion criteria may have not been referred into the study; or the staging of the women's cancer may have been more advanced following the pathology results received after the surgery. In addition, the majority of women were recruited from the public health system. Women accessing the private health system were under represented in the study and may be living in a higher economic social group, higher educated and more active in *Information Seeking*.

The above-described selection biases might have led to a sample of women that was more homogeneous than the target population. Hence, one could argue that the overall effect of the selection bias was towards the null hypothesis and that therefore the observed differences in the sample were smaller than differences in the target population. If the sample was more homogenous than the target population and if there is a link between MADS and satisfaction of decision making, then one can argue that most extreme cases have been left out of the sample. However if these more extreme cases were included in the sample a stronger relationship between MADS and satisfaction is seen.

Using a structured interview and a self-report questionnaire may have led to measurement bias. In the baseline-structured interview, women may have answered the questions based on what they thought the researcher or research nurse expected. This bias was reduced by the researcher preparing, rehearsing, and coaching the nurse researchers prior to the commencement of data collection. The researcher made regular visits to the sites to monitor the data collection by nurse researchers. In addition, access to data collection occurred at baseline using a structured interview, after many women may have decided on a preferred treatment choice. Consequently, the study may not have completely captured the entire phenomenon of the women's process of unaided decision-making. Another measurement (instrument bias) was the *BSI-18* instrument stem to the item question was altered from, "In the last seven days how much have you been psychological distressed by…" At the baseline measurement, this was altered to, "Since your diagnosis of breast cancer how much you have been psychological distressed by…" and at the subsequent data collection, "In the last three months how much have you been psychological distressed by…" and thus reduces the construct validity of the BSI used in this study.

Clinical Implications

Notwithstanding the above limitations, the present findings suggest that the *MADS* instrument has strong potential clinical implication for nurses and Special Breast Nurses (SBN) in providing decision support to women with early breast cancer. By using the *MADS* instrument nurses can assess women's desire to be involved in the treatment decision-making process; determine the level and amount of information or education required for women and their families; assess women's potential level of psychological distress and refer for specialist support, as appropriate. In addition, by nurses using the *MADS* to profile individual decision support, women's decision satisfaction may be increased. All women need help from nurses in clarifying their treatment values and verbalising their fears about each option, so any misconceptions can be addressed. Nurses also need to screen women for psychological distress following a diagnosis of early breast cancer to identify those at risk of developing post-treatment psychological conditions such as anxiety and depression.

Unfortunately, the BSI-18 (Derogatis, 2000) is a screening tool and only commercially available and therefore not economically viable for use by nurses. However, the National Breast and Ovarian Cancer Centre (2008) have just introduced a psychosocial care referral checklist, which includes identification of some of the known risk factors leading to distress, such those women living alone. This psychosocial checklist is freely available to nurses and is easy and quick to use to help nurses and other health professionals identify women who require referral to special services for management.

Recommendations

The identification of a relationship was found between women's decision styles using the *MADS* (Pierce, 1995a) and their decision satisfaction (PTDS) post treatment. Added to the routine care of women it is recommended nurses use the *MADS* (Pierce, 1995a) instrument prior to women declaring a treatment decision to guide individualised decision support interventions. Also, nurses need to include in this assessment the level of women's psychosocial distress by using the referral checklist (National Breast and Ovarian Cancer Centre, 2008). Nurses can then identify those women who require referral to specialist services for the management of psychosocial distress. For women's profile scores on the decision style factors (*MADS*) the following interventions are recommended:

1. Women who score high in *Avoidance* Factor

   These women require a great deal of emotional support by nurses in dealing and adjusting to the diagnosis. Therefore, nurses need to help women develop effective coping skills before trying to engage them in the decision-making process. Brief targeted information about the risks and outcomes of both mastectomy surgery and breast conservation surgery (BCS) need to be provided to these women by nurses in a non-threatening manner.

2. Women who score high in *Deferring Responsibility* Factor

Nurses need to help these women find a doctor they feel comfortable with and with whom they can have meaningful, honest conversations about their values and lifestyle. Women need assistance in understanding the consequences of each treatment option to determine how these decision choices may affect their quality of life.

3. Women who score high in *Information Seeking* Factor

Women need assistance from nurses in locating the type and amount of information they prefer about treatment options. Nurses need to assess and clarify women’s understanding of the information and refer them to speciality sources such as the National Breast Cancer Centre (NBCC) for further information.

4. Women who score high in *Deliberation* Factor

Women in this cohort need to be informed in detail by nurses about the risks and possible outcomes involved in each treatment option and given scientific information to read. Women need permission to take their time in choosing a treatment and have frequent access to doctors in order to clarify information about each treatment option.

Future Research

Following a diagnosis of early breast cancer the relationship between women's decision style factors and decision satisfaction is not well understood. The science of decision support by nurses can be enhanced through further research designs such as Randomised Controlled Trials (RCT). The next step to extend the knowledge is to develop specific decision support interventions based on women's scores for each of the decision style factors (*MADS*). Assessing and profiling women individually allows a distinctive set of decision support interventions to be delivered by nurses. These specialised decision support interventions could then be evaluated through longitudinal studies determining women's decision satisfaction following treatment over the long-term. In Australia, although the Specialist Breast Care Nurse is a recent initiative, other nurses would best place these nurses in conducting these Randomised Control Trials (RCT) and refining the decision support interventions for the general use.

Contribution to the Discipline of Nursing

One of the roles of the disciple of nursing versus the professional practice of nursing is that the discipline employs the twin filters of research and theory to refine practice and support clinicians (Hayes, 1995). The researcher has achieved this by building on previous research and the findings now offer the clinician a clear pathway to assist women in their pre-treatment decision-making to increase their post-treatment decision satisfaction. These findings are a major contribution to the discipline of nursing. Importantly, they also have utility for application by other disciplines and health professionals.

The researcher discovered despite the developing prevalence of decision aids, finding efficient and effective ways for nurses to assess and provide for women's individual decision support needs, has remained a problem. Current decision aids have been uni-dimensional in nature and have only focused on a "one size fits all" approach related to either education or counselling. The recent evidence collated through a Cochrane systematic review suggests that while these decision aids can increase patients knowledge, they do not increase their decision satisfaction (O'Connor et al., 2003).

The current original research has built on the earlier work of Pierce on decision styles (Pierce, 1995a; Pierce, 1985, 1988; Pierce, 1993) and applied the *MADS* instrument to a sample of Australian women when they were choosing treatment for early breast cancer. In addition, an instrument has been developed by the researcher to determine women's decision satisfaction following medical treatment. Both of these instruments have wider application and could be used in other patient disease groups when they are choosing between medical treatments and to further test reliability and validity. The results of this study contribute to the discipline of Nursing by providing new knowledge and evidence that can be transferred to existing knowledge of nurses so that they can assess women's individually profiles in terms of their decision support needs. This information can be used by nurses to design and deliver decision support interventions to women when they choosing medical treatment for early breast cancer.

As nursing is a practice centred discipline by supporting the clinician this research impacts on the patient who in this case is a distressed woman who has been diagnosed with early breast cancer. Thus this research keeps faith with the central tenet of nursing both as a discipline and as a profession, which is to make a positive difference in the physical and psychological comfort of women with early breast cancer. Nurses take an active role in the provision of information and support to women following a diagnosis of early breast cancer. Women need help from nurses to clarify their preferences and values in choosing a treatment. The *MADS* instrument and the *PTDS* can be used by nurses and Specialist Breast Nurses (SBN) to assess and guide individualised, structured decision support intervention.

Conclusions

The results of this study demonstrate an essential step for building a best practice model for the assessment and delivery of decision support interventions by nurses to breast care patients. The *MADS* (Pierce, 1995a) instrument is an effective, readily available, pre-decision assessment tool which can be used by nurses to guide the decision support interventions delivered to breast cancer patients. The outcomes of these customised decision support interventions are increased decision satisfaction post-treatment.

This thesis has examined the relationship between women’s decision styles and decision satisfaction for treatment of early breast cancer. The literature relating to women's decision-making for early breast cancer treatment has been comprehensively reviewed and identified a largely under explored area in the relationship between women's decision styles and decision satisfaction for early breast cancer. This study has sought to contribute to the growing body of research about women's decision-making. The new knowledge generated from this research contributes to developing evidence-based decision support interventions delivered by nurses.

Although many questions remain, the findings of the study are exciting in their potential application in the clinical setting by nurses. This original research has extended the work of decision styles by Pierce (Pierce, 1995a; Pierce, 1985, 1988; Pierce, 1993). The major outcome of this study is that significant relationships exist between decision styles (*MADS*) and decision satisfaction (*PTDS*) in women with early breast cancer. This unique groundwork study provides support for the use of an efficient instrument (*MADS*) by nurses to profile women's individual decision support needs prior to them declaring a choice for early breast cancer treatment.

This is the first prospective study internationally, using the *MADS* instrument and measuring decision satisfaction conducted on women with early breast cancer. Further randomised control trials (RCT) using the *Michigan Assessment of Decision Styles* (*MADS)* (Pierce, 1995a) and *Patient Treatment Decision Satisfaction* (*PTDS)* (Budden & Pierce, 2001) are ideally suited to be conducted by Specialist Breast Nurses (SBN) to determine the applicability for generalist nurses. Individualised decision support interventions by nurses can help to increase women's decision satisfaction and psychological adjustment following a diagnosis of early breast cancer.

The results of this study demonstrate an essential step for building a best practice model for the assessment and delivery of decision support interventions by nurses to breast care patients. The *MADS* (Pierce, 1995a) instrument is an effective, readily available, pre-decision assessment tool which can be used by nurses to guide the decision support interventions delivered to breast cancer patients. The outcomes of these customised decision support interventions are increased decision satisfaction post-treatment.

REFERENCES

Abu-Nab, Z., & Grunfeld, E. A. (2007). Satisfaction with outcome and attitudes towards scarring among women undergoing breast reconstructive surgery. *Patient Education and Counselling, 66*(2), 243-249.

Adachi, K., Ueno, T., Fujioka, T., Fujitomi, Y., & Ueo, H. (2007). Psychosocial Factors Affecting the Therapeutic Decision-making and Postoperative Mood States in Japanese Breast Cancer Patients who underwent Various Types of Surgery: Body Image and Sexuality. *Japanese Journal of Clinical Oncology*.

Al-Ghazal, S. K., Fallowfield, L., & Blamey, R. W. (1999a). Does cosmetic outcome from treatment of primary breast cancer influence psychosocial morbidity? *European Journal of Surgical Oncology, 25*(6), 571-573.

Al-Ghazal, S. K., Fallowfield, L., & Blamey, R. W. (1999b). Patient evaluation of cosmetic outcome after conserving surgery for treatment of primary breast cancer. *European Journal of Surgical Oncology, 25*(4), 344-346.

Al-Ghazal, S. K., Fallowfield, L., & Blamey, R. W. (2000). Comparison of psychological aspects and patient satisfaction following breast conserving surgery, simple mastectomy and breast reconstruction. *Eur J Cancer, 36*(15), 1938-1943.

Alderman, A. K., Hawley, S. T., Waljee, J., Morrow, M., & Katz, S. J. (2007). Correlates of referral practices of general surgeons to plastic surgeons for mastectomy reconstruction. *Cancer, 109*(9), 1715-1720.

American Cancer Society. (2006). Overview of breast cancer, 2006. Retrieved 17/01/06, from http://www.cancer.org/docroot/CRI/content/CRI_2_2_1X_How_many_people_get_breast_cancer_5.asp?sitearea=

Andrews, G., Hall, W., Teeson, M., & Henderson, S. (1999). *The mental health of Australians*. Canberra: Mental Health Branch, Commonwealth Department of Health and Aged Care.

Andritsch, E., Dietmaier, G., Hofmann, G., Zloklikovits, S., & Samonigg, H. (2007). Global quality of life and its potential predictors in breast cancer patients: an exploratory study. *Support Care Cancer, 15*(1), 21-30.

Andrykowski, M. A., Cordova, M. J., Studts, J. L., & Miller, T. W. (1998). Posttraumatic stress disorder after treatment for breast cancer: prevalence of diagnosis and use of the PTSD Checklist-Civilian Version (PCL-C) as a screening instrument. *Journal of Consulting Clinical Psychology, 66*(3), 586-590.

Arman, M., Backman, M., Carlsson, M., & Hamrin, E. (2006). Women's perceptions and beliefs about the genesis of their breast cancer. *Cancer Nursing, 29*(2), 142-148.

Arving, C., Sjoden, P. O., Bergh, J., Lindstrom, A. T., Wasteson, E., Glimelius, B., et al. (2006). Satisfaction, utilisation and perceived benefit of individual psychosocial support for breast cancer patients--a randomised study of nurse versus psychologist interventions. *Patient Education and Counselling, 62*(2), 235-243.

Aspinal, F., Addington-Hall, J., Hughes, R., & Higginson, I. J. (2003). Using satisfaction to measure the quality of palliative care: a review of the literature. *Journal of Advanced Nursing, 42*(4), 324-339.

Australian Institute of Health and Welfare and National Breast Cancer Centre. (2006). *Breast cancer in Australia: An overview, 2006*. Canberra: Australian Institute of Health and Welfare and National Breast Cancer Centre.

Australian Nursing and Midwifery Council. (2003). Code of professional conduct by nurses in Australia. Retrieved 30/10/2007, from http://www.anmc.org.au/docs/Publications/ANMC%20Professional%20Conduct.pdf.

Back, M. F., & Morgan, G. W. (2000). The rate of breast-conserving surgery in early breast cancer: an audit of surgical practice at St Vincent's campus, NSW in 1990 and 1994. *Australasian Radiology, 44*(1), 60-64.

Back, A.L. (2002). Communicating bad news. *Western Journal of Medicine, 176(3),* 177-180.

Baider, L., Andritsch, E., Uziely, B., Ever-Hadani, P., Goldzweig, G., Hofmann, G., et al. (2003). Do different cultural settings affect the psychological distress of women with breast cancer? A randomized study. *European Journal of Cancer Care (England), 12*(3), 263-273.

Baider, L., Andritsch, E., Uziely, B., Goldzweig, G., Ever-Hadani, P., Hofman, G., et al. (2003). Effects of age on coping and psychological distress in women diagnosed with breast cancer: review of literature and analysis of two different geographical settings. *Critical Reviews of Oncology Hematology, 46*(1), 5-16.

Baider, L., Goldzweig, G., Ever-Hadani, P., & Peretz, T. (2006). Psychological distress and coping in breast cancer patients and healthy women whose parents survived the Holocaust. *Psychooncology, 15*(7), 635-646.

Baider, L., Goldzweig, G., Ever-Hadani, P., & Peretz, T. (2007). Breast cancer and psychological distress: mothers' and daughters' traumatic experiences. *Support Care Cancer*.

Balneaves, L. G., & Long, B. (1999). An embedded decisional model of stress and coping: implications for exploring treatment decision making by women with breast cancer. *Journal of Advanced Nursing, 30*(6), 1321-1331.

Barclay, S., Brown, R. G., Kelly, C. W., Peterson, C. R., Phillips, L. D., & Selvidge, J. (1977). *Handbook for Decision Analysis*. McLean: Decision & Designs Inc.

Baron, J. (1994). *Thinking and deciding* (2nd ed.). New York: Cambridge University Press.

Baron, J. (2000). *Thinking and Deciding* (3rd ed.). Cambridge: Cambridge University Press.

Beaver, K., Luker, K. A., Owens, R. G., Leinster, S. J., Degner, L. F., & Sloan, J. A. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing, 19*(1), 8-19.

Beck, A. T., Steer, R. A., & Garbin, M. G. (1988). Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review, 8*, 77-100.

Beisecker, A. E. (1988). Aging and the desire for information and input in medical decisions: Patient consumerism in medical encounters. *The Gerontologist, 28*(3), 330-335.

Bell, D. E., Raiffa, H., & Tversky, A. (Eds.). (1988). *Decision making: descriptive, normative and prescriptive interactions*. Cambridge: Cambridge University Press.

Ben-Zur, H., Gilbar, O., & Lev, S. (2001). Coping with breast cancer: patient, spouse, and dyad models. *Psychosom Med, 63*(1), 32-39.

Bender, C. M., Ergyn, F. S., Rosenzweig, M. Q., Cohen, S. M., & Sereika, S. M. (2005). Symptom clusters in breast cancer across 3 phases of the disease. *Cancer Nursing, 28*(3), 219-225.

Bilodeau, B. A., & Degner, L. F. (1996). Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology Nursing Forum, 23*(4), 691-696.

Blanchard, C. G., Labrecque, M. S., Ruckdeschel, J. C., & Blanchard, E. B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med, 27*(11), 1139-1145.

Bleiker, E. M., Pouwer, F., van der Ploeg, H. M., Leer, J. W., & Ader, H. J. (2000). Psychological distress two years after diagnosis of breast cancer: frequency and prediction. *Patient Education and Counselling, 40*(3), 209-217.

Bloom, J. R., Stewart, S. L., Johnston, M., Banks, P., & Fobair, P. (2001). Sources of support and the physical and mental well-being of young women with breast cancer. *Social Science Medicine, 53*(11), 1513-1524.

Boyle, F. M., Dunn, S. M., & Heinrich, P. (2003). More than one way to foster communication skills for medical oncology fellows: a national program in Australia. *Journal of Clinical Oncology, 21*(22), 4255.

Bredart, A., Razavi, D., Robertson, C., Brignone, S., Fonzo, D., Petit, J. Y., et al. (2002). Timing of patient satisfaction assessment: effect on questionnaire acceptability, completeness of data, reliability and variability of scores. *Patient Education and Counselling, 46*(2), 131-136.

Brennan, P. F. (1995). Patient satisfaction and normative decision theory. *J Am Med Inform Assoc, 2*(4), 250-259.

Budden, L. M. & Pierce, P.F. (2001). Patient Treatment Decision Satisfaction Questionnaire. Unpublished Questionnaire. School of Nursing Sciences James Cook University Townsville Queensland Australia. Unpublished.

Budden, L. M., Hayes, B. A., Pierce, P. F., & Buettner, P. G. (2007). Australian women's prediagnostic values and influencing sociodemographic variables relating to treatment choices for early breast cancer treatment. *Australian Journal of Cancer Nursing, 8*(1), 9-20.

Budden, L. M., Pierce, P. F., Hayes, B. A., & Buettner, P. G. (2003). Australian women's pre-diagnostic decision- making styles relating to treatment choices for early breast cancer. *Research Theory for Nursing Practice: An International Journal, 17*(2), 1-20.

Burns, N., & Grove, S. K. (2005). *The Practice and Nursing Research: Conduct, Critique, and Utilization* (5th ed.). St Louis: Elsevier Saunders.

Butler, R. G., & Howarth, A. L. (1999). *Out-of-pocket expenses incurred by women for diagnosis and treatment of breast cancer in Australia*. Kings Cross: NHMRC National Breast Cancer Centre.

Butow, P., Cockburn, J., Girgis, A., Bowman, D., Schofield, P., D'Este, C., et al. (2007). Increasing oncologists' skills in eliciting and responding to emotional cues: evaluation of a communication skills training program. *Psychooncology*.

Butow, P. N., Hiller, J. E., Price, M. A., Thackway, S. V., Kricker, A., & Tennant, C. C. (2000). Epidemiological evidence for a relationship between life events, coping style, and personality factors in the development of breast cancer. *Journal of Psychosomatic Research, 49*(3), 169-181.

Campbell, D., Khan, A., Rankin, N., Williams, P., & Redman, S. (2006). Are specialist breast nurses available to Australian women with breast cancer? *Cancer Nursing, 29*(1), 43-48.

Campbell, E.M. & Sanson-Fisher, R.W. (1998) Breaking bad news 3: Encouraging the adoption of best practices. *Behavioral Medicine, 24*(2), 73-80.

Campora, E., Naso, C., Vitullo, M. T., Giudici, S., Camoirano, A., Repetto, L., et al. (1992). The impact of chemotherapy on the quality of life of breast cancer patients. *Journal of Chemotherapy, 4*(1), 59-63.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., et al. (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *Journal of Personality and Social Psychology, 65*(2), 375-390.

Carver, C. S., Smith, R. G., Antoni, M. H., Petronis, V. M., Weiss, S., & Derhagopian, R. P. (2005). Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. *Health Psychology, 24*(5), 508-516.

Charles, C.A., Whelan, T., Gafni, A., Willan., A., & Farrell, S. (2003). Shared Treatment decsion making: What does it mean tp physcians? *Journal of Clinical Oncology, 21*(5), 932-936.

Chen, J. Y., Diamant, A. L., Thind, A., & Maly, R. C. (2008). Determinants of breast cancer knowledge among newly diagnosed, low-income, medically underserved women with breast cancer. *Cancer.*

Cimprich, B. (1992). Attentional fatigue following breast cancer surgery. *Research in Nursing and Health, 15*(3), 199-207.

Cimprich, B. (1999). Pretreatment symptom distress in women newly diagnosed with breast cancer. *Cancer Nursing, 22*(3), 185-194.

Cimprich, B., & Ronis, D. L. (2001). Attention and symptom distress in women with and without breast cancer. *Nursing Research, 50*(2), 86-94.

Cimprich, B., So, H., Ronis, D. L., & Trask, C. (2005). Pre-treatment factors related to cognitive functioning in women newly diagnosed with breast cancer. *Psychooncology, 14*(1), 70-78.

Compas, B. E., Stoll, M. F., Thomsen, A. H., Oppedisano, G., Epping-Jordan, J. E., & Krag, D. N. (1999). Adjustment to breast cancer: age-related differences in coping and emotional distress. *Breast Cancer Research and Treatment, 54*(3), 195-203.

Contant, C. M., van Wersch, A. M., Wiggers, T., Wai, R. T., & van Geel, A. N. (2000). Motivations, satisfaction, and information of immediate breast reconstruction following mastectomy. *Patient Education and Counselling, 40*(3), 201-208.

Coyne, E., & Borbasi, S. (2006). Holding it all together: breast cancer and its impact on life for younger women. *Contemporary Nurse, 23*(2), 157-169.

Craft, P. S., Primrose, J. G., Lindner, J. A., & McManus, P. R. (1997). Surgical management of breast cancer in Australian women in 1993: analysis of Medicare statistics. *Medical Journal of Australia, 166*(12), 626-629.

Davis, C., Williams, P., Parle, M., Redman, S., & Turner, J. (2004). Assessing the support needs of women with early breast cancer in Australia. *Cancer Nursing, 27*(2), 169-174.

Dean, C. (1987). Psychiatric morbidity following mastectomy: preoperative predictors and types of illness. *Journal of Psychosomatic Research, 31*(3), 385-392.

Dean, C., & Surtees, P. G. (1989). Do psychological factors predict survival in breast cancer? *Journal of Psychosomatic Research, 33*(5), 561-569.

Degner, L. (1992). Patient participation in treatment decision making. *Axone, 14*(1), 13-14.

Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., et al. (1997). Information needs and decisional preferences in women with breast cancer. *Jama, 277*(18), 1485-1492.

Degner, L. F., & Russell, C. A. (1988). Preferences for treatment control among adults with cancer. *Research in Nursing and Health, 11*(6), 367-374.

Degner, L. F., & Sloan, J. A. (1992). Decision making during serious illness: what role do patients really want to play? *Journal of Clinical Epidemiologyl, 45*(9), 941-950.

Derogatis, L. R. (1993). *Brief Symptom Inventory (BSI) administration, scoring, and procedures manual* (3rd ed.). Minneapolis: National Computer Systems.

Derogatis, L. R. (2000). *BSI 18- Brief Symptom Inventory 18: Administration, scoring, and procedures manual*. Minneapolis: National Computer Systems Incorporated.

Derogatis, L. R., & Cleary, P. A. (1977). Factorial invariance across gender for the primary symptom dimensions of the SCL-90. *British Journal of Social Clinical Psychology, 16*(4), 347-356.

Derogatis, L. R., & Melisaratos, N. (1983). The Brief Symptom Inventory: an introductory report. *Psychology and Medicine, 13*(3), 595-605.

Derogatis, L. R., Rickels, K., & Rock, A. F. (1976). The SCL-90 and the MMPI: a step in the validation of a new self-report scale. *British Journal Psychiatry, 128*, 280-289.

Devine, E. C., & Westlake, S. K. (1995). The effects of psychoeducational care provided to adults with cancer: meta-analysis of 116 studies. *Oncology Nursing Forum, 22*(9), 1369-1381.

Dolan, N. C., Feinglass, J., Priyanath, A., Haviley, C., Sorensen, A. V., & Venta, L. A. (2001). Measuring satisfaction with mammography results reporting. *Journal of General Internal Medicine, 16*(3), 157-162.

Dunn, J., Steginga, S. K., Occhipinti, S., Wilson, K., & McCaffrey, J. (1998). The profiles of distress in women following treatment for primary breast cancer. *The Breast, 7*, 251-254.

Duric, V. M., Butow, P. N., Sharpe, L., Boyle, F., Beith, J., Wilcken, N. R., et al. (2007). Psychosocial factors and patients' preferences for adjuvant chemotherapy in early breast cancer. *Psychooncology, 16*(1), 48-59.

Early Breast Cancer Trialist's Collaborative Group. (2000). Favourable and unfavourable effects of long-term survival of radiotherapy for early breast cancer; an overview of randomised trials. *Lancet, 355*, 1757-1770.

Early Breast Cancer Triallists' Collaborative Group. (1995). Effects of radiotherapy and surgery in early breast : an overview of the randomized trials. *New England Journal of Medicine, 335*, 1444-1455.

Edwards, W. (1954). The theory of decision making. *Psychological Bulletin, 51*, 380-417.

Engel, J., Kerr, J., Schlesinger-Raab, A., Sauer, H., & Holzel, D. (2004). Quality of life following breast-conserving therapy or mastectomy: results of a 5-year prospective study. *Breast Journal, 10*(3), 223-231.

Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K., et al. (1999). Psychological adjustment in breast cancer: processes of emotional distress. *Health Psychology, 18*(4), 315-326.

Fagerlin, A., Lakhani, I., Lantz, P. M., Janz, N. K., Morrow, M., Schwartz, K., et al. (2006). An informed decision? Breast cancer patients and their knowledge about treatment. *Patient Education and Counselling, 64*(1-3), 303-312.

Fallowfield, L., Hall, A., Maguire, G. P., & Baum, M. (1990). Psychological outcomes in women with early breast cancer. *British Medical Journal, 301*(6765), 1394.

Fallowfield, L. J., Hall, A., Maguire, G. P., & Baum, M. (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *British Medical Journal, 301*(6752), 575-580.

Fasching, P. A., Thiel, F., Nicolaisen-Murmann, K., Rauh, C., Engel, J., Lux, M. P., et al. (2007). Association of complementary methods with quality of life and life satisfaction in patients with gynecologic and breast malignancies. *Support Care Cancer*.

Festinger, L. A. (1957). *Theory of cognitive dissonance*. Stanford: Stanford University Press.

Fischhoff, B. (1975). Hindsight and foresight: The effect of outcome knowledge on judgment under uncertainty. *Journal of Experimental Psychology: Human Perception and Performance, 1*, 288-299.

Fischhoff, B. (1982). For those condemned to study the past: Heuristics in hindsight. In D. Kahneman, P. Slovic & A. Tversky (Eds.), *Judgment under uncertainty: Heuristics and biases*. New York: Cambridge University Press.

Fisher, B., Anderson, S., Redmond, C. K., Wolmark, N., Wickerham, D. L., & Cronin, W. M. (1995). Reanalysis and results after 12 years of follow-up in a randomized clinical trial comparing total mastectomy with lumpectomy with or without irradiation in the treatment of breast cancer. *New England Journal of Medicine, 333*(22), 1456-1461.

Fisher, B., Redmond, C., Poisson, R., Margolese, R., Wolmark, N., & Wickerham, P. e. a. (1989). Eight-year result of a randomized clinical trial comparing total mastectomy and lumpectomy with of without radiation in the treatment of breast cancer. *The New England Journal of Medicine, 320*, 822-828.

Folkman, S., & Moskowitz, J. T. (2004). Coping: pitfalls and promise. *Annual Review Psychology, 55*, 745-774.

Ford, S., Lewis, S., & Fallowfield, L. (1995). Psychological morbidity in newly referred patients with cancer. *Journal of Psychosomatic Research, 39*(2), 193-202.

Fukui, S., Kugaya, A., & Okamura, H. (2001). A psychosocial group intervention reduced psychological distress and enahanced coping in primary breast cancer. *Evidence-Based Mental Health, 4*(1), 15.

Gallagher, J., Parle, M., & Cairns, D. (2002). Appraisal and psychological distress six months after diagnosis of breast cancer. *British Jounral of Health Psychology, 7*(Part 3), 365-376.

Gerstman, B. B. (1998). *Epidemiology Kept Simple: An Introduction to Classic and modern Epidemiology*. New York: Wiley-Liss.

Goel, V., Sawka, C. A., Thiel, E. C., Gort, E. H., & O'Connor, A. M. (2001). Randomized trial of a patient decision aid for choice of surgical treatment for breast cancer. *Medical Decision Making, 21*(1), 1-6.

Goldberg, D. P. (1978). *Manual of the General Health Questionnaire*. Windsor: NFER-Nelson.

Graling, P. R., & Grant, J. M. (1995). Demographics and patient treatment choice in stage I breast cancer. *American Operating Room Nurse, 62*(3), 376-384.

Grassi, L., Biancosino, B., Marmai, L., & Righi, R. (2004). Effect of reboxetine on major depressive disorder in breast cancer patients: an open-label study. *Journal of Clinical Psychiatry, 65*(4), 515-520.

Griggs, J. J., Sorbero, M. E., Mallinger, J. B., Quinn, M., Waterman, M., Brooks, B., et al. (2007). Vitality, mental health, and satisfaction with information after breast cancer. *Patient Education and Counselling, 66*(1), 58-66.

Hack, T. F., Degner, L. F., & Dyck, D. G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Socal Science Medicine, 39*(2), 279-289.

Hack, T. F., Degner, L. F., Watson, P., & Sinha, L. (2006). Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psychooncology, 15*(1), 9-19.

Hanson Frost, M., Suman, V. J., Rummans, T. A., Dose, A. M., Taylor, M., Novotny, P., et al. (2000). Physical, psychological and social well-being of women with breast cancer: the influence of disease phase. *Psychooncology, 9*(3), 221-231.

Harrison, J., & Maguire, P. (1994). Predictors of psychiatric morbidity in cancer patients. *British Journal of Psychiatry, 165*(5), 593-598.

Hathaway, D. (1986). Effect of preoperative instruction on postoperative outcomes; a meta-analysis. *Nursing Research, 35*, 269-275.

Hayes, B.A. (1995) Scholarship in practice discipline: The logical consequences. In G.Gray & R. Pratt (Eds) *Scholarship in the discipline of nursing*. Melbourne: Churchill Livingstone.

Hawley, S. T., Lantz, P. M., Janz, N. K., Salem, B., Morrow, M., Schwartz, K., et al. (2007). Factors associated with patient involvement in surgical treatment decision making for breast cancer. *Patient Education and Counselling, 65*(3), 387-395.

Hegney, D., Pearce, S., Rogers-Clark, C., Martin-McDonald, K., & Buikstra, E. (2005). Close, but still too far. The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment. *European Journal of Cancer Care (Engl), 14*(1), 75-82.

Henman, M. J., Butow, P. N., Brown, R. F., Boyle, F., & Tattersall, M. H. (2002). Lay constructions of decision-making in cancer. *Psychooncology, 11*(4), 295-306.

Hill, J. M., Kornblith, A. B., Jones, D., Freeman, A., Holland, J. F., Glicksman, A. S., et al. (1998). A comparative study of the long term psychosocial functioning of childhood acute lymphoblastic leukemia survivors treated by intrathecal methotrexate with or without cranial radiation. *Cancer, 82*(1), 208-218.

Hjorleifsdottir, E., Hallberg, I. R., Bolmsjo, I. A., & Gunnarsdottir, E. D. (2006). Distress and coping in cancer patients: feasibility of the Icelandic version of BSI 18 and the WOC-CA questionnaires. *European Journal of Cancer Care (England), 15*(1), 80-89.

Hogan, B. (2000). Patient satisfaction: expectations and experiences of nursing care. *Contemporary Nurse, 9*(3-4), 275-283.

Hogarth, R. M. (1994). *Judgment and Choice: The Psychology of Decision* (2nd ed.). Chicester: John Wiley & Sons.

Holland, J. C., & Mastrovito, R. (1980). Psychologic adaptation to breast cancer. *Cancer, 46*(4 Suppl), 1045-1052.

Holmes-Rovner, M., Kroll, J., Schmitt, N., Rovner, D. R., Breer, M. L., Rothert, M. L., et al. (1996). Patient satisfaction with health care decisions: the satisfaction with decision scale. *Medical Decision Making, 16*(1), 58-64.

Hughes, K. K. (1993). Decision making by patients with breast cancer: the role of information in treatment selection. *Oncology Nursing Forum, 20*(4), 623-628.

International Council of Nurses. (2004). Scope of nursing practice. Retrieved 30/10/2007, from http://www.icn.ch/psscope.htm

Irvine, D., Brown, B., Crooks, D., Roberts, J., & Browne, G. (1991). Psychosocial adjustment in women with breast cancer. *Cancer, 67*(4), 1097-1117.

Iwamitsu, Y., Shimoda, K., Abe, H., Tani, T., Okawa, M., & Buck, R. (2005). Anxiety, emotional suppression, and psychological distress before and after breast cancer diagnosis. *Psychosomatics, 46*(1), 19-24.

Jacobsen, P. B., Donovan, K. A., Trask, P. C., Fleishman, S. B., Zabora, J., Baker, F., et al. (2005). Screening for psychologic distress in ambulatory cancer patients. *Cancer, 103*(7), 1494-1502.

Janis, I. L., & Mann, L. (1977). *Decision-making:a psychological analysis of conflict, choice and commitment*. New York: Free Press.

Janz, N. K., Wren, P. A., Copeland, L. A., Lowery, J. C., Goldfarb, S. L., & Wilkins, E. G. (2004). Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. *Journal of Clinical Oncologyl, 22*(15), 3091-3098.

Johnson, J. D., Roberts, C. S., Cox, C. E., Reintgen, D. S., Levine, J. S., & Parsons, M. (1996). Breast cancer patients' personality style, age, and treatment decision making. *Journal of Surgical Oncology, 63*(3), 183-186.

Johnston, M., & Voegele, C. (1993). Benefits of psychological preparation for surgery: A meta-analysis. *Annals of Behavioral Medicine, 15*, 245-256.

Jones, R., Pearson, J., McGregor, S., Gilmour, W. H., Atkinson, J. M., Barrett, A., et al. (1999). Cross sectional survey of patients' satisfaction with information about cancer. *British Medical Journal, 319*(7219), 1247-1248.

Kahneman, D., Slovic, P., & Tversky, A. (1982). *Heuristics and Biases: Judgments Under Uncertainty*. Cambridge: Cambridge University Press.

Kahneman, D. J., & Tversky, A. (1979). Prospect Theory: An analysis of decision under risk. *Econometrica*(47), 263-291.

Kaplan, S., Greenfield, S., & Ware, J. E. (1989). Assessing the effects of physician-patient interactions the outcomes of chronic disease. *Medical Care, 27*, S110-S127.

Katz, S. J., & Hawley, S. T. (2007). From policy to patients and back: surgical treatment decision making for patients with breast cancer. *Health Aff (Millwood), 26*(3), 761-769.

Katz, S. J., Lantz, P. M., Janz, N. K., Fagerlin, A., Schwartz, K., Liu, L., et al. (2005). Patient involvement in surgery treatment decisions for breast cancer. *Journal of Clinical Oncology, 23*(24), 5526-5533.

Keating, N. L., Guadagnoli, E., Landrum, M. B., Borbas, C., & Weeks, J. C. (2002). Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? *Journal of Clinical Oncology, 20*(6), 1473-1479.

Kelly-Powell, M. L. (1997). Personalizing choices: patients' experiences with making treatment decisions. *Research Nursing and Health, 20*(3), 219-227.

Kenny, P., Quine, S., Shiell, A., & Cameron, S. (1999). Participation in treatment decision-making by women with early stage breast cancer. *Health Expectations, 2*(3), 159-168.

Kiebert, G. M., de Haes, J. C., & van de Velde, C. J. (1991). The impact of breast - conserving treatment and mastectomy on the quality of life of early stage breast cancer patients: A review. *Journal of Clinical Oncology, 9*(6), 1059-1070.

Kissane, D. W., Clarke, D. M., Ikin, J., Bloch, S., Smith, G. C., Vitetta, L., et al. (1998). Psychological morbidity and quality of life in Australian women with early-stage breast cancer: a cross-sectional survey. *Medical Journal of Australia, 169*(4), 192-196.

Klein, G. A., Oransanu, J., Calderwood, R., & Zsambok, C. E. (Eds.). (1993). *Decision making in action: models and methods*. Norwood: Ablex Publishing Corporation.

Kleinbaum, D. K., & Morgenstern, H. (1982). *Epidemiologic Research: Principles and Quantitative Methods*. New York: Van Nostrand Reinhold.

Kok, D. L., Chang, J. H., Erbas, B., Fletcher, A., Kavanagh, A. M., Henderson, M. A., et al. (2006). Urban-rural differences in the management of screen-detected invasive breast cancer and ductal carcinoma in situ in victoria. *ANZ J Surg, 76*(11), 996-1001.

Koshy, A., Buckingham, J. M., Zhang, Y., Craft, P., Dahlstrom, J. E., & Tait, N. (2005). Surgical management of invasive breast cancer: a 5-year prospective study of treatment in the Australian Capital Territory and South-Eastern New South Wales. *ANZ J Surg, 75*(9), 757-761.

Kraetschmer, N., Sharpe, N., Urowitz, S., & Deber, R. B. (2004). How does trust affect patient preferences for participation in decision-making? *Health Expectations, 7*(4), 317-326.

Landman, J. (1987). Regret: A theoretical and conceptual analysis. *Journal for the Theory of Social Behaviour, 17*(2), 135-160.

Lantz, P. M., Janz, N. K., Fagerlin, A., Schwartz, K., Liu, L., Lakhani, I., et al. (2005). Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Service Research, 40*(3), 745-767.

Lazarus, R. S. (1993). From psychological stress to emotions: A history of changing outlooks. *Annual Reviews of Psychology, 44*, 1-21.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Company.

Lerman, C., Daly, M., Walsh, W. P., Resch, N., Seay, J., Barsevick, A., et al. (1993). Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer, 72*(9), 2612-2620.

Lewis, F. M., & Bloom, J. R. (1978). Psychosocial adjustment to breast cancer: a review of selected literature. *International Journal of Psychiatry Medicine, 9*(1), 1-17.

Llewellyn-Thomas, H. A., McGreal, M. J., & Thiel, E. C. (1995). Cancer patients' decision making and trial-entry preferences: the effects of "framing" information about short-term toxicity and long-term survival. *Medical Decision Making, 15*(1), 4-12.

Lobb, E. A., Butow, P. N., Kenny, D. T., & Tattersall, M. H. (1999). Communicating prognosis in early breast cancer: do women understand the language used? *Medical Journal of Australia, 171*(6), 290-294.

Lobb, E. A., Kenny, D. T., Butow, P. N., & Tattersall, M. H. (2001). Women's preferences for discussion of prognosis in early breast cancer. *Health Expectations, 4*(1), 48-57.

Love, A. W., Grabsch, B., Clarke, D. M., Bloch, S., & Kissane, D. W. (2004). Screening for depression in women with metastatic breast cancer: a comparison of the Beck Depression Inventory Short Form and the Hospital Anxiety and Depression Scale. *Aust N Z J Psychiatry, 38*(7), 526-531.

Luce, R. D., & Raiffa, H. (1957). *Games and decision: Introduction and critical survey*. New York: Wiley and Sons.

Luker, K. A., Beaver, K., Leinster, S. J., Owens, R. G., Degner, L. F., & Sloan, J. A. (1995). The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing, 22*(1), 134-141.

Luxford, K., & Fletcher, J. (2006). Leading the way-Best Practice in psychosocial care in cancer patients. *CancerForum, 30*(1), 25-28.

Maguire, G. P., Lee, E. G., Bevington, D. J., Kuchemann, C. S., Crabtree, R. J., & Cornell, C. E. (1978). Psychiatric problems in the first year after mastectomy. *British Medical Journal, 1*(6118), 963-965.

Maguire, P., Tait, A., Brooke, M., Thomas, C., & Sellwood, R. (1980). Effect of counselling on the psychiatric morbidity associated with mastectomy. *British Medical Journal, 281*(6253), 1454-1456.

Mallinger, J. B., Griggs, J. J., & Shields, C. G. (2005). Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Education and Counselling, 57*(3), 342-349.

Man-Son-Hing, M., O'Connor, A. M., Drake, E., Biggs, J., Hum, V., & Laupacis, A. (2002). The effect of qualitative vs. quantitative presentation of probability estimates on patient decision-making: a randomized trial. *Health Expectations, 5*(3), 246-255.

Maraste, R., Brandt, L., Olsson, H., & Ryde-Brandt, B. (1992). Anxiety and depression in breast cancer patients at start of adjuvant radiotherapy. Relations to age and type of surgery. *Acta Oncology, 31*(6), 641-643.

Martin-McDonald, K., Rogers-Clark, C., Hegney, D., McCarthy, A., & Pearce, S. (2003). Experiences of regional and rural people with cancer being treated with radiotherapy in a metropolitan centre. *International Journal of Nursing Practice, 9*(3), 176-182.

Massie, M. J., & Holland, J. C. (1991). Psychological reactions to breast cancer in the pre- and post-surgical treatment period. *Seminars in Surgical Oncology, 7*(5), 320-325.

Matheson, J. E., & Howard, R. A. (1977). An introduction to decision analysis. In S. D. A. Group (Ed.), *Readings in decision analysis*. Menlon PArk CA: Stanford Research Institute.

Maunsell, E., Brisson, J., & Deschenes, L. (1989). Psychological distress after initial treatment for breast cancer: a comparison of partial and total mastectomy. *J Clinical Epidemiology, 42*(8), 765-771.

Maunsell, E., Brisson, J., & Deschenes, L. (1992). Psychological distress after initial treatment of breast cancer. Assessment of potential risk factors. *Cancer, 70*(1), 120-125.

Mazur, D. J., & Hickam, D. H. (1994). The effect of of physicians explanations on patients treatment preferences. *Medical Decision Making, 14*, 255-258.

McArdle, A. L. (1996). Psychological support for patients undergoing breast cancer surgery: a randomised study. *British Medical Journal, 312*, 813-817.

McGrath, P., Patterson, C., Yates, P., Treloar, S., Oldenberg, B., & Loos, C. (1999). A study of postdiagnosis breast cancer concerns for women living in rural and remote Queensland : Part 11: Support issues. *Australian Journal of Public Health, 7*(1), 43-52.

McGrath, P., Patterson, C., Yates, P., Treloar, S., Oldenburg, B., & Loos, C. (1999). A study of postdiagnosis breast cancer concerns for women living in rural and remote Queensland. Part I: Personal concerns. *Australia Journal of Rural Health, 7*(1), 34-42.

McNeil, B. J., Pauker, S. G., Sox, H. C., Jr., & Tversky, A. (1982). On the elicitation of preferences for alternative therapies. *New England Journal of Medicine, 306*(21), 1259-1262.

McWilliam, C. L., Brown, J. B., & Stewart, M. (2000). Breast cancer patients' experiences of patient-doctor communication: a working relationship. *Patient Education and Counselling, 39*(2-3), 191-204.

Merkouris, A., Papathanassoglou, E. D., & Lemonidou, C. (2004). Evaluation of patient satisfaction with nursing care: quantitative or qualitative approach? *Internation Journal of Nursing Studies, 41*(4), 355-367.

Meyer, B. J., Russo, C., & Talbot, A. (1995). Discourse comprehension and problem solving: decisions about the treatment of breast cancer by women across the life span. *Psychology of Aging, 10*(1), 84-103.

Meyer, B. J., Talbot, A. P., & Ranalli, C. (2007). Why older adults make more immediate treatment decisions about cancer than younger adults. *Psychology Aging, 22*(3), 505-524.

Meyerowitz, B. E. (1980). Psychosocial correlates of breast cancer and its treatments. *Psychological Bulletin, 87*(1), 108-131.

Molenaar, S., Sprangers, M. A., Rutgers, E. J., Luiten, E. J., Mulder, J., Bossuyt, P. M., et al. (2001). Decision support for patients with early-stage breast cancer: effects of an interactive breast cancer CDROM on treatment decision, satisfaction, and quality of life. *Journal of Clinical Oncology, 19*(6), 1676-1687.

Montgomery, G. H., & Bovbjerg, D. H. (2004). Presurgery distress and specific response expectancies predict postsurgery outcomes in surgery patients confronting breast cancer. *Health Psychology, 23*(4), 381-387.

Morlan, K. K., & Tan, S. Y. (1998). Comparison of the Brief Psychiatric Rating Scale and the Brief Symptom Inventory. *Journal of Clinical Psychology, 54*(7), 885-894.

Morris, A. D., Morris, R. D., Wilson, J. F., White, J., Steinberg, S., Okunieff, P., et al. (1997). Breast-conserving therapy vs mastectomy in early-stage breast cancer: a meta-analysis of 10-year survival. *Cancer Journal of Sci Am, 3*(1), 6-12.

Moyer, A. (1997a). Psychosocial outcomes of breast conserving surgery versus mastectomy: A meta- analytic review. *Health Psychology, 16*(284-298).

Moyer, A. (1997b). Psychosocial outcomes of breast-conserving surgery versus mastectomy: a meta-analytic review. *Health Psychology, 16*(3), 284-298.

Nano, M. T., Gill, P. G., Kollias, J., Bochner, M. A., Malycha, P., & Winefield, H. R. (2005). Psychological impact and cosmetic outcome of surgical breast cancer strategies. *ANZ J Surg, 75*(11), 940-947.

National Breast Cancer Centre. (1995). *Clinical practice guidelines for the management of breast cancer*. Canberra: Commonwealth of Australia.

National Breast Cancer Centre. (1996). *All about early breast cancer*. Camperdown, Sydney: National Breast Cancer Centre.

National Breast Cancer Centre. (2001). *Clinical practice guidelines for the management for early breast cancer* (2nd ed.). Canberra: Commonwealth of Australia.

National Breast Cancer Centre. (2003a). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Sydney: National Breast Cancer Centre.

National Breast Cancer Centre. (2003b). *A guide for women with early breast cancer*. Sydney: National Breast Cancer Centre.

National Breast Cancer Centre. (2004a). *Clinical guidelines for the management and support of younger women with breast cancer*. Sydney: National Health And Medical Research Centre.

National Breast Cancer Centre. (2004b). *The Identification of Psychological Distress in Women with Breast Cancer*. Camperdown: National Breast Cancer Centre.

National Breast Cancer Centre. (2004c). *National survey of women with early breast cancer: their perceptions of care 1997*. Camperdown: National Breast Cancer Centre.

National Breast Cancer Centre. (2006). *Breast cancer in Australia: an overview 2006*. Canberra: Australian Health and Welfare.

National Breast and Ovarian Cancer Centre. (2008). *Psychosocial care referral checklist for patients with cancer.* Canberra: Australian Health and Welfare.

National Comprehensive Cancer Network. (2003). Distress management clinical practice guidelines in oncology. *Journal National Comprehensive Cancer Network, 1*(3), 344-374.

National Comprehensive Cancer Network. (2007). NCCN Clinical Practice Guidelines in Oncology: Distress Management. National Comprehensive Cancer Network.

National Health and Medical Research Council. (1993). *General guidelines for medical practitioners on providing information to patients*. Canberra: Australian Government Publishing Service.

National Health and Medical Research Council. (2001). *Clinical practice guidelines:Management of the early breast cancer.* Canberra: Commonwealth of Australia.

National Health and Medical Research Council National Breast Cancer Centre. (2000). *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer.* Canberra: Commonwealth of Australia.

National Health Scheme Breast Cancer. (2006). NHS Cancer Screening Programmes 2006 Retrieved 17/01/2006, from http://www.cancerscreening.nhs.uk/breastscreen/breastcancer.html

Neville, K. (1996). Psychological distress in adolescents with cancer. *Journal of Pediatriatric Nursing, 11*(4), 243-251.

Newell, A., & Simon, H. A. (1972). *Human Problem Solving*. Englewood Cliffs: Prentice-Hall.

Newell, A., & Simon, H. A. (1984). *Human Problem Solving*. Englewood Cliffs: Prentice Hall Incoporated.

NHMRC and National Breast Cancer Centre. (2001). *Clinical practice guidelines for the management for early breast cancer* (2nd ed.). Canberra: Commonwealth of Australia.

NHMRC National Breast Cancer Centre. (1998). *Talking about prognosis with women who have early breast cancer: what they prefer to know and guideleines to help explain it effectively*. Kings Cross: NHMRC National Breast Cancer Centre.

Nold, R. J., Beamer, R. L., Helmer, S. D., & McBoyle, M. F. (2000). Factors influencing a woman's choice to undergo breast-conserving surgery versus modified radical mastectomy. *American Journal of Surgery, 180*(6), 413-418.

Northouse, L. (1989). A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncology Nursing Forum, 16*(4), 511-516.

Northouse, L. L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science Medicine, 41*(1), 69-76.

Northouse, L. L., & Swain, M. A. (1987). Adjustment of patients and husbands to the initial impact of breast cancer. *Nursing Research, 36*(4), 221-225.

Northouse, L. L., Templin, T., Mood, D., & Oberst, M. (1998). Couples' adjustment to breast cancer and benign breast disease: a longitudinal analysis. *Psychooncology, 7*(1), 37-48.

Nosarti, C., Roberts, J. V., Crayford, T., McKenzie, K., & David, A. S. (2002). Early psychological adjustment in breast cancer patients: a prospective study. *J Psychosomatic Research, 53*(6), 1123-1130.

Noyan, M. A., Sertoz, O. O., Elbi, H., Kayar, R., & Yilmaz, R. (2006). Variables affecting patient satisfaction in breast surgery: a cross-sectional sample of Turkish women with breast cancer. *International Journal of Psychiatry Medicine, 36*(3), 299-313.

O'Connor, A., & O'Brien-Pallas, L. (1989). Decisional conflict. In E. A. McFarlane (Ed.), *Nursing diagnosis and intervention* (pp. 573). Toronto: C.V. Mosby.

O'Connor, A. M. (1989). Effects of framing and level of probability on patients' preferences for cancer chemotherapy. *Journal of Clinical Epidemiology, 42*(2), 119-126.

O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making, 15*(1), 25-30.

O'Connor, A. M., Drake, E. R., Fiset, V., Graham, I. D., Laupacis, A., & Tugwell, P. (1999). The Ottawa patient decision aids. *Effective Clinical Practice, 2*(4), 163-170.

O'Connor, A. M., Rostom, A., Fiset, V., Tetroe, J., Entwistle, V., Llewellyn-Thomas, H., et al. (1999). Decision aids for patients facing health treatment or screening decisions: systematic review. *British Medical Journal, 319*(7212), 731-734.

O'Connor, A. M., Stacey, D., Entwistle, V., Llewellyn-Thomas, H., Rovner, D., Holmes-Rovner, M., et al. (2003). Decision aids for people facing health treatment or screening decisions. *Cochrane Database System Review*(2), CD001431.

O'Connor, A. M., Stacey, D., Rovner, D., Holmes-Rovner, M., Tetroe, J., Llewellyn-Thomas, H., et al. (2001). Decision aids for people facing health treatment or screening decisions. *Cochrane Database System Review*(3), CD001431.

O'Leary, K. A., Estabrooks, C. A., Olson, K., & Cumming, C. (2007). Information acquisition for women facing surgical treatment for breast cancer: influencing factors and selected outcomes. *Patient Education and Counselling, 69*(1-3), 5-19.

O'Neill, E. S. (1995). Heuristics reasoning in diagnostic judgment. *Journal of Professional Nursing, 11*(4), 239-245.

Omne-Ponten, M., Holmberg, L., Burns, T., Adami, H. O., & Bergstrom, R. (1992). Determinants of the psycho-social outcome after operation for breast cancer. Results of a prospective comparative interview study following mastectomy and breast conservation. *European Journal of Cancer, 28A*(6-7), 1062-1067.

Parle, M., Gallagher, J., Gray, C., Akers, G., & Liebert, B. (2001). From evidence to practice: factors affecting the specialist breast nurse's detection of psychological morbidity in women with breast cancer. *Psychooncology, 10*(6), 503-510.

Pasacreta, J. V. (1997). Depressive phenomena, physical symptom distress, and functional status among women with breast cancer. *Nursing Research, 46*(4), 214-221.

Payne, D. K., Hoffman, R. G., Theodoulou, M., Dosik, M., & Massie, M. J. (1999). Screening for anxiety and depression in women with breast cancer. Psychiatry and medical oncology gear up for managed care. *Psychosomatics, 40*(1), 64-69.

Petrisek, A. C., Laliberte, L. L., Allen, S. M., & Mor, V. (1997). The treatment decision-making process: age differences in a sample of women recently diagnosed with nonrecurrent, early-stage breast cancer. *Gerontologist, 37*(5), 598-608.

Pierce, F. P. (1993). Women's participation in breast cancer treatment decisions questionnaire. School of Nursing, University of Michigan. Unpublished.

Pierce, F. P. (1995, October 14- 17). *The Michigan Assessment of Decision styles (MADS). Development of an instrument to measure pre-decision behaviour in a clinical setting.* Paper presented at the 17th Annual Meeting of the Society for Decision Making, Tempe, Arizona.

Pierce, F. P. (1995b). Pre-decision Portfolio questionnaire.
Ann Arbor, Unpublished.

Pierce, F. P., (1995a, October 14- 17). *The Michigan assessment of decision behaviour (MADS). Development of an instrument to measure pre-decision behaviour in a clinical setting.* Paper presented at the 17th Annual Meeting of the Society for Decision Making, Tempe, Arizona.

Pierce, P. F. (1985). Decision-making of women with early stage breast cancer: A qualitative study of treatment choices. *Dissertation Abstracts, International. (Science), 46*, 3784.

Pierce, P. F. (1988). Women's experience of choice: confronting the options for treatment of breast cancer. In J. Harness, Obermas, H., Lichter, A., Alder, D. and Cody, R. (Ed.), *Breast Cancer: Collaborative Management*. Chelsea: Lewis Publishers.

Pierce, P. F. (1993). Deciding on breast cancer treatment: a description of decision behavior. *Nursing Research, 42*(1), 22-28.

Pierce, P. F. (1996). When the patient chooses: describing unaided decisions in health care. *Human Factors, 38*(2), 278-287.

Pierce, P. F. (1997). What is an ethical decision? *Critical Care Nursing Clinics of North America, 8*(1), 11.

Pierce, P. F., & Hicks, F. D. (2001). Patient decision-making behavior: an emerging paradigm for nursing science. *Nursing Research, 50*(5), 267-274.

Pinder, K. L., Ramirez, A. J., Black, M. E., Richards, M. A., Gregory, W. M., & Rubens, R. D. (1993). Psychiatric disorder in patients with advanced breast cancer: prevalence and associated factors. *European Journal of Cancer, 29A*(4), 524-527.

Pliske, R., & Klein, G. A. (2003). The naturalistic decision-making perspective. In S. L. Schneider & J. Shanteau (Eds.), *Emerging perspectives on judgement and decision research* (pp. 559-587). Cambridge: Cambridge University Press.

Plous, S. (1993). *The psychology of judgment and decision making*. New York: McGraw-Hill, Inc.

Polit, D. F., & Beck, C. T. (2004). *Nursing Research: Principles and Methods* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.

Queensland Cancer Registry. (2007). *Cancer in Queensland: incidence and mortality 1982-2004*. Brisbane: Queensland Cancer Fund.

Reaby, L. L. (1996). *Post-mastectomy self -perceptions, attitudes and breast restoration decision-making*. Canberra: University of Canberra.

Reaby, L. L. (1998a). The quality and coping patterns of women's decision-making regarding breast cancer surgery. *Psychooncology, 7*(3), 252-262.

Reaby, L. L. (1998b). Reasons why women who have mastectomy decide to have or not to have breast reconstruction. *Plastic Reconstructive Surgery, 101*(7), 1810-1818.

Reaby, L. L., Hort, L. K., & Vandervord, J. (1994). Body image, self concept and self-esteem in women who had a mastectomy and either wore an external breast prosthesis or had breast reconstruction and women who had not experienced mastectomy. *Health Care for Women International., 15*, 361-375.

Recklitis, C. J., Parsons, S. K., Shih, M. C., Mertens, A., Robison, L. L., & Zeltzer, L. (2006). Factor structure of the brief symptom inventory--18 in adult survivors of childhood cancer: results from the childhood cancer survivor study. *Psychology Assessment, 18*(1), 22-32.

Redelmeier, D., Rozin, P., & Kahneman, D. (1993). Understanding patient's decisions: cognitive and emotional perspectives. *Journal of American Medicine, 270*(1), 34-38.

Rehnberg, G., Absetz, P., & Aro, A. R. (2001). Women's satisfaction with information at breast biopsy in breast cancer screening. *Patient Education and Counselling, 42*(1), 1-8.

Ryan, H., Schofield, P., Cockburn, J., Butow, P., Tattersall, M., Turner, J., et al. (2005). How to recognize and manage psychological distress in cancer patients. *European Journal of Cancer Care (England), 14*(1), 7-15.

Sabo, B., St-Jacques, N., & Rayson, D. (2007). The decision-making experience among women diagnosed with stage I and II breast cancer. *Breast Cancer Research and Treatment, 102*, 51-59.

Sainfort, F., & Booske, B. C. (2000). Measuring post-decision satisfaction. *Medical Decision Making, 20*(1), 51-61.

Sammarco, A. (2001a). Perceived social support, uncertainty, and quality of life of younger breast cancer survivors. *Cancer Nursing, 24*(3), 212-219.

Sammarco, A. (2001b). Psychosocial stages and quality of life of women with breast cancer. *Cancer Nursing, 24*(4), 272-277.

Sammarco, A. (2003). Quality of life among older survivors of breast cancer. *Cancer Nursing, 26*(6), 431-438.

Sandelin, K., King, E., & Redman, S. (2003). Breast reconstruction following mastectomy: current status in Australia. *ANZ J Surg, 73*(9), 701-706.

Schou, I., Ekeberg, O., Ruland, C. M., Sandvik, L., & Karesen, R. (2004). Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology, 13*(5), 309-320.

Schulmeister, L., Quiett, K., & Mayer, K. (2005). Quality of life, quality of care, and patient satisfaction: perceptions of patients undergoing outpatient autologous stem cell transplantation. *Oncology Nursing Forum, 32*(1), 57-67.

Sharpley, C. F., & Christie, D. R. (2007). 'How I was then and how I am now': current and retrospective self-reports of anxiety and depression in Australian women with breast cancer. *Psychooncology, 16*(8), 752-762.

Shilling, V., Jenkins, V., & Fallowfield, L. (2003). Factors affecting patient and clinician satisfaction with the clinical consultation: Can communication skills training for clinicians improve satisfaction? *Psychooncology, 12*(6), 599-611.

Siegel, K., Gluhoski, V., & Gorey, E. (1999). Age related distress among young women with breast cancer. *Journal of Psychosocial Oncology, 17*(1), 1-20.

Siminoff, L. A., & Fetting, J. H. (1989). Effects of outcome framing on treatment decisions in the real world: impact of framing on adjuvant breast cancer decisions. *Medical Decision Making, 9*(4), 262-271.

Siminoff, L. A., & Fetting, J. H. (1991). Factors affecting treatment decisions for a life-threatening illness: the case of medical treatment of breast cancer. *Social Science Medicine, 32*(7), 813-818.

Simon, H. A. (1956). Rational choice and the structure of the environment. *Psychological Review, 63*, 129-138.

Simon, H. A. (1957). *Models of man: Social and rational*. New York: Wiley.

Simon, H. A. (1974). How big is a chunk? *Science, 183*(8), 482-488.

Simon, H. A., & Newell, A. (1964). Information Processing in Computer and Man. *American Scientist, 52*, 281-300.

Smitt, M. C., & Heltzel, M. (1997). Women's use of resources in decision-making for early-stage breast cancer: results of a community-based survey. *Annuals of Surgical Oncology, 4*(7), 564-569.

Sneed, N. V., Edmund, B., & Dias, J. K. (1992). Adjustment of gynaecological and breast cancer patients to the cancer diagnosis: comparisons with males and females having other cancer sites. *Health Care Women International, 13*(1), 11-22.

Solso, R. L. (1995). *Cognitive Psychology* (4th ed.). Boston: Allyn and Bacon.

Spagnola, S., Zabora, J., BrintzenhofeSzoc, K., Hooker, C., Cohen, G., & Baker, F. (2003). The Satisfaction with Life Domains Scale for Breast Cancer (SLDS-BC). *Breast Journal, 9*(6), 463-471.

Stafford, D., Szczys, R., Becker, R., Anderson, J., & Bushfield, S. (1998). How breast cancer treatment decisions are made by women in North Dakota. *American Journal of Surgery, 176*(6), 515-519.

Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., et al. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting Clinical Psychology, 68*(5), 875-882.

Stanton, A. L., Danoff-Burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psychooncology, 11*(2), 93-102.

Steginga, S., Occhipinti, S., Wilson, K., & Dunn, J. (1998). Domains of distress: the experience of breast cancer in Australia. *Oncology Nursing Forum, 25*(6), 1063-1070.

Street, R. L., Jr., Voigt, B., Geyer, C., Jr., Manning, T., & Swanson, G. P. (1995). Increasing patient involvement in choosing treatment for early breast cancer. *Cancer, 76*(11), 2275-2285.

Streiner, D. L., & Norman, G. R. (2000). *Health measurement scales: A practical guide to their development and use* (2nd ed.). Oxford: Oxford University Press.

Taylor, R., Stubbs, J. M., Langlands, A. O., & Boyages, J. (1999). Predictors of Mastectomy for Women with Breast Cancer in the Greater Western Region of Sydney. *Breast Journal, 5*(2), 116-121.

Tchekmedyian, N. S., Kallich, J., McDermott, A., Fayers, P., & Erder, M. H. (2003). The relationship between psychologic distress and cancer-related fatigue. *Cancer, 98*(1), 198-203.

Temple, W. J., Russell, M. L., Parsons, L. L., Huber, S. M., Jones, C. A., Bankes, J., et al. (2006). Conservation surgery for breast cancer as the preferred choice: a prospective analysis. *Journal of Clinical Oncology, 24*(21), 3367-3373.

Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004). The psychosocial needs of breast cancer survivors; a qualitative study of the shared and unique needs of younger versus older survivors. *Psychooncology, 13*(3), 177-189.

Thind, A., & Maly, R. (2006). The surgeon-patient interaction in older women with breast cancer: what are the determinants of a helpful discussion? *Annuals of Surgical Oncology, 13*(6), 788-793.

Thistlethwaite, J. E., & Ewart, B. R. (2003). Valuing diversity: helping medical students explore their attitudes and beliefs. *Medical Teaching, 25*(3), 277-281.

Thistlethwaite, J. E., Raynor, D. K., & Knapp, P. (2003). Medical students' attitudes towards concordance in medicine taking: exploring the impact of an educational intervention. *Educational Health (Abingdon), 16*(3), 307-317.

Thomas, S., Wearing, A., & Bennett, M. (1991). *Clinical Decision Making for Nurses and Health Professionals*. Sydney: W.B.Saunders Bailliere Tindall.

Thompson, C., & Dowding, D. (2002). *Clinical Decision Making and Judgement*. Edinburgh: Churchill Livingston.

Titler, M.G., Reoter, R.C., & Corry, L.,(1996) Decision-support interventions for patients. *Medical Surgical Nursing, 5*(1), 57-61.

Tjemsland, L., Soreide, J. A., & Malt, U. F. (1998). Posttraumatic distress symptoms in operable breast cancer III: status one year after surgery. *Breast Cancer Research and Treatment, 47*(2), 141-151.

Turner, J., Hayes, S., & Reul-Hirche, H. (2004). Improving the physical status and quality of life of women treated for breast cancer: a pilot study of a structured exercise intervention. *Journal of Surgical Oncology, 86*(3), 141-146.

Turner, J., Kelly, B., Swanson, C., Allison, R., & Wetzig, N. (2005). Psychosocial impact of newly diagnosed advanced breast cancer. *Psychooncology, 14*(5), 396-407.

Turner, J., Wooding, S., & Neil, C. (1998). *Psychosocial impact of breast cancer: A summary of the literature 1986-1996*. Sydney: NHMRC National Breast Cancer Centre.

Turner, J., Wooding, S., & Neil, C. (2004). *Psychosocial impact of breast cancer: a summary of the literature 1986-1996*. Kings Cross: NHMRC National Breast Cancer Centre.

Turner, J., Zapart, S., Pedersen, K., Rankin, N., Luxford, K., & Fletcher, J. (2005). Clinical practice guidelines for the psychosocial care of adults with cancer. *Psychooncology, 14*(3), 159-173.

Tversky, A., & Kaheman, D. (1974). Judgement under uncertainty: heuristics and biases. *Science, 185*, 1124-1131.

Tversky, A., & Kaheman, D. (2000). Judgement and Uncertainty: Heuristics and Biases. In T. Connolly, H. A. Arkes & K. R. Hammond (Eds.), *Judgement and Decision Making: An Interdisciplinary Reader* (2nd ed.). Cambridge: Cambridge University Press.

Tversky, A., & Kahneman, D. (1981). The framing of decisions and the psychology of choice. *Science, 211*, 453-458.

van Dongen, J. A., Bartelink, H., Fentiman, I. S., Lerut, T., Mignolet, F., Olthuis, G., et al. (1992). Randomized clinical trial to assess the value of breast-conserving therapy in stage I and II breast cancer, EORTC 10801 trial. *Journal of National Cancer Institute Monograms*(11), 15-18.

Veronesi, U., Luini, A., Del Vecchio, M., Greco, M., Galimberti, V., Merson, M., et al. (1993). Radiotherapy after breast-preserving surgery in women with localized cancer of the breast. *N Engl J Med, 328*(22), 1587-1591.

Vogel, B. A., Helmes, A. W., & Hasenburg, A. (2007). Concordance between patients' desired and actual decision-making roles in breast cancer care. *Psychooncology*.

Waljee, J. F., Hawley, S., Alderman, A. K., Morrow, M., & Katz, S. J. (2007). Patient satisfaction with treatment of breast cancer: does surgeon specialization matter? *Journal of Clinical Oncology, 25*(24), 3694-3698.

Waljee, J. F., Rogers, M. A., & Alderman, A. K. (2007). Decision aids and breast cancer: do they influence choice for surgery and knowledge of treatment options? *Journal of Clinical Oncology, 25*(9), 1067-1073.

Ward, S., & Griffin, J. (1990). Developing a test of knowledge of surgical options for breast cancer. *Cancer Nursing, 13*(3), 191-196.

Watson, M., Denton, S., & Baum, M. (1998). Counselling breast cancer patients: A specialist nurse service. *Counselling Psychology Quarter*, 1.

Weinstein, M. C., Fineberg, H. V., Elstein, A. S., Frazier, H. S., Neuhauser, D., Neutra, R. R., et al. (1980). *Clinical Decision Analysis*. Philadelphia: Saunders.

Wenzel, L. B., Fairclough, D. L., Brady, M. J., Cella, D., Garrett, K. M., Kluhsman, B. C., et al. (1999). Age-related differences in the quality of life of breast carcinoma patients after treatment. *Cancer, 86*(9), 1768-1774.

Whelan, T., Gafni, A., Charles, C., & Levine, M. (2000). Lessons learned from the Decision Board: a unique and evolving decision aid. *Health Expectations, 3*(1), 69-76.

Whelan, T., Levine, M., Gafni, A., Sanders, K., Willan, A., Mirsky, D., et al. (1999). Mastectomy or lumpectomy? Helping women make informed choices. *Journal of Clinical Oncology, 17*(6), 1727-1735.

Whelan, T., Levine, M., Willan, A., Gafni, A., Sanders, K., Mirsky, D., et al. (2004). Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *Journal of American Medical Association, 292*(4), 435-441.

Wiggers, J. H., Donovan, K. O., Redman, S., & Sanson-Fisher, R. W. (1990). Cancer patient satisfaction with care. *Cancer, 66*(3), 610-616.

Wilkes, L., White, K., & Beale, B. (2002). Life after breast cancer: Australian women's stories of support. *Collegian, 9*(2), 22-26.

Wilkes, L., White, K., Beale, B., Cole, R., & Tracy, S. (1999). Supportive care for women with breast cancer: Australian nurses' perspective. *Nursing Health Science, 1*(2), 71-76.

Williams, P., Redman, S., Rankin, N., Davis, C., Armstrong, B., & Malycha, P. (2002). Is breast cancer care in accord with clinical practice guidelines: a consumer audit. *Breast, 11*(6), 509-515.

Wills, C. E., & Holmes-Rovner, M. (2003). Preliminary validation of the Satisfaction With Decision scale with depressed primary care patients. *Health Expectations, 6*(2), 149-159.

Wolberg, W. H. (1990). Mastectomy or breast conservation in the management of primary breast cancer: psychosocial factors. *Oncology (Huntingt), 4*(10), 101-104; discussion 104, 106, 108.

Women's perspectives sub-group NHMRC Working Party. (1994). *Report on the treatment of diagnosed breast cancer: What do women say about treatment of breast cancer?*

Wonghongkul, T., Dechaprom, N., Phumivichuvate, L., & Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing, 29*(3), 250-257.

Wonghongkul, T., Moore, S. M., Musil, C., Schneider, S., & Deimling, G. (2000). The influence of uncertainty in illness, stress appraisal, and hope on coping in survivors of breast cancer. *Cancer Nursing, 23*(6), 422-429.

Yates, J. F. (1990). *Judgment and Decision Making*. Englewood Cliffs: Prentice Hall.

Yates, J. S.(1992). The risk construct. In J. Yates (Ed.), *Risk taking behaviour* (pp. 2-25). Chichester: Wiley.

Young, W. W., Marks, S. M., Kohler, S. A., & Hsu, A. Y. (1996). Dissemination of clinical results. Mastectomy versus lumpectomy and radiation therapy. *Medical Care, 34*(10), 1003-1017.

Yurek, D., Farrar, W., & Andersen, B. L. (2000). Breast cancer surgery: comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consulting Clinical Psychology, 68*(4), 697-709.

Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psychooncology, 10*(1), 19-28.

Zabora, J., BrintzenhofeSzoc, K., Jacobsen, P., Curbow, B., Piantadosi, S., Hooker, C., et al. (2001). A new psychosocial screening instrument for use with cancer patients. *Psychosomatics, 42*(3), 241-246.

Zabora, J. R., Smith-Wilson, R., Fetting, J. H., & Enterline, J. P. (1990). An efficient method for psychosocial screening of cancer patients. *Psychosomatics, 31*(2), 192-196.

Zigmond, A., & Snaith, R. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavia, 67*, 361-370.

Zimmermann, C., Baldo, C., & Molino, A. (2000). Framing of outcome and probability of recurrence: breast cancer patients' choice of adjuvant chemotherapy (ACT) in hypothetical patient scenarios. *Breast Cancer Res Treat, 60*(1), 9-14.

Zsambok, C. E. (1997). Naturalistic Decision Making: Where are we now? In C. E. Zsambok & G. Klein (Eds.), *Naturalistic Decision Making* (pp. 9-16). Mahwah: Lawerence Erlbaum Associates.

APPENDICES

Appendix 1- JCU ethics approval

Appendix 2 –Pre-diagnostic *MADS* article

Appendix 3- Pre-diagnostic values article

Appendix 4- Baseline structured survey

Appendix 5- Follow-up questionnaire at three to four months

Appendix 6- Letter of support

Appendix 7- Participant’s consent form

Appendix 8- Participant’s information sheet

Appendix 9- Participant’s eligibility sheet

Appendix 1- JCU ethics approval

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ETHICS REVIEW COMMITTEE

(Human Ethics Sub-Committee)

APPROVAL FOR RESEARCH OR TEACHING INVOLVING HUMAN SUBJECTS

PRINCIPAL INVESTIGATOR	*Ms Lea Budden*
CO-INVESTIGATOR	*Professor Barbara Hayes*
CO-INVESTIGATOR	*Dr Petra Buettner*
SCHOOL	*Nursing Sciences*
PROJECT TITLE	***Women's distress, decision-making and satisfaction relating to early breast cancer treatment***
DATE	*1 July 2001 – 31 January 2004*
CATEGORY	*1*

This project has been allocated Ethics Approval Number with the following provisos and reservations: **H1218**

1. All subsequent records and correspondence relating to this project must refer to this number.
2. The Principal Investigator is to advise the responsible Monitor appointed by the Ethics Review Committee:
   - periodically of the progress of the project;
   - when the project is completed or if suspended or prematurely terminated for any reason.
3. In compliance with the National Health and Medical Research Council (NHMRC) ***"National Statement on Ethical Conduct in Research Involving Humans"*** you are required to provide an annual report detailing security of records and compliance with conditions of approval. The report should very briefly summarise progress.

NAME OF RESPONSIBLE MONITOR	*Dr Kim Usher*
SCHOOL	*Nursing Sciences*
APPROVED AT MEETING	***Date: 30 May 2001***
APPROVED (Conditions Approved by Monitor)	***Date:***
EXECUTIVE APPROVAL Chair, Ethics Review Committee	***Date:***
[forwarded by email without signature] Tina Langford	Date: 31 May 2001

Leininger, M. M. (1991). *Culture care diversity and universality: A theory of nursing.* New York: National League of Nursing Press.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* London: Sage.

McCance, T. V. (1999). *An exploration of the experience of caring in nursing: A hermeneutic approach.* Unpublished doctoral dissertation, University of Ulster, Northern Ireland.

McCance, T. V., McKenna, H. P., & Boore, J. R. P. (1997). Caring: Dealing with a difficult concept. *International Journal of Nursing Studies, 34,* 241-248.

McCance, T. V., McKenna, H. P., & Boore, J. R. P. (1999). Caring: Theoretical perspectives of relevance to nursing. *Journal of Advanced Nursing, 30,* 1388-1395.

McCance, T. V., McKenna, H. P., & Boore, J. R. P. (2001). Exploring caring using narrative methodology: An analysis of the approach. *Journal of Advanced Nursing, 33,* 350-356.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook.* London: Sage.

Morse, J. M., Solberg, S. M., Neander, W. L., Bottorff, J. L., & Johnson, J. L. (1990). Concepts of caring and caring as a concept. *Advances in Nursing Science, 13,* 1-14.

Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research, 5,* 147-149.

Munhall, P. & Oiler, C. (1986). *Nursing research: A qualitative perspective.* New York: Appleton.

Paley, J. (2001). An archaeology of caring knowledge. *Journal of Advanced Nursing, 36,* 188-198.

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. In J. A. Hatch & R. Wisniewski (Ed.), *Life History and Narrative* (pp. 5-23). London: The Falmer Press.

Roach, S. (1984). *Caring: The human mode of being.* Toronto: University of Toronto.

Roach, S. (1987). *The human act of caring.* Ottawa: Canadian Hospital Association.

Sourial, S. (1997). An analysis of caring. *Journal of Advanced Nursing, 26,* 1189-1192.

Reissman, C. K. (1993). *Narrative Analysis.* London: Sage.

Stevens, A. (1999). Named nursing: In whose best interest? *Journal of Advanced Nursing, 29,* 341-347.

Tesch, R. (1990). *Qualitative research: Analysis types and software tools.* Hampshire, England: The Falmer Press.

Watson, J. (1979). *Nursing: The philosophy and science of caring.* Boston: Little Brown.

Watson, J. (1985). *Nursing: Human science and human care—A theory of nursing.* New York: National League of Nursing Press.

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Appendix 2 –Pre-diagnostic *MADS* article

Australian Women's Prediagnostic Decision-Making Styles, Relating to Treatment Choices for Early Breast Cancer Treatment

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Women diagnosed with early breast cancer are now asked by their doctors to choose from a range of options for their preferred medical treatment plan. Little information is known about women's treatment decision-making and therefore nurses do not have evidence to guide this decision support. The aim of this descriptive survey was to investigate the prediagnostic decision-making behavior of a sample ($N = 377$) of Australian women, regarding their treatment choices for early breast cancer. The data were collected using the Pre-Decision Portfolio Questionnaire (PDPQ) by Pierce (1996), which includes the Michigan Assessment of Decision Styles (MADS). Of 366 participating women, 19.9% strongly agreed to all three items of the MADS factor Deferring Responsibility; 0.3% strongly agreed to all four factors of Avoidance; 32.7% strongly agreed on all four items of Information Seeking; and 63.4% strongly agreed to all five items of Deliberation. Women showed a variety of preferred decision styles, depending on age, education, occupation and employment status. Only 36% of women indicated it was critically important to "get the treatment over as soon as possible;" 55% to "participate in selecting treatment;" and 53% to "read a lot of information." The understanding of factors that are important to women when they are making decisions for medical treatment is a mandatory step in designing customized evidence-based decision support, which can be delivered by nurses to help women during this distressing experience.

Breast cancer remains a major cause of illness and death in women, particularly in the western world. The incidence of women developing this disease during their lifetime is 1 in 11 in Australia (Australian Institute of Health and Welfare, 1998) and 1 in 8 in the United States (American Cancer Society, 2000). Women who are diagnosed with this life-threatening disease are usually asked by their doctors to choose between equally effective treatment options (mastectomy or lumpectomy with radiation/adjunct treatment) (Fisher et al., 1989).

In addition, the psychological stress created by a diagnosis of breast cancer can lead women into a state of mental and emotional paralysis (Pierce, 1993) that can ultimately minimize their cognitive ability to function adequately (Cimprich, 1999) and make quality decisions (Pierce, 1993). Quality decisions occur when people are able to use an adaptive pattern of cognitive and behavioral processes, which limits the postdecisional regret and increases adherence to the final choice (Campora & Vitullo, 1992; Janis, 1977). This problem can be further compounded by the fact that up to 30% of women with breast cancer experience clinically significant anxiety problems (Kissane et al., 1998; Maraste, Brandt, Olsson, & Ryde-Brandt, 1992; Pinder, Ramirez, & Black, 1993).

Although women can choose a treatment plan that is more suited to their values, preferences and lifestyle, the available choices may confuse some women. Women's process of decision-making for breast cancer treatment can be further complicated for women who seek intervention, because they are asked to decide between multiple treatment alternatives, and weigh each modality's risks and benefits. In addition, these risks and benefits are often communicated in unfamiliar language (Pierce, 1993). This problem was illustrated in an Australian study that reported that 74% of women with early breast cancer did not understand the statistical language used by the medical specialist (NHMRC National Breast Cancer Centre, 1998). Consequently, it can be very difficult for many women to understand the risk involved with each treatment alternative offered, when the prognostic information is given using probabilities by their doctor (Hughes, 1993). To understand the risk for each treatment option, women need to understand the potential losses, the significance of the losses and the uncertainty of those losses (Yates, 1992). Furthermore, these results indicate that health care professionals labor under the illusion of giving information to women at a time when this information cannot be processed by all of these women.

While there are many normative and descriptive decision-making models, these do not adequately explain the decision processes, which occur in a naturalistic setting when a person is deciding on medical treatment for life-threatening disease under uncertainty, in an intensely stressful and, time limited situation (Pierce, 1996; Pierce & Hicks, 2001). Also, normative models have been criticized as being too rational, inflexible and probabilistic when applied to stressful decisions related to treatment for life threatening illness (Balneaves & Long, 1999). However, one approach, which has been used in research describing patient decision-making behavior (Pierce, 1988; Pierce 1993; Pierce, 1996), is Information Processing Theory (Newell, 1972). Research using this theory traces the decision processes of a person while they are making a decision.

Few studies have attempted to capture and describe the decision styles and processes of decision-making of women when they are asked to choose between treatment alternatives for early breast cancer. One qualitative study (Pierce, 1993), which attempted to describe the decision-making process of 48 women with early breast cancer, used qualitative analysis and identified three primary decision style groups. These groups were identified by Pierce (Pierce, 1993) as Deferrer, Delayer and Deliberator. The women in each group were described as having the following characteristics. Women in the Deferrer group (41%) were strongly influenced by the salience of an alternative and made quick, conflict-free decisions. Women in the Delayer (44%) decision style group tended to put off making a decision until a salient feature of one of the alternatives influenced the preference. Delayers tended to use an unstructured approach and were strongly influenced by the emotional response to characteristics of various treatment options. In contrast, the women in the Deliberator group (15%) usually identified the decision-making as their personal responsibility and investigated each alternative in a systematic and thorough manner (Pierce, 1993).

Other research has found that there can be wide variation in women's preferences for their involvement in their treatment decisions (Leinster, 1989) and that these preferences can alter over time (Butow, 1997) and under differing contexts (Pierce & Hicks, 2001). Furthermore, some other studies have reported that, generally women diagnosed with early breast cancer wanted to play a passive role in their treatment decision-making (Beaver et al., 1996; Degner et al., 1997; Johnson et al., 1996; Siminoff & Fetting, 1991). In addition, socio-demographic factors such as a woman's age (Beisecker, 1988; Johnson et al., 1996; Meyer, Russo, & Talbot, 1995) and level of education (Graling & Grant, 1995; Siminoff & Fetting, 1991; Street, Voigt, Geyer, Manning, & Swanson, 1995) have been reported to influence their preferred participation level for decision making related to their treatment. Other influencing factors on the process of treatment decision-making cited are women's values, expectations, psychological and physical state and risk perceptions about the treatment options (Pierce & Hicks 2001).

Nonetheless, many women who have been offered a choice between breast cancer treatments have reported less depression and anxiety, regardless of their choice (Fallowfield, 1990) and their participation in choosing a treatment has been found to influence women's psychological well being (Owens, Ashcroft, Leinster, & Slade, 1987; Pierce, 1986; Sinsheimer & Holland, 1987). This has been the case even when the woman's decision has been to defer the choice to their doctor (Kaplan, 1989).

The nature of the process of decision-making of women who are confronted with this diagnosis is poorly understood around the world. Although there have been attempts to develop techniques and decision aids to match women's treatment plan that are consistent with their preferences (O'Connor, 1985), there is a paucity of research regarding the customizing of decision support by bolstering women's decision style processes. Therefore, it is difficult for health professionals such as nurses, to determine the best ways to help women with their process of treatment decision-making. Many women when they are unsure about how they should make this treatment decision seek assistance from nurses.

Specialist Breast Care Nurses are now an important part of the treatment team in many countries and if nurses are to provide women with adequate decision support, more evidence is needed to assist in developing customized measures to help guide women with their process of choosing early breast cancer treatment. Currently, nurses do not have any structured methods to guide the matching of women's decision styles and preferences with this care. To better understand and interpret this treatment decision-making process, it is essential that a foundation is laid about the prediagnostic treatment decision-making behavior of women by using an accurate predecision measure.

The aim of this study was to identify women's prediagnostic decision-making styles, decision processes and influencing socio-demographic variables relating to choosing early breast cancer treatment. To address this aim, the following research questions were posed by this study:

1. What are women's pre-diagnostic decision-making styles related to choosing early breast cancer treatment?
2. What are women's pre-diagnostic decision-making styles and influencing socio-demographic variables related to choosing early breast cancer treatment?
3. What are women's pre-diagnostic decision processes related to choosing early breast cancer treatment?
4. What are women's pre-diagnostic decision processes and influencing socio-demographic variables related to choosing early breast cancer treatment?

METHOD

The research variables for the study were defined as follows:

- Decision-making behavior referred to the decision-making processes and decision styles used to choose treatment for early breast cancer.
- Decision-making processes were the influential considerations deemed important when choosing medical treatment for early breast cancer.
- Decision styles related to Michigan Assessment of Decision Styles (MADS) (Pierce, 1996) which consists of scores on the four decision style factors of Deferring, Avoiding, Information Seeking and Deliberation. These factors represent the patient's position on a continuum from avoidance to engagement in the decision making process (Pierce, 1996).
- Prediagnostic decision-making was the process women use to choose medical treatment if they were hypothetically diagnosed with early breast cancer.

Sample

Following the conduct of a pilot study ($N = 47$) the present study consisted of a nonprobability sample of 377 women who were seeking routine mammography screening at a Brisbane breast clinic. Brisbane is the capital city of the state of Queensland (Australia) and contains a population of approximately 1 million people.

The rationale for selecting this sample was that mammography is a screening procedure for breast cancer and therefore, these women are most likely to be in the mindset of possibly being diagnosed with breast cancer. Consequently, for these women, the factors concerning breast cancer are forefront in their mind; gathering data at this time is the closest match to women diagnosed with breast cancer without increasing additional stress to women in the midst of a breast cancer diagnosis or treatment. Also, this prediagnostic information lays the foundation in an attempt to better understand the way the process of women's decision-making may alter once they are diagnosed with early breast cancer. This data collection method also allowed the questionnaire (PDPQ) to be further developed and refined before being tested on women with early breast cancer and facilitated access in a feasible time period to a large number of women who were seeking routine breast cancer screening.

Procedure

Women were given written information about the study when they arrived at the breast-screening clinic. If the women expressed a desire to participate (nonprobability sampling) in the research, they were given the consent form and the questionnaire to complete while waiting for their mammography screening. After completing the questionnaire the participants placed both items in a sealed box located in the waiting room.

Ethics

This study gained ethical approval from the researchers' university human research ethics committee (James Cook University) and included a component where the clinic's Specialist Breast Nurses gave support to women in the study, if required. That is, if women felt distressed by any questions contained on the questionnaire, they were asked to talk to the Specialist Breast Nurse. No women approached the clinic nurses or identified in the open-ended questions at the end of the questionnaire that they expressed distress while participating in the study.

Questionnaire

The Pre-Decision Portfolio Questionnaire used in this study was developed by Pierce (1996), following the analysis of a grounded theory study of 48 women diagnosed with early breast cancer (Pierce, 1993). This instrument consisted of items collecting information from the participants relating to their socio-demographic background; decision-making process and decision style relating to early breast cancer treatment and, had established content and construct validity (Pierce, 1996). Specifically, the questionnaire consisted of the following closed-ended questions relating to:

- Demographic variables: consisted of 13 items relating to age; education; marital status; postcode; occupation; employment status; income; family structure; health insurance status; personal and family history experience of breast cancer.
- Decision-making process: 25 items asked for a rating of the importance of items, which described the decision-making process relating to early breast cancer treatment, for example, "How important is it to you when making a decision that you participate in selecting a treatment?" The rating of the importance of items relating to the decision-making process were measured on a 5- point Likert scale (not important at all = 1 to critically important = 5).
- Decision-making style: the Michigan Assessment of Decision Style (MADS) is a 16-item instrument (Pierce, 1996) on a 5-point Likert scale to measure four key predecision behaviors. For MADS the Likert scale ranged from "strongly disagree" to "strongly agree (score 1 to 5, respectively). Two factors, Avoidance ($\alpha = 0.63$) consisted of four items (total possible score = 20) and Deferring Responsibility ($\alpha = 0.76$) consisted of three items (total possible score = 15), indicate a tendency or preference to minimize personal involvement in the decision and defer the responsibility to another. The two remaining factors, Information Seeking ($\alpha = 0.80$) consisted of four items (total possible score = 20) and Deliberation ($\alpha = 0.85$) consisted of five items (total possible score = 25), indicate an inclination of the participants for being involved in the decision-making process and seeking information and structuring a systematic plan for making a decision.

Statistical Analysis

In meeting the study's aims, a descriptive analysis of all the data was performed following the data cleaning process. The MADS (Pierce, 1996) items in each factor (Avoidance [4 items], Deferring Responsibility [3 items], Information Seeking [4 items] and Deliberation [5 items]) were totaled. Numerical variables were described as mean values and standard deviations (*SD*) or median values and inter-quartile ranges (IQR). The MADS decision style factors were described by median values and IQR, as their distributions were skewed. Mean values and *SD* were additionally presented for comparisons with previously published data. Chi-square tests, Fisher's exact tests, *t*-tests, Analysis of Variance, and nonparametric tests were used to assess bivariate associations between demographic variables and variables of decision styles and processes, as appropriate.

Multiple linear regression analyses were used to identify independent demographic predictors of the four decision style factors. All potential demographic predictors were dummy coded for the multivariate analyses and stepwise forward and backward modeling processes were used. The MADS decision style factors were logarithmic transformed as their distributions were skewed. A model was accepted as stable if both forward and backward results were identical. Potential confounders were added to the model as independent variables and their effects were judged based on changes in the regression coefficients of the predictors in the model. The confounder age was adjusted by the process of entering the independent variables into the equation hierarchically following the procedure as detailed by Kleinbaum and colleagues (1982). Results of multiple linear regression analyses were presented as regression coefficients together with 95%-confidence intervals (95% CI). Statistical analysis was performed using SPSS for Windows, release 6.1.3. Throughout the statistical analysis a significance level of 0.05 was assumed.

RESULTS

Socio-Demographic Characteristics

A total of 377 women participated in the study (response rate = 66%). Many women who declined to participate in the study attended the clinic during a break from their workplace and did not want to be delayed in going back to work. The participants' ages ranged between 33 and 76 years (mean age 52 years, *SD* ± 8.2 years) with 80.6% living in the urban area of Brisbane, Queensland, Australia. The highest level of education reported by the participants was completion of High School (57.9%), Technical and Further Education (TAFE) (8.3%) and University (33.8%). The majority (86%) of the participants reported living with somebody else in their household. A majority of participants (83.9%) reported they believed in God. Over one-half (66.1%) of the women were employed. Six participants reported a personal history of breast cancer and 47.1% identified that they had a family history of breast cancer. A large percentage (82.9%) of the sample reported paying private health insurance and 23.9% of the women said their household income was more than $27,500 (AUS) per person per year.

The participants were also asked that if they were diagnosed with breast cancer at the time of the survey which treatment would they choose. Almost three-quarters (73.3%) indicated they would choose to undergo a lumpectomy with radiation, as compared to 26.7% of the participants who chose mastectomy treatment.

Decision Styles (MADS)

What are women's pre-diagnostic decision-making styles related to choosing early breast cancer treatment? Of 366 participating women (11 missing values), 19.9% strongly agreed to all three items of the MADS factor Deferring Responsibility (median = 11, IQR = [9,14], mean = 11.2, *SD* = 2.8), 0.3% strongly agreed to all four factors of Avoidance (median = 4, IQR = [4, 7], mean = 5.8, *SD* = 2.6), 32.7% strongly agreed on all four items of Information Seeking (median = 16, IQR = [12, 20], mean = 15.9, *SD* = 3.9) and 63.4% strongly agreed to all five items of Deliberation (median = 25, IQR = [23, 25], mean = 23.1, *SD* = 3.3).

Decision Styles (MADS) and Socio-Demographic Variables

What are women's pre-diagnostic decision-making styles and influencing socio-demographic variables related to choosing early breast cancer treatment? Older participants were more likely to score higher on Deferring Responsibility items ($p = 0.003$) than younger participants (see Table 1). Participants who were currently employed were more likely to score lower in the Avoidance factor ($p = 0.032$), but higher in the Information Seeking ($p = 0.004$) and Deliberation factors ($p = 0.005$)

TABLE 1. Median and Inter-Quartile Ranges of Decision Style Factors (MADS) in Categories of Socio-Demographic Information of Australian Women Screening for Breast Cancer

	Deferring Responsibility	Avoidance	Information Seeking	Deliberation
Age < 50 yrs ($n < 173$)	11 [9,13]	4 [4, 7]	17 [12, 20]	25 [23, 25]
Age > 50 yrs ($n = 196$)	12 [9, 15]**	5 [4, 8]	16 [12, 20]	25 [22, 25]
Living non-urban ($n = 63$)	11 [9, 13]	4 [4, 7]	16 [12.25, 20]	25 [23, 25]
Living urban ($n = 261$)	11 [9, 14]	4.5 [4, 7]	17 [12, 20]	25 [23, 25]
Living with somebody ($n = 314$)	11 [9, 14]	4 [4, 7]	16 [12, 20]	25 [23, 25]
Single living ($n = 51$)	11 [9, 13]	5 [4, 7]	17 [13, 20]	25 [22, 25]
Up to high school education ($n = 209$)	11 [9, 14]	5 [4, 8]	16 [12, 20]	25 [22, 25]
TAFE ($n = 30$)	10 [9, 12.5]	4.5 [4, 6.75]	18 [12, 20]	25 [23, 25]
University education ($n = 122$)	11 [9, 13.25]	4 [4, 6]***	17 [13.75, 20]	25 [23, 25]
Believer in God(s) ($n = 308$)	11 [9, 14]	4 [4, 7]	16 [12, 20]	25 [23, 25]
Non-believer ($n = 59$)	12 [9, 14]	4 [4, 7]	16 [14, 20]	25 [20.75, 25]
Non-professional occupation ($n = 233$)	11 [9, 14]	5 [4, 7]	16 [12, 20]	25 [23, 25]
Professional occupation ($n = 98$)	11 [9, 13]	4 [4, 6]	18 [14, 20]	25 [25, 25]
Retired ($n = 46$)	11 [9, 15]	6 [4, 8]*	13.5[12, 16]**	25 [17, 25]**
Currently employed ($n = 238$)	11 [9, 14]	4 [4, 6]	18 [13, 20]	25 [23, 25]
Currently unemployed ($n = 76$)	11 [9, 13.75]	5 [4, 8]	16 [12, 20]	25 [19.25, 25]
Retired ($n = 46$)	11 [9, 15]	6 [4, 8]*	13.5[12, 16]**	25 [17, 25]**
Household income per person per year				
< AUS $ 20,000 ($n = 188$)	11 [9, 13]	5 [4, 7]	16 [12, 20]	25 [21.25, 25]
> AUS $ 20,000 ($n = 118$)	11 [9, 14]	4 [4, 7]*	18 [13, 20]	25 [24, 25]*
Personal history of breast cancer				
No ($n = 363$)	11 [9, 14]	4 [4, 7]	16 [12, 20]	25 [23, 25]
Yes ($n = 6$)	11.5 [10, 14]	4.5 [4, 7.5]	14.5 [9.75, 20]	24 [15.75, 25]
Family history of breast cancer				
No ($n = 193$)	11 [9, 13]	4 [4, 6]	16 [12, 20]	25 [23, 25]
Yes ($n = 172$)	11 [9, 14]	5 [4, 8]*	17 [13, 20]	25 [23, 25]
Private health insurance				
No ($n = 63$)	11 [9, 14]	5.5 [4, 8]	18 [12, 20]	25 [23.75, 25]
Yes ($n = 306$)	11 [9, 14]	4 [4, 7]*	16 [12, 20]	25 [23, 25]

*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

compared to participants who were currently unemployed or retired. Similarly, participants in professional occupations or with household income of more than $20,000 per person per year scored higher in Deliberation ($p = 0.003$, $p = 0.020$, respectively) and lower in Avoidance ($p = 0.022$ and $p = 0.024$, respectively).

Multivariate linear regression analysis found that increasing age was significantly related to an increasing score in the decision style factor Deferring Responsibility (regression coefficient = 0.0053, 95% CI = 0.00095 to 0.0097, $p = 0.017$); adjusted for the confounding effect of employment status (unemployed versus employed: $p = 0.238$, retired versus employed: $p = 0.545$). Increasing age (regression coefficient = 0.0056, 95% CI = 0.00085 to 0.010, $p = 0.021$) and level of education (TAFE versus up to high school: $p = 0.096$; university versus up to high school: $p < 0.001$) were significantly related to an increasing score in the decision style factor Avoidance. Compared to nonprofessionals, professional women were more likely to score higher (regression coefficient = 0.079, 95% CI = 0.0014 to 0.149, $p = 0.026$), while retired women were more likely to score lower (regression coefficient = -0.134, 95% CI = -0.247 to -0.021, $p = 0.021$) on the decision style factor Information Seeking (adjusted for the confounding effect of age: $p = 0.405$). Compared to employed women, unemployed (regression coefficient = -0.076, 95% CI = -0.119 to -0.034, $p < 0.001$) and retired (regression coefficient = -0.010, 95% CI = -0.154 to -0.045, $p < 0.001$) women scored lower on Deliberation.

Decision Processes

What are women's pre-diagnostic decision processes related to choosing early breast cancer treatment? More than half (63.5%) of the participants indicated that in making a decision for early breast cancer treatment they would rate wanting to "know if there might be unexpected problems with treatment" as "critically important." Almost three-quarters of participants (74.1%) rated it "critically important" to know the chances of the cancer returning. Over three-quarters (75.8%) of participants indicated it was "critically important" to trust their doctor, ask questions (71.3%) and read a lot of information (53.1%) when they were making a decision about treatment. In addition, when making a decision they would prefer to seek advice from a breast cancer specialist (77.7%, "strongly agreed") and would want to know the possible outcomes of each alternative they were being offered (82.3%, "strongly agreed"). Furthermore, a majority "strongly disagreed" with the following statements: "I would like someone else to make the decision for me" (80.3%) and, "I prefer not knowing the possibility that unexpected things could happen to me" (86.8%). Only 4% of participants indicated it was "critically important" "to have a women doctor" and 3% to "have a doctor the same race as you."

Decision Processes and Socio-Demographic Information

What are women's pre-diagnostic decision processes and influencing socio-demographic variables related to choosing early breast cancer treatment? Table 2 outlines participants' agreement to the importance ("critically important" = High) of items considered being required when making a decision for breast cancer treatment. In Table 2 only the variables, which were found to have significant effects, were presented.

Of the participating women, 35% found it "critically important" to "follow the doctor's advice." Women who judged this statement as "critically important" were on average older (53 years) compared to women who judged this statement as less important (51 years) ($p = 0.044$). Age was identified as an influencing variable to the following questions, "follow your doctor's advice" ($p = 0.044$); "trust your doctor" ($p = 0.024$); "have faith in God" ($p < 0.001$); "know the chances the cancer might return" ($p < 0.001$); "have a doctor who asks what you want" ($p = 0.011$); and "have a doctor who cares about you" ($p = 0.028$). Other influencing variables to the decision process questions were whether the participants were currently employed, worked as a professional, believed in God, had private health insurance, their education status, and whether they lived alone.

DISCUSSION

Many women in the present study were found to obtain higher scores for Deliberation, Deferring Responsibility and Information Seeking but lower scores on the Avoidance decision style factor. The large percentage of women obtaining a higher score on the Deliberation decision style factor contrasts with the findings by Pierce (1993). However, this result may be explained by the fact that in this study these women were undergoing routine mammography screening and therefore not necessarily experiencing the same levels of distress and cognitive demand as women diagnosed with breast cancer. Although it is interesting to speculate whether women's decision styles alter when they are diagnosed with a life threatening illness such as breast cancer, and if so, in what way these changes to decision styles occur. Also women may change their decision as well as their involvement in the decision-making process when diagnosed with early breast cancer.

However, the major limitation of this study is that it examined the decision processes and style of women undergoing routine breast cancer screening. Therefore, the results report what these women predict their decision-making processes would be for treatment if diagnosed with early breast cancer. These women were answering these questions while undergoing some stress from the mammography screening, but not necessarily the intense psychological stress expressed by women newly diagnosed with breast cancer. Therefore the women in the sample may have been able to process the treatment information more effectively and match their treatment choices with their values, preferences and belief system more likely leading to quality decision-making. Some research (Cimprich, 1999) has demonstrated that the intense emotional distress experienced by women diagnosed with breast cancer can affect some women's cognitive function and their ability to compare options for early breast cancer. As women's processes or style of decision-making involves specific cognitive skills, there is no clear evidence, to

TABLE 2. Australian Women Screening for Breast Cancer Ratings of the Importance of Questions of Decision Processes for Choosing Early Breast Cancer Treatment (N = 377) and Relationships to Potential Influencing Factors*

Question	Score		Influencing Variables			
"Follow your doctor's advice"	Low	65%	Age	51 yr.		
	High	35%		53 yr.		
				$p = 0.044$	Employed	58%
"Trust your doctor"	Low	24%	Age	53 yr.		69%
	High	76%		51 yr.		$p = 0.04$
				$p = 0.024$		
"Have faith in God"	Low	62%	Age	50 yrs	Believer in God	78%
	High	38%		54 yr.		95%
				$p < 0.001$		$p < 0.01$
"Get the treatment over as soon as possible"	Low	64%				
	High	36%				
"Participate in selecting treatment"	Low	45%	Employed	60%		
	High	55%		72%		
				$p = 0.017$		
"Ask questions"	Low	29%	Professional	22%	Employed	50%
	High	71%		78%		73%
				$p < 0.001$		$p < 0.001$
"Read a lot of information"	Low	47%	Professional	22%		
	High	53%		30%		
				$p = 0.026$		
"Talk to other women who have cancer"	Low	62%	Single Living	18%		
	High	38%		8%		
				$p = 0.018$		
"Have the advice of the best specialists"	Low	20%				
	High	80%				
"Know if there are any side effects"	Low	31%	Employed	59%	Health Insurance	89%
	High	69%		70%		81%
				$p = 0.037$		$p = 0.045$
"Know if there might be unexpected problems with treatment"	Low	37%	Employed	59%		
	High	63%		70%		
				$p = 0.032$		
"Know the chances that the cancer might return"	Low	26%	Age	54 yr.	Employed	56%
	High	74%		51 yr.		70%
				$p < 0.001$		$p = 0.020$
"Feel in control of choosing treatment"	Low	56%				
	High	44%				
"Have a doctor who asks what you want"	Low	36%	Age	53 yr.	Employed	55%
	High	64%		51 yr.		73%
				$p = 0.011$		$p < 0.001$
"Have a woman doctor"	Low	96%				
	High	4%				
"Have a doctor the same race as you"	Low	97%	University Education	35%		
	High	3%		0%		
				$p = 0.023$		
"Tell the doctor how you feel about treatment"	Low	53%				
	High	47%				

TABLE 2. Continued

Question	Score		Influencing Variables	
"Have a doctor who cares about you"	Low	32%	Age	53 yr.
	High	68%		51 yr.
				$p = 0.028$
"Have someone to talk to"	Low	68%		
	High	32%		
"Have a doctor who listens to you"	Low	36%	University	30%
	High	64%	Education	36%
				$p = 0.028$
"Have a doctor who tells you what to expect"	Low	30%	Employed	56%
	High	70%		70%
				$p = 0.023$
"Have friends and family come to the doctor's visits with you"	Low	76%	Single	16%
	High	24%	Living	8%

*A high score relates to a judgment of "critically important," a low score relates to a judgment of "less than critically important."

date, that indicates whether, or not, women's processes or style of decision-making remains stable under the stressful conditions of being diagnosed with breast cancer and of selecting an immediate treatment option. In addition, while there were many statistically significant findings between the decision style factors and socio-demographic background, these regression coefficients are small. Therefore, decision style factors must be influenced by many more aspects, other than the socio-demographic features measured in this study. These results only explain a little of the variation in the decision style factors and the socio-demographic background measured and hence, there are numerous variables which remain unaccounted and unexplained.

Furthermore, the characteristics of the sample reflect a higher percentage of women who were university educated than the general population and may explain the higher scoring on the MADS factor of Deliberation. Consequently, it is not known how closely the results resemble what occurs in the naturalistic setting and further research is required to examine women's decision styles and processes and the effect of distress on these variables after being diagnosed with early breast cancer. A positive correlation was found between Deliberation and whether women were employed. Women who are employed may be used to taking an active role in decision-making on a day-to-day basis in their workplace and therefore have adapted these processes to hypothetically imagine how they would choose between treatment options for early breast cancer. In addition, over half of the women in the sample were employed and seeking mammography screening on their lunch hour, which may explain the relatively low study participation response rate. Almost three-quarters of the women indicated they would choose the treatment option of lumpectomy with radiation, rather than a mastectomy. This figure is higher than previously reported treatments women choose in Australia (Burcham, 2000) for early breast cancer. However, in Australia, the long distances women often need to travel for treatment and the lack of breast surgeons have been reported by women as influencing their final decision for a mastectomy even if their initial preference may have been for a lumpectomy with radiation treatment (Burcham, 2000). Also, women's final choice for treatment for breast cancer is known to be influenced by personal factors such as the woman's values, participation preference, expectations, psychological and physical state and risk perceptions (Pierce & Hicks, 2001). In addition, the decision-making context consisting of risk, information; time frame, urgency, patient-provider interaction, and environmental stressors (Pierce & Hicks, 2001) are also considered by women and can influence their final treatment choice for early breast cancer. Furthermore, the surgeon's recommendation and the women's perception of cure have been reported as strong influences affecting the women's final treatment choice (Smitt & Heltzel, 1997).

In the present study, positive correlations were identified between the Information Seeking decision style factor and employment. Interestingly, while it is assumed by many health professionals that women want all the information about breast cancer and its treatment, only approximately half (53%) of the women in this study indicated they would want to read a lot of information. It is surprising that more women in the sample did not want to read a lot of information even though approximately one-third of women were well educated and had completed a university degree and therefore would be used to reading and understanding detailed material. Yet, in part, this result may be understood in the context of almost three-quarters of women in the sample wanted to seek advice from a breast cancer specialist, identifying that it was important to trust your doctor. Therefore, the women may believe some information is important when choosing treatment in conjunction with the treatment advice given by the expert namely, the breast cancer specialist. These preferences for information have been reported to be influenced by the woman's age (Galloway et al., 1997; Meyer et al., 1995). Some studies have reported that the woman's age is also an influencing factor for the amount of information women want. For instance, older women have reported to want less information than younger women newly diagnosed with breast cancer (Galloway et al., 1997; Meyer et al., 1995). These findings relate very well with the results of the present study, showing that older women are more likely to score higher on the MADS factors of Deferring Responsibility and Avoidance.

Furthermore, the amount and type of information women require to aid their treatment decision-making is worthy of consideration for nurses, in light of evidence that 94% of Australian women diagnosed with early breast cancer wanted the information they received summarized (Lobb et al., 2001). As a result, the type and amount of information provided is of critical importance to nurses when they are planning decision support for these women. This is because, it has been found that women who want an active role in their treatment decision-making want detailed information about their illness (Hack, Degner, & Dyck, 1994). Also, while many women may want to talk to other women who have had cancer only about one-third (38%) of women in the present study indicated that this factor would be important to them when making a decision for breast cancer treatment. Then again, these women's preference to talk to breast cancer survivors may change if they were diagnosed with the disease and deciding on a treatment option.

Age was identified as the strongest predictor for influencing women's scores on the Avoidance and Deferring Responsibility decision style factors and, their ranking of the importance of items relating to the decision process. These results are consistent with the findings of other studies, which have reported that older patients gave more authority to doctors in their decision relating to their medical treatment and were less likely to challenge the authority of physicians (Beisecker, 1988). In addition, older women have been found to make faster decisions than younger women (Meyer et al., 1995). It has been suggested that the reason for this may lie in their wanting to reduce the period of uncertainty and cognitive overload involved in making the decision (Meyer et al., 1995). Other studies have reported that college educated patients younger than 65 years were more likely to be active participants in these consultations (Street et al., 1995) and younger women under the age of 40 years wanted their surgeon to decide on a treatment plan, including the type of surgery required if they also considered breast restoration by mammoplasty (Reaby, 1998). However, this finding is not surprising since younger women of this age group are usually diagnosed with a more aggressive tumor and are at a higher risk of psychological morbidity (Bloom, 1987) and therefore, would defer the treatment choice to the breast cancer specialist.

Interestingly, over one-half the women in the sample indicated they thought it was critically important for them to "participate in selecting treatment," which is higher than some other reports (Beisecker, 1988) although lower than other studies (Petrisek, Laliberte, Allen, & Mor, 1997). This finding is particularly interesting since the majority of women obtained higher scores for the Deliberation decision style factor, which asked questions such as, "I would carefully consider the risks of each option as I was making a choice." This last finding raises the question about what action women believe is involved in participating in decision making for treatment and whether women interpret the meaning of participation in different ways. Certainly, in a study of cancer patients it has been reported that patients expressed considerable variations in their views about their participation in decision making (Sainio & Eriksson, 2001). In addition, the finding that 65% of women would follow their doctor's advice is lower from other reported findings (Sinsheimer & Holland, 1987).

Increasing the understanding of factors which assist women in their treatment decisions can aid nurses in designing customized decision support interventions which facilitate informed consent and guide women to making a quality decision that leads to their satisfaction. This is especially important since there is evidence that discussions with a specialist breast nurse can reduce psychological morbidity of women and increase their understanding of information and perceptions of the support available for women with breast cancer (Clacey, Thomas, & Pearson, 1988; Maguire, Brooke, Tait, Thomas, & Sellwood, 1983; Maguire, Tait, & Brooke, 1980; McArdle, 1996). Therefore, further research is required to determine the clinical significance of this study, by comparing these results with women diagnosed with early breast cancer to determine if the distributions of decision style factors alter during this time and, the impact of distress on these variables. However, the findings of this study suggest women can vary dramatically in their process of decision making and therefore, it is recommended that women receive individual assessment by nurses to determine their desired level of engagement in decisions for medical treatment for early breast cancer.

The literature shows that quality decisions lead to greater satisfaction, better postsurgical adjustment, improved convalescence, and minimal regret by women. Thus discovering more of what constitutes a quality decision is important.

In conclusion, this preliminary study provides baseline data about Australian women's prediagnostic decision-making for early breast cancer treatment and the PDPQ measure. This information can be used to design future studies of women who are diagnosed with early breast cancer in an attempt to better understand the unaided decision-making process in designing adequate customized decision support interventions.

REFERENCES

American Cancer Society. (2000). *National breast cancer awareness month.* American Cancer Society. Retrieved July 2, 2001 from www.cancer.org/NBCAM_fastfacts.html

Australian Institute of Health and Welfare. (1998). *Australia's Health 1998.* Canberra, Australian: Australian Government Publishing Service.

Balneaves, L. G., & Long, B. (1999). An embedded decisional model of stress and coping: Implications for exploring treatment decision making by women with breast cancer. *Journal of Advanced Nursing, 30*(6), 1321-1331.

Beaver, K., Luker, K. A., Owens, R. G., Leinster, S. J., Degner, L. F., & Sloan, J. A. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing, 19*(1), 8-19.

Beisecker, A. E. (1988). Aging and the desire for information and input in medical decisions: Patient consumerism in medical encounters. *The Gerontologist, 28*(3), 330-335.

Bloom, J. (1987). Psychological response to mastectomy. *Cancer, 59,* 189-196.

Burcham, J. (2000). *Breast Reconstruction: A Review of the research and patient and professional resources.* Kings Cross: NHMRC National Breast Cancer Centre.

Butow, P. M., Dunn, S., Maclean, M., Tattersall, M. H., & Boyer, M. J. (1997). The dynamics of change: Cancer patient's preferences for information, involvement and support. *Annals of Oncology, 8,* 857-863.

Campora, E., & Vitullo, M. T., Naso, C., Giudici, S., Camoirano, A., Repetto, L., & Russo, R. (1992). The impact of chemotherapy on the quality of life of breast cancer patients. *Journal of Chemotherapy, 4*(1), 59-63.

Cimprich, B. (1999). Pretreatment symptom distress in women newly diagnosed with breast cancer. *Cancer Nursing, 22*(3), 185-195.

Clacey, R., Thomas, C., & Pearson, H. (1988). Does counselling by nurses for mastectomy patients work? In M. Watson, & C. Thomas (Eds.), *Psychosocial Oncology* (pp. 159-168). Oxford: Permagon.

Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., Bilodeau, B., Watson, P., & Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. *Journal of the American Medical Association, 277*(18), 1485-1492.

Fallowfield, L. J. (1990). Psychosocial adjustment after treatment for early breast cancer. *Oncology, 4*(4), 89-97.

Fisher, B., Redmond, C., Poisson, C., Margolese, R., Wolmark, N., Wickerham, L., Fisher, E., Deutsch, M., Caplan, R., & Pilch, Y. (1989). Eight-year result of a randomized clinical trial comparing total mastectomy and lumpectomy with of without radiation in the treatment of breast cancer. *The New England Journal of Medicine, 320,* 822-828.

Galloway, S., Graydon, J., Harrison, D., Evans-Boyden, B., Palmer-Wickham, S., Burlein-Hall, S., Rich-van der Biji, L., West, P., & Blair, A. (1997). Informational needs of women with a recent diagnosis of breast cancer: Development and initial testing of a tool. *Journal of Advanced Nursing, 25*(6), 1175-1183.

Graling, P. R., & Grant, J. M. (1995). Demographics and patient treatment choice in stage I breast cancer. *American Operating Room Nurse Journal, 62*(3), 376-384.

Hack, T. F., Degner, L. F., & Dyck, D. G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science Medicine, 39*(2), 279-289.

Hughes, K. K. (1993). Psychosocial and functional status of breast cancer patients. The influence of diagnosis and treatment choice. *Cancer Nursing, 16*(3), 222-229.

Janis, I. L., & Mann, L. (1977). *Decision-making: A psychological analysis of conflict, choice and commitment.* New York: Free Press.

Johnson, J. D., Roberts, C. S., Cox, C. E., Reintgen, D. S., Levine, J. S., & Parsons, M. (1996). Breast cancer patients' personality style, age, and treatment decision making. *Journal of Surgical Oncology, 63*(3), 183-186.

Kaplan, S., Greenfield, S., & Ware, Jr., J. E. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical Care, 27,* S110-S127.

Kissane, D. W., Clarke, D. M., Ikin, J., Bloch, S., Smith, G. C., Vitetta, L., & McKenzie, D. P. (1998). Psychological morbidity and quality of life in Australian women with early-stage breast cancer: A cross-sectional survey. *Medical Journal Australia, 169*(4), 192-196.

Kleinbaum, D. K. L., & Morgenstern, H. (1982). *Epidemiologic research: Principles and quantitative methods.* New York: Van Nostrand Reinhold.

Leinster, S., Ashcroft, J., Slade, P., et al. (1989). Mastectomy versus conservative surgery: Psychosocial effects of the patient's choice of treatment. *Journal of Psychosocial Oncology, 23*(1), 179-192.

Lobb, E. A., Kenny, D. T., Butow, P. N. & Tattersall, M. H. (2001). Women's preferences for discussion of prognosis in early breast cancer. *Health Expectations, 4,* 48-57.

Maguire, P., Brooke, M., Tait, A., Thomas, C., & Sellwood, R. (1983). The effect of counselling on physical disability and social recovery after mastectomy. *Clinical Oncology, 9*(4), 319-324.

Maguire, P., Tait, A., & Brooke, M., Thomas, C., & Sellwood, R. (1980). Effect of counselling on the psychiatric morbidity associated with mastectomy. *British Medical Journal, 281,* 1454-1456.

Maraste, R., Brandt, L., Olsson, H., & Ryde-Brandt, B. (1992). Anxiety and depression in breast cancer patients at start of adjuvant radiotherapy. Relations to age and type of surgery. *Acta Oncologica, 31*(6), 641-643.

McArdle, A. L. (1996). Psychological support for patients undergoing breast cancer surgery. *British Medical Journal, 312,* 813-817.

Meyer, B. J., Russo, C., & Talbot, A. (1995). Discourse comprehension and problem solving: Decisions about the treatment of breast cancer by women across the life span. *Psychological Aging, 10*(1), 84-103.

Newell, A. S. (1972). *Human problem solving.* Englewood Cliffs, NJ: Prentice-Hall.

NHMRC National Breast Cancer Centre. (1998). *Talking about prognosis with women who have early breast cancer: What they prefer to know and guidelines to help explain it effectively.* Kings Cross, Sydney: NHMRC National Breast Cancer Centre.

O'Connor, A. M., Boyd, N. F., Tritchler, D. C., Kriukov, Y., Sutherland, H. & Till, J. E. (1985). Eliciting preferences for alternative cancer drug treatments: The influence of framing, medium and rate variables. *Medical Decision Making, 5*(4), 453-463.

Owens, R. G., Ashcroft, J. J., Leinster, S. J., & Slade, P. D. (1987). Informal decision analysis with breast cancer patients: An aid to psychological preparation for surgery. *Journal of Psychosocial Oncology, 5*(2), 23-33.

Petrisek, A. C., Laliberte, L. L., Allen, S. M., & Mor, V. (1997). The treatment decision-making process: Age differences in a sample of women recently diagnosed with non-recurrent, early-stage breast cancer. *The Gerontologist, 37*(5), 598-608.

Pierce, P. F. (1986). *Decision-making of women with early stage breast cancer: A qualitative study of treatment choices.* UMI Dissertation Services, University of Michigan, Ann Arbor.

Pierce, P. F. (1988). Women's experience of choice: Confronting the options for treatment of breast cancer. In J. Harness, H. Obermas, A. Lichter, D. Alder, & R. Cody (Eds.), *Breast cancer: Collaborative management.* Chelsea, MI: Lewis Publishers.

Pierce, P. F. (1993). Deciding on breast cancer treatment: A description of decision behavior. *Nursing Research, 42*(1), 22-28.

Pierce, P. F. (1996). When the patient chooses: Describing unaided decisions in health care. *Human Factors, 38*(2), 278-287.

Pierce, P. F., & Hicks, F. D. (2001). Patient decision-making behavior: An emerging paradigm for nursing science. *Nursing Research, 50*(5), 267-274.

Pinder, K. L., Ramirez, A., & Black, M. (1993). Psychiatric disorder in patients with advanced breast cancer. *European Journal Cancer, 29A*(4), 524-527.

Reaby, L. L. (1998). The quality and coping patterns of women's decision-making regarding breast cancer surgery. *Psycho Oncology, 7*(3), 252-262.

Sainio, C. L., & Eriksson, E. (2001). Cancer patient's views and experiences of participation in care and decision making. *Nursing Ethics, 8*(2), 97-113.

Siminoff, L. A., & Fetting, J. H. (1991). Factors affecting treatment decisions for a life-threatening illness: The case of medical treatment of breast cancer. *Social Science Medicine, 32*(7), 813-818.

Sinsheimer, L. M., & Holland, J. C. (1987). Psychological issues in breast cancer. *Seminars in Oncology, 14*(1), 75-82.

Smitt, M. C., & Heltzel, M. (1997). Women's use of resources in decision-making for early-stage breast cancer: Results of a community-based survey. *Annals of Surgical Oncology, 4*(7), 564-569.

Street, R. L., Jr., Voigt, B., Geyer, C., Jr., Manning, T., & Swanson, G. P. (1995). Increasing patient involvement in choosing treatment for early breast cancer. *Cancer, 76*(11), 2275-2285.

Yates, J. S. (1992). The risk construct. In J. Yates (Ed.), *Risk taking behaviour* (pp. 2-25). Chichester, England: Wiley.

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The Experience of the Family Caregivers' Role: A Qualitative Study

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In Ireland, there is a dearth of research exploring the perceived health and social care needs and experiences of family caregivers of older people. In response, this research study was conducted to explore the profile, role and needs of family caregivers as a means of understanding their experience of caring. The study also set out to identify coping strategies employed by caregivers and explore positive aspects of the caring relationship in relation to quality of life, information needs, day care and respite care, transport and emotional support. A multimethod approach used interviews, focus groups and postal questionnaires. In the main study a pretested questionnaire, comprising closed and open questions was used with a stratified, systematically randomized sample of caregivers in urban and rural home care settings, of which 52% of respondents to the questionnaire volunteered to partake in in-depth interviews. This article per deals predominantly with the findings arising from 10 in-depth qualitative interviews. The data yielded a rich and

Appendix 3- Pre-diagnostic values article

Australian women's prediagnostic values and influencing sociodemographic variables relating to treatment choices for early breast cancer treatment

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Abstract

Women are often asked by their doctors to choose their preferred treatment for early breast cancer. Evidence shows that many women are distressed and confused about how to make this treatment decision and frequently seek help from nurses. Very little is known about women's value-centred decision-making in relation to selecting treatment for breast cancer and for nurses it is difficult to know how to assist these women with this process. In this study, 377 women participated prior to undergoing routine mammography screening and the data were collected using the Pre-Decision Portfolio Questionnaire (PDPQ) by Pierce[1]. The partipants identified that expected treatment outcomes were the most important factor in choosing early breast cancer treatment. The majority reported that it was very important that a treatment would reduce the chances the cancer would return (95.6%), increase the length of their life (82.1%) and lead them to being healthy (80.4%). In addition, the participants indicated that it was important, or very important, that the emotional consequences of the treatment did "not make you depressed" (88.6%) or "sad" (90.4%) and should "keep you from worrying" (97%) and "give you peace of mind" (98.6%). Other factors, such as treatment's side effects, were identified as less important. Age, employment, education and having a family history of breast cancer were found to be significant influencing variables on the values of the participants. It was concluded that assessing and understanding the treatment values of women can help nurses focus on areas of importance to the woman and lead to informed decision-making when they are choosing treatment for early breast cancer.

Introduction

Throughout the industrialised world, breast cancer remains a major cause of morbidity and mortality in women. In western countries the incidence of women developing this disease during their lifetimes is one in eleven in Australia[2], one in nine in the UK[3]; one in eight in the USA[4]. Each year over 11,000 Australian women are diagnosed with breast cancer[2] and up to one third of these women are aged <50 years[2,5].

Women who are diagnosed with an early stage of breast cancer have more treatment choices and a better prognosis than women who have developed an advanced form of the disease. In Australia, the TNM Clinical Classification defines early breast cancer as a tumour >2cm and <5cm in diameter, with no fixed lymph nodes and no evidence of metastases (this corresponds to tumours T11-2, N0-12, M0)[6]. The surgical recommendations for women diagnosed with early breast cancer are a mastectomy or breast conservation surgery (lumpectomy); both treatment options include auxiliary dissection[6].

After diagnosis of breast cancer, women are vulnerable to high levels of stress [7,8,9] psychological distress, and they suffer the consequent upheaval to their emotional wellbeing [10,11]. The emotional turmoil places them at risk of developing interpersonal difficulties, body image and sexuality problems, depression and anxiety [12]. Of Australian women diagnosed, A 34% will be highly distressed or will experience high levels of psychological disturbance; 35.4% will be experiencing distress at three months post-diagnosis and up to 20% at twelve months post-diagnosis [12].

Breast cancer treatment decision-making

The recent fundamental paradigm shift in western countries from the traditional, paternalistic model of healthcare to consumer focused healthcare encourages doctors to shift the treatment decision-making responsibility to the patient. Following a diagnosis of early breast cancer, women are encouraged to participate with their doctor in choosing between equally effective treatment options – mastectomy and lumpectomy with adjuvant radiotherapy and possibly chemotherapy [13,14] – and women choose a treatment plan based on their values, preferences and lifestyle [9].

Many sociodemographic factors, such age [5,16,17] and education [18,19,20] have been identified as influencing this decision-making process. Other factors such as expectations of quality of life, psychological and physical state, perception of risks and preferences about the treatment options [21,22,23] are also known to influence choices for early breast cancer treatment.

There is evidence that women experience better psychological outcomes, such as less depression and anxiety, when they have been involved with their doctor in choosing between breast cancer treatments [7,24,25,26,27]. However, some women do not wish to participate in the responsibility of such decisions and the burden of choice can cause further anxiety [23,28]. The varieties of treatment and information can cause confusion for women, who are already distressed. This is especially the case when asked to make quality of life decisions from unfamiliar medical language [29] and uncertain outcomes [7,6,30]. In Australia, these circumstance can be further compounded by a number of health system barriers, such as a lack of continuity of care for women with breast cancer, the short time between diagnosis and treatment, inconsistency of information given, and the geographical distance of treatment options [4,12].

However, in the last five years in Australia, a number of initiatives to address these deficiencies have been put in place: communication skills training for oncologists [31]; the assessment of cancer patients communication needs [32]; distress levels [33]; the development of the Psychosocial Clinical Practice Guidelines for women with breast cancer [12]; the development of the role of the specialist breast care nurse and their specific competency based standards [34].

Many women may not have suitable access to health services, or possess the emotional and cognitive resources and skills following the diagnosis of breast cancer to make informed quality treatment decisions [35]. Many women are uncertain about choosing treatment and often seek supplementary information and guidance from nurses [9]. Nurses currently do not have structured methods to provide this support and may feel inadequate. The support of nurses in helping women in this decision-making process is vital because women often reflect on their decision both before and after consulting with their doctors.

Decision-making models

Although there are many normative and descriptive decision-making models, these do not adequately explain the process of choosing medical treatment in a naturalistic setting when the person is in a distressed state [8]. Normative models describe what people should do; descriptive models describe what people actually do [36]. Recently, decision science has evolved a new area called 'naturalistic decision-making' to describe how people actually make a decision in a natural setting. Naturalistic decision-making consists of four key features: it is a dynamic process with changing conditions; it has real time reactions to these condition changes; it has ill-defined goals and ill structured tasks; and it involves knowledgeable people [37].

Decision-making for medical treatment

Three major components make up the decision-making process for medical treatment:

1. The decision problem (which has at least two possible choices).
2. The decision-maker (patient).
3. The context (or environment) [21,22].

The conceptual model adapted in this study was the "empiric description of the decision-making" [22]. This model enables nurses to assist patients in their decision-making in difficult, distressing and uncertain situations. The first stage of determining the salience of the problem can be applied to assessing women's values involved in choosing medical treatment [22]. This model examines the problem for the decision-maker (patient) and discusses the sequential stages of diagnostics:

1. Salience of the problem (understanding of the problem, the risks and possible outcomes of each alternative).
2. Decomposition of alternatives (understanding the components of alternatives).
3. Information seeking (need or avoidance for further information).
4. Strategy (existence of a treatment plan).
5. Declaration of choice (decision).
6. Post-decision appraisal (satisfaction of decision choice/s).

Included in the model are questions that nurses can apply to determine (diagnose) the decision support (such as information and psychosocial interventions) necessary to assist the patient in the process of decision-making.

The role of the nurse in decision support

Nurses have an ethical responsibility, "to promote health, to prevent illness, to restore health and alleviate suffering"[38]. For nurses to fulfil these ethical imperatives, it is critical that women receive sufficient information in a way they can process, interpret, and use it as a base for informed consent for choosing care and treatment for early breast cancer. However, the nature of the value-centred decision-making process of women with cancer is complex and not fully understood, and research of aspects of women with breast cancer continues[39,40,41,42,43]. Published studies and future research should guide and assist nurses in their decision support assessment and interventions.

For nurses to help women choose medical treatments that are consistent with their values and lifestyle and improve their satisfaction, more information and understanding is required about what factors women believe are important and what sociodemographic variables influence choice of treatment. Values can be defined as 'ideals, beliefs, customs, modes of conduct, qualities, or goals that are highly prized or preferred by individuals, groups or society', which are culturally based[44]. In decision science, a 'value' is described as attractiveness of a possible outcome[45] and a 'utility' is defined as a patient's preference for a particular alternative[21,46]. Individual decisions are value-centred and choices are mediated (influenced) by their religious, personal and cultural values[22] and satisfaction is related to choices that are consistent with a person's values and expectations[47]. If nurses are able to accurately assess women's values and understand some of the influencing sociodemographic variables, they are able to target and deliver clear information that is important to women to help them make informed treatment decisions. Nurses need to provide information about treatment outcomes in a clear format that women can process and understand in order to help them make informed decisions that are value–centred and suit their lifestyles.

The study

Aim

The aim of this cross-sectional explorative survey was to investigate the prediagnostic values and sociodemographic variables of Australian women that influenced their choice of treatment for early breast cancer. Before evidence-based decision support interventions can be further developed and evaluated, it is essential to obtain an understanding of women's unaided decision-making for choosing medical treatment. Currently, there is limited information available for nurses that provides a structured method to guide the matching of women's values with the care provided. To redress this gap, this study provides a baseline to compare the treatment values of women and the sociodemographic factors that influence them.

Research Question

The research question developed for this study was: What are women's prediagnostic values and influencing sociodemographic variables involved in choosing early breast cancer treatment in a hypothetical scenario?

Definitions

The research variables for the study were defined as:

- Treatment values – the factors important to women when they are choosing hypothetical medical treatment for early breast cancer.
- Pre-diagnostic decision-making – the choosing of medical treatment if they are hypothetically diagnosed with early breast cancer.
- Socio-demographic variables – the background of participants such as age, education level, employment status, occupation and personal and family history of breast cancer.
- Hypothetical scenario – questions relating to what treatment choices they would make if diagnosed with early breast cancer.

Participants

The total non-probability (convenience) sample consisted of 377 women (response rate 66%) who were undertaking routine mammography screening at a Brisbane breast clinic. Brisbane is the capital city of the state of Queensland in Australia. Women who had declined the invitation to participate in the study stated that they had attended the breast clinic during their work time and wanted to return to their workplace as soon as possible.

The rationale for selecting this sample was that mammography is a screening procedure for breast cancer and so the women are already aware of the possibility of being diagnosed with breast cancer. Data gathered from these women are the closest match to women actually diagnosed with breast cancer without increasing the distress to women already in the midst of diagnosis or treatment. This sample also provided contact with a large number of women who were attending routine breast cancer screening.

"How important is it to you that the treatment..."		Result	Influencing variables#			
Treatment outcome						
"allow you to get well quickly?"	Very important	64.9%				
	Average important	28.2%				
	Less important	6.9%				
"be a tried and true treatment?"	Very important	74.0%	Believers in God	86.3%		
	Average important	19.6%		82.4%		
	Less important	6.4%		59.1%		
				p=0.0038		
"let you be healthy?"	Very important	80.4%				
	Average important	19.1%				
	Less important	0.5%				
"let you live a long life?"	Very important	82.1%	Age Mean (±SD)##	51.3 ±7	Professional Occupation	27.2%
	Average important	15.7%		54.4 ±9.1		21.1%
	Less important	2.2%		57.8 ±8.6		37.5%
				p=0.0033		p=0.0082
"help you get completely well?"	Very important	90.1%	Age Mean (±SD)##	51.5 ± 8.0	Employed	69.5%
	Average important	9.6%		56.2 ± 8.1		37.5%
	Less important	0.3%		42		100%
				p=0.022		p=0.067*
"cure you?"	Very important	90.9%	Age Mean (±SD)##	51.5± 8.0	Employed	69.1%
	Average important	8.2%		54.8± 8.6		40.7%
	Less important	0.8%		62.3±3.2		33.3%
				p=0.0090		p= 0.0122*
"get rid of the cancer?"	Very important	93.6%	Employed	68.3%		
	Average important	6.4%		45.0%		
	Less important	0%		0%		
				p=0.0234		
"reduce chances the cancer will come back?"	Very important	95.6%	Employed	68.2%		
	Average important	4.4%		28.6%		
	Less important	0%		0%		
				p=0.098		

Table 1: Participant's (N = 377) rating of the importance of different values relating to potential breast cancer treatment and influencing sociodemographic background variables.

Influencing variables of categorical nature given as percentages in the categories 'very important', 'average important', and 'less important'. For example, for the treatment outcome "be a tried and true treatment?", 86.3% who rated this 'very important' also reported belief in God; 82.4% who rated this 'average important' reported belief in God; and 59.1% who rated this 'less important' reported belief in God (p = 0.0038).

Age is presented by mean value and standard deviation (SD). For example, women who rated the treatment outcome "let you live a long life" as 'very important' had a mean age of 51.3 years; 'average important' a mean age of 54.4 years; and 'less important' a mean age of 57.8 years (p = 0.0033).

* These p-values are results of Fisher's exact test.

"How important is it to you that the treatment...."		Result	Influencing variables			
Side effects						
"not be painful?"	Very important	32.5%				
	Average important	33.9%				
	Less important	33.6%				
"not make you sick?"	Very important	40.2%	University Education	26.3%		
	Average important	32.0%		35.1%		
	Less important	27.8%		47.8%		
				p=0.0112		
"not have many side effects?"	Very important	45.2%				
	Average important	36.8%				
	Less important	18.0%				
"not have serious side effects?"	Very important	59.9%				
	Average important	31.0%				
	Less important	9.1%				
"not be dangerous?"	Very important	82.2%	Professional Occupation	26.6%		
	Average important	14.2%		21.2%		
	Less important	3.6%		46.2%		
				p=0.0243		
Emotional consequences						
"not make you depressed?"	Very important	56.1%	Family history of breast cancer	51.0%		
	Average important	32.5%		47.4%		
	Less important	11.4%		25.6%		
				p=0.0148		
"not make you sad?"	Very important	60.1%	Family history of breast cancer	50.2%	University Education	31.0%
	Average important	30.3%		48.6%		33.3%
	Less important	9.6%		23.5%		57.6%
				p=0.0412		p=0.0363
"keep you from worrying?"	Very important	76.6%	Urban living	78.1%		
	Average important	20.3%		92.4%		
	Less important	3.0%		62.5%		
				p=0.0136		
"give you peace of mind?"	Very important	87.9%				
	Average important	10.7%				
	Less important	1.4%				

Table 1 (continued)

Instrument and data collection

The Pre-Decision Portfolio Questionnaire[1] was used to collect data for the study. This instrument was developed following the analysis of interviews from 48 women diagnosed with early breast cancer in a grounded theory study[9]. Information was collected from participants about their sociodemographic background and their decision-making treatment values relating to early breast cancer treatment[1]. A small group of Australian women representative of the study's population were used to validate the instrument prior to data collection of the sample. The internal consistency reliability of the value items was assessed by the Cronbach alpha method and the results were: Treatment Outcomes = 0.84; Side Effects = 0.80; Emotional Consequences = 0.73; Effects of Treatment on Energy Levels = 0.93; General Perceptions = 0.84; Characteristics of Treatment = 0.75.

The questionnaire was a series of closed-ended questions about women's demographic details and decision-making values for treatment. The questionnaire was divided into two areas: socio-demographic variables and treatment values. Socio-demographic variables included thirteen items: age, education, marital status, address postcode, occupation, employment status, income, private health insurance status, and experience with breast cancer or cancer in the family and/or a close person, medical diagnosis and significant support person. Treatment Values covered thirty-one items scored on a 5-point scale from 'not at all important' to 'critically important'. These items included questions relating to general characteristics of the treatment, the effect of treatment on energy, side effects, treatment outcome, and emotional and perception consequences of the treatment. For comparative analysis, the scale was reduced to a 3-point scale ('not so important', 'average important', and 'very important'). A full list of the items can be found in Tables 1 and 2.

When women arrived at the breast screening clinic, they were given written information about the study while waiting

"How important is it to you that the treatment...."		Result	Influencing variables	
Effects of treatment on energy levels				
"not limit your activities?"	Very important	50.7%		
	Average important	35.6%		
	Less important	13.7%		
"not make you tired?"	Very important	53.8%		
	Average important	34.7%		
	Less important	11.5%		
"keep you physically active?"	Very important	54.7%		
	Average important	36.3%		
	Less important	9.1%		
"keep your energy level up?"	Very important	56.4%		
	Average important	36.5%		
	Less important	7.1%		
"not interfere with your daily life?"	Very important	50.4%		
	Average important	31.6%		
	Less important	18.0%		
"let you control your life"	Very important	64.7%	Believers in God	84.6%
	Average important	29.8%		78.1%
	Less important	5.5%		100% p=0.0404
General perceptions				
"not change the way people think about you?"	Very important	16.4%		
	Average important	19.4%		
	Less important	64.2%		
"not interfere with your sex life?"	Very important	27.6%		
	Average important	31.0%		
	Less important	41.4%		
"allow you to wear clothes and look normal?"	Very important	31.1%	University Education	27.5%
	Average important	40.5%		34.8%
	Less important	28.4%		43.0% p=0.0286
"not make you feel bad about your body?"	Very important	37.6%		
	Average important	28.7%		
	Less important	33.7%		
"allow you to still feel like a woman?"	Very important	47.9%	University Education	26.8%
	Average important	36.6%		44.0%
	Less important	15.4%		34.5% p=0.0104

Table 2

"How important is it to you that the treatment..."		Result	Influencing variables			
General characteristics of treatment						
"be convenient?"	Very important	14.9%				
	Average important	30.6%				
	Less important	54.5%				
"be affordable?"	Very important	18.7%	Living with somebody	77.6%	With private health insurance	70.6%
	Average important	29.1%		81.6%		82.9%
	Less important	52.2%		91.2%		87.4%
				p=0.0083		p=0.0071
"be quick?"	Very important	22.6%	University Education	26.3%		
	Average important	30.4%		35.5%		
	Less important	46.9%		40.0%		
				p=0.0284		
"allow you to get back to work soon?"	Very important	38.1%				
	Average important	29.8%				
	Less important	32.1%				

Table 2 (continued)

for their mammography screening. If women consented to participate in the research, they were asked to complete the consent form and a questionnaire and to place both items in a sealed box located in the waiting room. The information sheet for the study included an explanation of the two surgical options for early breast cancer; mastectomy (total removal of the breast) and lumpectomy (removal of breast lump).

Pilot Study

A pilot study of 47 women who completed a questionnaire prior to routine mammography screening was conducted and evaluated, using the protocol described above. No changes were required to the data collection procedure and protocol, so the entire pilot data collected was included in the study.

Ethical considerations

The researchers applied and obtained ethical approval for the study from the Experimentation Ethics Committee of James Cook University and permission from the site for conducting of the study. During the study the clinic's specialist breast nurses were available to give support to the women in the study if they felt distressed by the questionnaire. No women approached the specialist breast nurses or indicated in the open-ended questions at the end of the questionnaire that they had experienced distress while participating in the study.

Data analysis

Descriptive and inferential analyses of the data were performed following the data cleaning process. Because of low response rates in the extreme categories, the treatment outcomes were reduced from a 5-point scoring scale ('not at all important' to 'critically important') to a 3-point scale ('very importan', 'average importan', 'less important'). Bivariate associations between sociodemographic variables and decision-making treatment values were assessed using Chi-square tests and Fisher's exact tests, if both characteristics were categorical (Fisher's exact test was used when expected frequencies were small), and analysis of variance, if one characteristic was categorical and the other numerical (age). Statistical analysis was performed using SPSS for Windows release 6.1.3 and, in the statistical analysis, a significance level of 0.05 was assumed.

Findings

Participants

The participants (N=377) in the study ranged in age from 33 to 76 years (mean age = 52 years, SD ± 8.2 years); 80.6% were living in the urban area of Brisbane; 57.9% had completed high school, 8.3% had completed Technical and Further Education (TAFE) and 33.8% had completed university; 86% reported residing with others; 83.9% reported a belief in God; 66.1% reported being in employment; 82.9% held private health insurance; 23.9% reported a household income of >$AUS 27,500 per person per year. Six of the participants reported a personal history of breast cancer and 47.1% a family history of breast cancer.

Almost three-quarters (73.3%)(N=377) of the participants reported that they would choose to undergo a lumpectomy with radiation, compared with 26.7% who would choose mastectomy treatment. Due to the amount of data collected, specific details about the decision-making styles and processes of the sample have been separated and discussed elsewhere [48].

Breast cancer treatment values

Table 1 presents the participant's rating of their values when deciding about early breast cancer treatment. The majority (82.2%) rated as 'very important' that the treatment "not be dangerous", that it should "get rid of the cancer " (93.6%), that it would "reduce chances the cancer will come back" (95.6%), that it would "cure you" (90.9%), and that it would "give you peace of mind" (87.9%).

Most high percentages in the 'very important' category were related to statements concerning treatment outcome. The vast majority rated as 'very important' that the treatment would "reduce chances the cancer will come back" (95.6%) and that it would "get rid of the cancer" (93.6%). Many were concerned about the side effects of treatment; an overwhelming majority desired that the treatment should "not be dangerous" (82.2%) and that it should "give you peace of mind" (87.9%). Practical consideration of expense and time taken to recover was rated 'less important'. Only 18.7% rated as 'very important' that treatment be affordable or to "allow you to get back to work soon" (38.1%).

Breast cancer treatment values and sociodemographic factors

Table 1 presents the influence of sociodemographic characteristics of the participants' ratings of values of breast cancer treatment. The sociodemographic factors considered – age, employment status, occupation, education, belief in God, family history of breast cancer, residence in urban or rural areas, living with alone or with others, and private health insurance coverage – were found to be influencing sociodemographic background variables. Younger participants were more likely than older participants to to rates as 'very important' the treatment outcome, "let you live a long life" (p=0.003), but 'less important' that it "helps you get completely well" (p=0.022). Participants who rated as 'very important' that the treatment should "cure you" were on average >10 years younger and more likely to be employed than participants who rated this as 'less important' (p=0.0090, p=0.0122, respectively).

Of the participants who rated "get rid of the cancer" as 'very important', 68.3% were currently employed compared with 45.0% rated this as of 'average importance' (p = 0.0234). Employment showed a similar trend in the treatment outcome "reduce chances the cancer will come back", although this was not significant (p = 0.098).

Discussion

Treatment values

The study identified that treatment outcomes were the most important consideration for selecting hypothetical medical treatment. These findings are consistent with other studies of women diagnosed with breast cancer [23,48]. Understanding information about the precise types of treatment that are important to individual women is critical for nurses, so that they can provide more focused information support to aid women's decision–making, reduce their distress levels and increase their psychological wellbeing [49]. By contrast, non-focused information can increase women's uncertainty and anxiety, and lead to depression and post-decision regret [6,9,50].

In decision-making, if the attractiveness between the alternatives are small, people will often seek further information [9,51,55]. Nurses require careful consideration to frame the problems of each treatment alternative, because this discussion may alter the women's preferences [52,53]. A study about women choosing adjuvant therapy following surgery reports that the global presentation of information is more important to the decision-making for women than other factors [54].

In this study 93.1% of the participants also rated as 'average important' and 'very important' that the treatment outcome "allow you to get well quickly". This result is not surprising since a diagnosis and treatment of breast cancer can have dramatic financial effects on the lifestyle of women and their ability to care for children and perform their daily activities [5]. In addition, given the remoteness of parts of Australia, women often have difficulty accessing information and services. Nurses who care for women in North Queensland anecdotally report that some women in this area may choose to undergo mastectomy (even if this is not the preferred option), so they can return home more quickly (particularly if living and running the family farm), rather than the time and travel needed to undertake radiation therapy.

Women's needs and preferences for decision involvement, specific types of information and psychosocial support , change throughout the course of the treatment and require frequent individualised [55] review and assessment by nurses. Inability to differentiate between treatment alternatives can lead to less satisfactory decisions [56] and post-decision regret [9]. Women need to understand clearly the differences between each alternative and the information should be individually customised to explain the consequences characteristic of each type of treatment[50] so that they can choose a treatment that matches their values and preferences[22].

Women will individually experience a myriad of psychological and emotional changes following diagnosis and in the treatment phase[12], and following breast cancer treatment one-third of women can experience severe psychological adjustment disorders such as anxiety and depression[57,58]. In Australia, a recent study of 132 women diagnosed with early breast cancer and prior to any initial treatment, found 23.5% were depressed and 28.8% were experiencing anxiety[59] measured using the Brief Symptom Inventory -18[60]. Therefore, nurses need to consider how they can provide short- and long-term psychological support and interventions for women after their initial treatment to increase their quality of life and improve their psychological wellbeing[12]. Women are being offered early discharge after treatment from some centres, and nurses need to assess their social support. If early discharge from hospital after surgery for breast cancer is safe and is well received by patients, early discharge seems to enhance the opportunity for social support within the family[61].

Almost three-quarters of the participants reported that they would hypothetically choose a lumpectomy with radiation therapy if they were diagnosed with early breast cancer, but 60% of Australian women diagnosed with breast cancer undergo a total mastectomy[62]. One possible explanation for this result in the study may be that the information is presented differently in a clinical setting when women are actually given a definitive diagnosis of early breast cancer and told that radiation treatment can be between six to nine weeks, as opposed to undergoing one operation. Because treatment outcome values were rated highest, diagnosed women may unconsciously choose the treatment (mastectomy) that they believe will best fulfill these values. Success of outcome appears more important than problems with body image despite the rational knowledge that both treatments are equal in outcome.

Women who have chosen a mastectomy often experience more difficulty with their self image and self esteem, whereas women with conservation surgery are often more concerned with a recurrence of breast cancer[50]. Consequently, nurses also need to provide women with information about the newer and safer techniques for breast reconstruction[63]. Individualised assessment of women's social support, resourcefulness and self esteem is essential to predict the wellbeing[64] and long-term psychological adjustment of women[22].

While many Australian nurses report that information about the physical aspect of breast cancer is integral to the provision of nursing care, and that they understand psychological support is important, they also feel that they often do not have the skills and time to provide this support[65,66]. In Australia, the role of specialist breast care nurses is evolving. More nurses in more locations can identify and care for women who are at increased risk of psychological morbidity[67,68]. Women who are separated or divorced or financially disadvantaged by earning a low income have little social support or specific cultural needs[6]

Socio-demographic variables

In the present study there was a positive correlations between participants' age treatment decision-making, and this is consistent with previous studies of women diagnosed with breast cancer[15,16,17]. For example, younger women want more information than older women[17,69], although older women often are less knowledgeable about breast cancer[70]. In addition, older women may not be as computer literate as younger women and nurses need to offer non-internet forms of information to meet individual preferences. Moreover, threatening information can lead to reacting in an adaptive or maladaptive manner. The order of the information may affect a women's adaptation[71] and requires careful planning by nurses.

Employed women were more likely to choose radical surgical treatment. Women in the sample were on average younger (mean=53yrs) and well educated (33.8% with university education). Reasons for this finding are not clear, but may include women taking notice of the education campaigns and reading more in media reports about the side effects of breast cancer treatment. Furthermore, this result raises questions about the possible relationship between education levels and the processing of information by women. Possibly, they understood that some negative treatment consequences might be necessary to achieve health. Positive correlations were found between participants' university education and perceptions of themselves and their bodies.

Participants with a family history of breast cancer were more likely to hypothetically prefer treatment that did not have negative psychological consequences of sadness or depression. These women possibly have experienced an affected family member suffering significant psychological problems, such as depression and anxiety. Likewise, women with a family history of breast cancer often experience a significant level of psychological distress that requires counselling[72]. There is evidence[73] that a woman's psychological state before breast cancer is one of the best predictors of adjustment following breast cancer treatment.

Limitations

The limitations of this study were the convenience sampling method and the fact that the sample consisted of women who were undergoing routine mammography screening for breast cancer and had not been diagnosed with breast cancer. The participants were asked to imagine if they had been diagnosed with early breast cancer and to consider what factors would be important to them in choosing between the equal alternatives of mastectomy or lumpectomy (conservation surgery). However, many women who undergo routine mammography screening experience anxiety[74,75,76] and fear a diagnosis of breast cancer[75,77]. The possible implications of being diagnosed with cancer are usually to the fore in a woman's mind at the time of mammography screening. Therefore, the results are probably similar to what they would report if they were diagnosed with early breast cancer.

The participants responded to questions while undergoing some stress from the mammography screening, but not necessarily the intense psychological distress experienced by women newly diagnosed with breast cancer. Therefore, the participants may have been able to process the treatment information more effectively and match their treatment choices with their values, preferences and belief system better than those in distress, and possibly make better decisions. The sample reflected a higher percentage than the general population of women who were university educated. Further research is required to examine the influence of education in women's treatment values. However, the findings suggest that factors influencing choice of medical treatment vary dramatically. Therefore, it is recommended that women receive individual assessment by nurses to determine their values, access to information, problem solving ability and desired level of engagement in decisions and decision support, when choosing medical treatment for early breast cancer.

Conclusion

This preliminary study provides baseline data about Australian women's unaided prediagnostic decision-making values for early breast cancer treatment. Participants in the study indicated that if they were hypothetically diagnosed with early breast cancer, treatment outcomes were the most important deciding consideration. Other treatment factors, such as the side effects and emotional consequences, were less important. Therefore, it is imperative that nurses assess the values and preferences that a woman brings to the decision-making process of treatment choice for early breast cancer. In addition, nurses should assess a woman's understanding and access to important information relating to treatment options and her ability to problem solve in designing an action plan with her doctor. Nurses need to provide focused information supports that frame the problems of each treatment alternative, so women can clearly differentiate between treatment options and make decisions that match their values and lifestyle, and use the current evidence available, such as the Psychosocial Clinical Practice Guidelines for women with breast cancer developed by the National Breast Cancer Centre[12].

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References

1. Pierce PF. Pre-decision Portfolio Questionnaire. School of Nursing University of Michigan, Ann Arbor, Unpublished, 1995.
2. National Breast Cancer Centre. What is breast cancer? 2005. http://www.breasthealth.com.au/whatisbreastcancer/index.html, Retrieved 1/12/05.
3. National Health Scheme Breast Cancer. NHS Cancer Screening Programmes 2006. http://www.cancerscreening.nhs.uk/breastscreen/breastcancer.html Retrieved 17/01/06.
4. American Cancer Society. Overview of breast cancer, 2006. http://www.cancer.org/docroot/CRI/content/CRI_2_2_1X_How_many_people_get_breast_cancer_5.asp?sitearea= Retrieved 17/01/06.
5. National Health and Medical Research Council. Clinical practice guidelines for the management and support of younger women with early breast cancer. Australian Government National Health and Medical Research Council, Canberra. 2003.
6. National Health and Medical Research Council Clinical practice guidelines: management of the early breast cancer, Commonwealth of Australia, Canberra, 2001.
7. Pierce P F. Decision-making of women with early stage breast cancer: a qualitative study of treatment choices, UMI Dissertation Services, Ann Arbor (1986)
8. Pierce PF. Women's experience of choice: confronting the options for treatment of breast cancer. In Breast Cancer: Collaborative Management (Ed. Harness J, Obermas H, Lichter A, Alder D & Cody R) Lewis Publishers, Chelsea, 1988.
9. Pierce PF. Deciding on breast cancer treatment: a description of decision behavior. Nursing Research, 1993;42(1):22-28.
10. Cimprich B. & Ronis D. Attention and symptom distress in women with and without breast cancer. Nursing Research, 2001; 50(2):86-94.
11. Cimprich, B. Pre-treatment symptom distress in women newly diagnosed with breast cancer. Cancer Nursing, 1999; 22(3): 185-194.
12. National Health and Medical Research Council. Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer, Commonwealth of Australia, Canberra, 2000.

13. Fisher B, Poisson R, Margolese R, Wolmark N. & Wickerham P, et al. Eight-year result of a randomized clinical trial comparing total mastectomy and lumpectomy with of without radiation in the treatment of breast cancer. The New England Journal of Medicine, 1989; 320: 822-828.

14. Early Breast Cancer Triallists' Collaborative Group. Effects of radiotherapy and surgery in early breast: an overview of the randomized trials. New England Journal of Medicine, 1995; 335: 1444-1455.

15. Beisecker A E. Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. The Gerontologist, 1988; 28(3): 330-335.

16. Johnson J D, Roberts CS, Cox CE, Reintgen DS, Levine J S. & Parsons M. Breast cancer patients' personality style, age, and treatment decision-making. Journal of Surgical Oncology, 1996;63(3): 183-186.

17. Meyer BJ, Russo C. & Talbot A. Discourse comprehension and problem solving: decisions about the treatment of breast cancer by women across the life span. Psychology of Aging, 1995; 10(1): 84-103.

18. Siminoff L A & Fetting JH. Factors affecting treatment decisions for a life-threatening illness: the case of medical treatment of breast cancer. Social Science Medicine, 1991; 32(7): 813-818.

19. Graling PR & Grant JM. Demographics and patient treatment choice in stage I breast cancer. American Operating Room Nurse Journal, 1995; 62(3): 376-384.

20. Street RL, Voigt B, Geyer C, Manning T. & Swanson G P. Increasing patient involvement in choosing treatment for early breast cancer. Cancer, 1995; 76(11): 2275-2285.

21. Pierce PF & Hicks FD. Patient decision-making behavior: An emerging paradigm for nursing science. Nursing Research, 2001; 50(5): 267-274.

22. Pierce PF. What is an ethical decision? Critical Care Nursing Clinics of North America, 1997; 8(1):1- 11.

23. Degner L F, Kristjanson LJ, Bowman D, Sloan J A, Carriere KC, O'Neil J, Bilodeau B, Watson P. & Mueller B. Information needs and decisional preferences in women with breast cancer. Journal of American Medical Association, 1997; 277(18): 1485-1492.

24. Fallowfield L J. Psychosocial adjustment after treatment for early breast cancer. Oncology (Huntingt), 1990; 4(4) 89-97; discussion 97-8, 100.

25. Kaplan S, Greenfield S & Ware J E. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Medical Care, 1989;27: S110-S127.

26. Owens RG, Ashcroft J J, Leinster S J. & Slade P D. Informal decision analysis with breast cancer patients: an aid to psychological preparation for surgery. Journal of Psychosocial Oncology, 1987; 5(2): 23-33.

27. Sinsheimer L M & Holland JC. Psychological issues in breast cancer. Seminars in Oncology, 1987; 14(1): 75-82.

28. Leinster S, Ashcroft J & Slade P, et al. Mastectomy versus conservative surgery: psychosocial effects of the patient's choice of treatment. Journal of Psychosocial Oncology, 1989; 23(1): 179-192.

29. Kee F. Patients' prerogatives and perceptions of benefit. British Medical Journal, 1996; 312(7036): 958-960

30. Hack T F, Degner, LF & Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. Social Science Medicine, 1994; 39(2): 279-289.

31. Boyle FM, Dunn SM. & Heinrich P. More than one-way to foster communication skills for medical oncology fellows: a national program in Australia, Journal of Clinical Oncology, 2003; 21(22): 4255.

32. Butow P. The communication goals and needs of cancer patients, Psycho-Oncology, 2005; 14(100): 846-847.

33. Ryan H, Schofield P, Cockburn J, Butow P, Tattersall M, Turner J, et al. How to recognize and manage psychosocial distress in cancer patients. European Journal of Cancer Care, 2005;14(1): 7-15.

34. National Breast Cancer Centre. Specialist breast nurse competency standards and associated educational requirements- executive summary. National Breast Cancer Centre, Camperdown, 2005.

35. Cimprich B & Ronis D L. An environmental intervention to restore attention in women with newly diagnosed breast cancer. Cancer Nursing, 2003;26(4): 284-292.

36. Reed SK. Cognition: Theory and Applications, Brooks/Cole Publishing Company, Pacific Grove, 1996.

37. Klein GO, Calderwood R & Zsambok CE. Decision making in action: models and methods, Ablex Publishing Corporation, Norwood, 1993.

38. International Council of Nurses. Code of Nurses Ethics, International Council of Nurses, Geneva, 2000.

39. Degner LF, Hack T., O'Neil, Ll & Kristjanson LJ. A new approach to elicit meaning in the context of breast cancer, Cancer Nursing, 2003; 26(3): 169-178.

40. Cimprich B, So H, Ronis DL & Trask C. Pre-treatment factors related to cognitive functioning in women newly diagnosed with breast cancer. Psycho-Oncology, 2005;14(1): 70-78.

41. Northouse L, Kershaw T, Mood D. & Schafenacker A. Effects of family intervention on the quality of life of women with recurrent breast caner and their caregivers, Psycho-Oncology, 2005;14(6): 478-491.

42. Fallowfield, L. Learning how to communicate in cancer settings. Support Care Cancer, 2005;13(6): 349-350.

43. O'Connor AM, Graham A & Visser A. Implementing shared decision-making in diverse health care systems: the role of patient aids. Patient Education Counselling, 2005; 57(3): 247-249.

44. Burkhardt MA & Nathaniel A K. Ethics and issues in contemporary nursing, Delmar: Thomson Learning, Albany, 2002.

45. Matheson JE & Howard RA. An introduction to decision analysis. in Readings in decision analysis. Stanford Research Institute, Menlo Park, 1977.

46. Luce RD & Raiffa H. Games and decision: introduction and critical survey, Wiley and Sons, New York, 1957.

47. O'Connor AM. & O'Brien-Pallas LL. Decisional Conflict. In Nursing diagnosis and Intervention (Eds, McFarland, G. K. & McFarland, E. A.) C.V.Mosby, Toronto, 1989.

48. Bilodeau BA & Degner LF. Information needs, sources of information, and decisional roles in women with breast cancer. Oncology Nursing Forum, 1996; 23(4): 691-696.

49. Devine EC & Westlake SK. The effects of psycho educational care provided to adults with cancer: meta-analysis of 116 studies. Oncology Nursing Forum, 1995; 22(9): 1369-1381.

50. Dunn J, Steginga, SK, Occhipinti S, Wilson K & McCaffrey, J. The profiles of distress in women following treatment for primary breast cancer. Breast, 1998;7: 251-254.

51. Bockenholt U, Albert D, Aschenbrenner M. & Schmalhofer F. The effects of attractiveness, dominance, and attribute differences on information acquisition in multiattribute binary choice. Organizational Behaviour and Human Decision Processes, 1991;49: 258-281.

52. Tversky A & Kahneman D. The framing of decisions and the psychology of choice. Science, 1981; 211: 453-458.

53. O'Connor AM, Pennie RA & Dales RE. Framing effects on expectations, decisions, and side effects experienced: the case of influenza immunization. Journal of Clinical Epidemiology, 1996; 49(11): 1271-1276.

54. Siminoff LA & Fetting JH. Effects of outcome framing on treatment decisions in the real world: impact of framing on adjuvant breast cancer decisions. Medical Decision Making, 1989; 9(4): 262-271.

55. Pierce PF. When the patient chooses: describing unaided decisions in health care. Human Factors, 1996;38(2): 278-87.

56. Yates JF. Judgment and Decision Making, Prentice Hall, Englewood Cliffs, 1990.

57. Keller M. Psychosocial care of breast cancer patients. Anticancer Research, 1998; 18(3C): 2257-2259.

58. Spiegel D. Psychosocial aspects of breast cancer treatment. Seminars in Oncology, 1997; 24(Suppl 1): S1-36-S1-47.

59. Budden LM, Pierce PF, Hayes, BA. & Buettner PG. Australian women's decision-making styles and levels of distress relating to the selection of surgical treatment for early breast cancer, North Queensland Cancer Research Forum, November 11, 2005. James Cook University School of Medicine, Townsville, Australia.

60. Derogatis LR. SI-18 Brief Symptom Inventory 18 Administration, Scoring, and Procedures Manual, National Computer Systems, Minneapolis, 2000.

61. Lipshitz R & Straus O. Coping with uncertainty: a naturalistic decision-making analysis. Organizational Behavior and Human Decision Processes, 1997; 69(2): 149-163

62. Back M.F. & Morgan G.W. The rate of breast conserving surgery in early breast cancer: an audit of surgical practice at St Vincent's campus NSW 1990-1994, Australian Radiology, 2000; 44: 60-64.

63. Reaby LL. Reasons why women who have mastectomy decide to have or not to have breast reconstruction. Plastic Reconstructive Surgery, 1998; 101(7): 1810-1818.

64. Dirksen SR. Predicting well being among breast cancer survivors. Journal of Advanced Nursing, 2000, 32(4): 937-943.

65. Wilkes L, White K, Beale B, Cole R. & Tracy S. Supportive care for women with breast cancer: Australian nurses' perspective. Nursing Health Sciences, 1999; 1(2): 71-76.

66. Parle M, Gallagher J, Gray C, Akers G & Liebert B. From evidence to practice: factors affecting the specialist breast nurses detection of psychological morbidity in women with breast cancer. Psycho-Oncology, 2001; 10: 503-510.

67. McArdle AL. Psychological support for patients undergoing breast cancer surgery: a randomised study. British Medical Journal, 1996; 312: 813-817.

68. Budden LM, Pierce PF, Hayes BA. & Buettner PG. Australian women's pre-diagnostic decision- making styles relating to treatment choices for early breast cancer. Research Theory for Nursing Practice: An International Journal, 2003; 17(2): 117-136.

69. Galloway S, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, Rich-van der Biji L, West P & Blair A. Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. Journal of Advanced Nursing, 1997;25(6): 1175-1183.

70. Vaeth PA. Women's knowledge about breast cancer: dimensions of knowledge and scale development. American Journal of Clinical Oncology, 1993; 16(5): 446-454.

71. Prentice-Dunn SF & Flournoy JM. Effects of persuasive message order on coping with breast cancer information. Health Education Research, 2001;16(1): 81-84.

72. Kash KM, Holland JC, Halper MS. & Miller DG. Psychological distress and surveillance behaviors of women with a family history of breast cancer. Journal of National Cancer Institute, 1992;84(1): 24-30.

73. Carlson M & Hamrin E. Psychological and psychosocial aspects of breast cancer and breast cancer treatment: a literature review. Cancer Nursing, 1994; 17(5): 418-428.

74. Silverman E, Woloshin S, Schwartz L M, Byram SJ, Welch HG. & Fischhoff B. Women's views on breast cancer risk and screening mammography: a qualitative interview study. Medical Decision Making, 2001;21(3): 231-240.

75. Speedy S & Hase S. Health beliefs and perceptions of women presenting or not presenting for mammographic screening in a rural health setting. Australian Journal of Rural Health, 2000; 8: 208-213.

76. Madden SJ & Parbhoo S. Evaluation of women's worries and the effects of a preparatory booklet for patients attending a breast clinic. Breast, 1994; 3: 169-172.

77. Ganz PA. Quality of life across the continuum of breast cancer care. The Breast Journal, 2000; 6(5): 324-330.

Appendix 4- Baseline structured survey

Breast Cancer Treatment Pre-Decision Questionnaire

The purpose of this study is to learn about Australian women's decision-making for early breast cancer treatment. Very little is known about the way women make these decisions. Therefore we do not know the best ways to help women during their process of making decisions. This study helps to fill in the gaps in knowledge and we will be able to use this information to improve ways that nurses can help other women, when they are making decisions about breast cancer treatment.

Participation in this survey is voluntary. If you decide to participate in the study, you will be asked to complete a consent form. All information you provide is treated in a confidential manner. You will not be identified in any way.

This survey contains questions about your process of making your treatment decision. There are no right or wrong answers to these questions. What is important to us is your perspective on this part of your life. If you come to a question you do not want to answer, just leave it blank and move to the next question. Take your time as you may find that some questions take longer for you to think about.

We understand that this time in your life may be very upsetting and confusing for you and appreciate your interest and commitment in participating in this study to help other women with breast cancer.

If you have any questions about this study please do not hesitate to contact me.

Thank you for your participation. Lea Budden

Women's Breast Cancer Decision Making Project

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Information About You

Place your answer in the box or circle the selection that applies to you or write in your answer.

What was your age on your last birthday?

What is your postcode?

Marital Status Single | Married | Living as married | Divorced | Widowed

What is the highest level of formal education you completed?

0-7 grade | 8-11 grade | high school graduate | TAFE graduate | university graduate

What is your religion?

What is your current employment status?

full time | part time | unemployed | student | disabled | homemaker | retired

What is your occupation?

What was your total household income ($) last year?

Less than 6,000 | 6,001-20,000 | 20,001-50,000 | 50,001-60,000 | 60,001 +

How many people live in your household?

Do you identify yourself as an Aboriginal? YES | NO

Do you identify yourself as a Torres Strait Islander? YES | NO

Have you ever had breast cancer? YES | NO

Have you ever had cancer? YES | NO
If you answered yes, which type of cancer have you had?

____

Has a member of your family or someone close to you had breast cancer?	YES	NO
Has a member of your family or someone close to you had cancer?	YES	NO

If you answered yes what type of cancer did they have?

____

Do you currently have private health insurance?	YES	NO

Information about your feelings of distress

The following questions are related to feelings of distress you may be experiencing. Please circle your answer to the following questions.

Since your diagnosis of breast cancer how much have you been distressed by....	Not at all 1	A little bit 2	Moderately 3	Quite a bit 4	Extremely 5
Faintness or dizziness	1	2	3	4	5
Feeling no interest in things	1	2	3	4	5
Nervousness or shakiness inside	1	2	3	4	5
Pains in the heart or chest	1	2	3	4	5
Feeling lonely	1	2	3	4	5
Feeling tense or keyed up	1	2	3	4	5
Nausea or upset stomach	1	2	3	4	5

Information about your feelings of distress

The following questions are related to feelings of distress you may be experiencing. Please circle your answer s to the following questions.

Since your diagnosis of breast cancer how much have you been distressed by….	**Not at all** 1	**A little bit** 2	**Moderately** 3	**Quite a bit** 4	**Extremely** 5
Feeling blue	1	2	3	4	5
Suddenly scared for no reason	1	2	3	4	5
Trouble getting your breath	1	2	3	4	5
Feelings of worthlessness	1	2	3	4	5
Spells of terror or panic	1	2	3	4	5
Numbness or tingling in parts of your body	1	2	3	4	5
Feeling hopeless about the future	1	2	3	4	5
Feeling so restless you couldn't sit still	1	2	3	4	5
Feeling weak in parts of your body	1	2	3	4	5
Thoughts of ending your life	1	2	3	4	5
Feeling fearful	1	2	3	4	5

The following questions are related to how you think you might go about making this decision for breast cancer treatment. Please circle your answer to each of the following questions.

How important is it to you making this decision that you?	**Not at all** 1	**Unimportant** 2	**Neither Important Nor Unimportant** 3	**Important** 4	**Critically Important** 5
Follow your doctor's advice?	1	2	3	4	5
Participate in selecting a treatment?	1	2	3	4	5
Ask questions?	1	2	3	4	5
Have a doctor who asks you what you want?	1	2	3	4	5
Trust your doctor?	1	2	3	4	5
Have faith in God?	1	2	3	4	5
Read a lot of information?	1	2	3	4	5
Talk to other women who have had cancer?	1	2	3	4	5
Get the treatment over with as soon as possible?	1	2	3	4	5
Have the advice of the best specialists?	1	2	3	4	5
Have your doctor answer all your questions?	1	2	3	4	5
Know if there are any side effects of the treatment?	1	2	3	4	5

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How important is it to you making this decision that you...	Not at all Important 1	Unimportant 2	Neither Important Nor Unimportant 3	Important 4	Critically Important 5
Know if there might be unexpected problems with the treatment?	1	2	3	4	5
Know the chances that the cancer might return?	1	2	3	4	5
Have a woman doctor?	1	2	3	4	5
Have a doctor of the same cultural background as you?	1	2	3	4	5
Feel in control of choosing a treatment?	1	2	3	4	5
Tell your doctor how you feel about the treatment?	1	2	3	4	5
Have a doctor that cares about you?	1	2	3	4	5
Have a private room when you are in hospital?	1	2	3	4	5
Have your parking expenses paid for?	1	2	3	4	5
Have someone to talk to?	1	2	3	4	5
Have a doctor who listens to you?	1	2	3	4	5
Have a doctor who tells you what to expect?	1	2	3	4	5
Have friends or family come to the doctor's visits with you?	1	2	3	4	5

We would like to know how women make decisions about breast cancer treatment. Here are some statements about how you might make this decision. Please indicate, how much you agree or disagree with these statements by circling your answer.

	Strongly Disagree 1	Disagree 2	Neither Agree Nor Disagree 3	Agree 4	Strongly Agree 5
I will make a quick decision once I was told what my options were	1	2	3	4	5
I will follow the recommendations of my doctor	1	2	3	4	5
I will agree to the option that seemed the most reasonable to me at the time	1	2	3	4	5
I will develop a plan for gathering further information	1	2	3	4	5
I will read magazines and articles about breast cancer and different treatment	1	2	3	4	5
I will read scientific articles about the treatments that were being offered to me	1	2	3	4	5
I will spend as much time as I could gathering information.	1	2	3	4	5
I prefer, to seek advice from specialists in breast cancer treatment	1	2	3	4	5

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Continued…

	Strongly Disagree 1	Disagree 2	Neither Agree Nor Disagree 3	Agree 4	Strongly Agree 5
I will ask about the risks with each treatment alternative	1	2	3	4	5
I will carefully consider the risks of each option as I was making a choice	1	2	3	4	5
I will want to know the possible outcomes of each alternative that was being offered to me	1	2	3	4	5
I will ask a lot of questions concerning the treatment options	1	2	3	4	5
I want someone else to make the decision for me	1	2	3	4	5
I prefer, in situations like these, that someone else tells me what to do	1	2	3	4	5
I prefer not knowing the possibility that unexpected things could happen to me	1	2	3	4	5
I believe that what will happen, will happen and there is little I can do to change things	1	2	3	4	5

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What advice do you have for other women who are facing this decision?

What should nurses know to help women make these decisions?

Thank You

Your participation in this survey is greatly appreciated. The information you have provided will be used to develop future programs to assist and support women who are faced with difficult and stressful health care decisions.

Please use the space proved to add any additional comments you may have about questions we should have asked or any suggestions you may have to improve upon the questions we did ask.

Appendix 5- Follow-up questionnaire at three to four months

Decision Satisfaction of Women Concerning Early Breast Cancer Treatment

The purpose of this study is to learn about Australian women's decision-making for early breast cancer treatment. Very little is known about the way women make these decisions. Therefore, we do not know what the best ways are to help women with this decision-making process. This study helps to fill in these gaps in knowledge and we will be able to use this information to improve ways that nurses can help other women, when they are making decisions about breast cancer treatment.

This survey contains questions about the way you made your treatment decision. There are **no right** *or* **wrong answers** to these questions. What is important to us is your experience of how you made this treatment decision. If you come to a question you do not want to answer, just leave it blank and move to the next question. Take your time as you may find that some questions take longer for you to think about.

Please do not hesitate to contact me if you need further information or assistance with completing this questionnaire.

Thank you for your participation. *Lea Budden*

Breast Cancer Treatment Decision Making Project

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Information about your treatment for early breast cancer.

Please tick and/or write your answer to the following questions (Tick, as many boxes as relevant).

1. What treatment/s did you have following your diagnosis of early breast cancer?

☐ No treatment
☐ Mastectomy
☐ Lumpectomy
☐ Axillary clearance
☐ Radiation therapy
☐ Chemotherapy
☐ Hormone Therapy (eg. Tamoxifen etc.)
☐ Alternative/Complementary therapy__________________ (please specify)
☐ Breast Reconstruction
☐ Other __________________ (please specify)

____

____

2. Were you offered choices by your doctor for your treatment of early breast cancer?

☐ Yes
☐ No
☐ Other (please specify) ____

____

____

3. How would be describe your involvement in the decision of your treatment plan for early breast cancer?

☐ Very actively involved in decision making (e.g. Doctor offered me choices for a treatment plan but, I made the decision).
☐ Involved in decision making (e.g. Doctor offered me choices for treatment but, recommended a treatment plan for me).
☐ Not involved in decision making (e.g. Doctor did not offer me choices for treatment but, recommended a treatment plan for me).

Please tick your answers to the following questions.

4. Did you obtain help from the nurse/s (e.g. Informational, psychological etc) when you were making decisions about your treatment for early breast cancer?

☐ Yes
☐ No
☐ Not sure

If you answered **YES** to Question 4 please move to question 5. If you answered **NO** to Question 4 please move to **Page 4.**

5. If you answered yes, what *type* of help did you receive from the nurse/s? (Tick as many boxes as relevant)

☐ Informational
☐ Spiritual
☐ Emotional
☐ Financial
☐ Psychological
☐ Other (please specify) ______________________________

6. How helpful was the support you received from the nurses?

☐ Completely unhelpful
☐ Unhelpful
☐ Slightly unhelpful
☐ Neither helpful nor Unhelpful
☐ Slightly helpful
☐ Helpful
☐ Very Helpful

Information about your feelings of distress

The following questions are related to feelings of distress you may be experiencing. Please circle your answer to the following questions.

In the last three (3) months how much have you been distressed by….	Not at all 1	A little Bit 2	Moderately 3	Quite a bit 4	Extremely 5
Faintness or dizziness	1	2	3	4	5
Feeling no interest in things	1	2	3	4	5
Nervousness or shakiness inside	1	2	3	4	5
Pains in the heart or chest	1	2	3	4	5
Feeling lonely	1	2	3	4	5
Feeling tense or keyed up	1	2	3	4	5
Feeling blue	1	2	3	4	5
Suddenly scared for no reason	1	2	3	4	5
Nausea or upset stomach	1	2	3	4	5

Information about your feelings of distress

The following questions are related to feelings of distress you may be experiencing. Please circle your answer to the following questions.

In the last three (3) months how much have you been distressed by….	Not at all 1	A little Bit 2	Moderately 3	Quite a bit 4	Extremely 5
Trouble getting your breath	1	2	3	4	5
Feelings of worthlessness	1	2	3	4	5
Spells of terror or panic	1	2	3	4	5
Numbness or tingling in parts of your body	1	2	3	4	5
Feeling hopeless about the future	1	2	3	4	5
Feeling so restless you couldn't sit still	1	2	3	4	5
Feeling weak in parts of your body	1	2	3	4	5
Thoughts of ending your life	1	2	3	4	5
Feeling fearful	1	2	3	4	5

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Information about your satisfaction with the way you made your decision and your final treatment decision.

Please indicate how much you agree or disagree by circling your answer to the following statements.

	Strongly Disagree	**Disagree**	**Slightly Disagree**	**Neither Agree Nor Disagree**	**Slightly Agree**	**Agree**	**Strongly Agree**
I am very satisfied with *my* Decision-making experience.	1	2	3	4	5	6	7
I am very satisfied with the *options* that were offered to me.	1	2	3	4	5	6	7
I am very satisfied with the *way* the options were offered to me.	1	2	3	4	5	6	7
I am very satisfied with my *participation* in the decision.	1	2	3	4	5	6	7
I am very satisfied that I had *sufficient time* to make my choice.	1	2	3	4	5	6	7
I am very satisfied with the *information* I used to make my choice.	1	2	3	4	5	6	7
I am very satisfied with the *way* nurses helped me to make my decision.	1	2	3	4	5	6	7
I am very confident that I *made* a satisfactory choice.	1	2	3	4	5	6	7

Information about your satisfaction with the way you made your decision and your final treatment decision.

Please indicate how much you agree or disagree by circling your answer to the following statements.

Continued….	Strongly Disagree	Disagree	Slightly Disagree	Neither Agree Nor Disagree	Slightly Agree	Agree	Strongl Agree
I am very satisfied with the *choice* I made.	1	2	3	4	5	6	7
I am very satisfied with the *quality* of my decision-making activity.	1	2	3	4	5	6	7
I am very satisfied with the *outcome* of the treatment.	1	2	3	4	5	6	7
I am very satisfied that at the time, I was making a *good decision.*	1	2	3	4	5	6	7
I am very satisfied with the *outcome* of my decision.	1	2	3	4	5	6	7
I have *no regrets* about the treatment choice I made.	1	2	3	4	5	6	7
I believe my decision will be *very successful* in the long run.	1	2	3	4	5	6	7
I believe there is *nothing* I could have done *differently* at the time I was making my decision.	1	2	3	4	5	6	7

Information about your satisfaction with the support you received when making your treatment decision.

Please circle your answer to each of the following questions.

Overall how would you rate your satisfaction with the support you received when making your treatment decision?	Very Unsatisfied	Unsatisfied	Slightly Unsatisfied	Neither Satisfied Nor Unsatisfied	Slightly Satisfied	Satisfied	Very Satisfi
Financial Support	1	2	3	4	5	6	7
Family Support	1	2	3	4	5	6	7
Social Support	1	2	3	4	5	6	7
Psychological Support	1	2	3	4	5	6	7
Emotional Support	1	2	3	4	5	6	7
Nursing Support	1	2	3	4	5	6	7
Informational Support	1	2	3	4	5	6	7
Spiritual support	1	2	3	4	5	6	7
Religious Support	1	2	3	4	5	6	7
Physical Support (e.g. housework etc)	1	2	3	4	5	6	7

What advice do you have for other women who are facing this decision?

What should nurses know about helping women make these decisions?

Thank You

Your participation in this survey is greatly appreciated. The information you have provided will be used to develop future programs to assist and support women who are faced with difficult and stressful breast cancer treatment decisions.

Please use the space proved to add any additional comments you may have about questions we should have asked or any suggestions you may have to improve upon the questions we did ask or to make any comments you believe might add to our understanding of the decision experience of women on the this sheet.

North Queensland

Appendix 6- Letter of support

19 June 2001

TO WHOM IT MAY CONCERN

Re: "Women's decision-making styles, levels of distress, and decision satisfaction relating to the selection of treatment for early breast cancer"

I write to introduce Professor Barbara Hayes and Ms Lea Budden from the James Cook University School of Nursing. Barbara and Lea are members of the reference group of the North Queensland Breast Cancer Collaboration (NQBCC) and are very interested in Nurse Education and its application to decision making by patients with breast cancer. Lea was actively involved in last years NQBCC inaugural workshop and illustrated the potential application of her PhD studies to the management of rural patients.

Lea has completed initial evaluation studies and now wishes to progress her project as outlined in the enclosed summary. She wishes to survey women recently diagnosed with breast cancer in North Queensland and would like to commence recruitment in the next few months.

Both Tony Green and I are very supportive of this initiative from Nursing Sciences and would be happy to encourage collaboration from North Queensland surgeons.

Yours sincerely

Professor Peter Donnelly
Co-Chief Investigator

A NATIONAL MULTIDISCIPLINARY BREAST CANCER CARE DEMONSTRATION PROJECT

JAMES COOK UNIVERSITY
Townsville campus
Townsville QLD 4811 AUSTRALIA
Telephone: (07) 4781 4111 Web: **www.jcu.edu.au**

Appendix 7- Participant's consent form

INFORMED CONSENT FORM

SCHOOL: NURSING SCIENCES

PROJECT: *Women's decision-making styles, levels of distress, and decision satisfaction relating to the selection of treatment for early breast cancer.*

CHIEF INVESTIGATOR: Ms Lea Budden

CONTACT DETAILS:
School of Nursing Sciences
James Cook University, Qld 4811
Douglas, Campus
Townsville: 07 47816411 or 07 47815354
E-mail: Lea.Budden @jcu.edu.au
Facsimile: 07 47814026

DESCRIPTION:

When women are given a diagnosis of early breast cancer they are often asked by their doctor to choose between treatment options. Many women are unsure about what process they should use to make this decision and often turn to nurses for help. Unfortunately, nurses currently do not have any information to guide their care to these women. The aim of this study is to find out about how women make treatment decisions and how nurses can more effectively help women with this process. The information gained from this study will guide the researchers who are experienced nurses, in designing methods that nurses can use to help other women when they are making their treatment decisions for early breast cancer. The only people who will know that you are participating in this study are the following: those you wish to tell; your doctor; and the researchers.

If you agree to participate in the study, one of the researchers will provide you with a questionnaire to complete. This questionnaire takes about 15 minutes to fill in and includes questions about how you think you will go about making your treatment decision. No attempts will be make by the researchers to influence or delay you decision. You will also be asked over the next six months to fill in three more short questionnaires that ask questions about the treatment decision you made. There are no right or wrong answers to any of the questions.

Cont'd over/..

CONSENT

The aims of this study have been clearly explained to me and I understand what is wanted of me. I know that taking part in this study is voluntary and I am aware that I can stop taking part in it at any time and may refuse to answer any questions.

I understand that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval.

Name: (printed)	
Signature:	**Date:**

WITNESSED BY RESEARCHER OBTAINING CONSENT

Name: (printed)	
Signature: (Principal Investigator)	**Date:**

JAMES COOK UNIVERSITY
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Townsville QLD 4811 AUSTRALIA
Telephone: (07) 4781 4111 Web: **www.jcu.edu.au**
CRICOS Provider Code: 00117J

Appendix 8- Participant's information sheet

An Invitation to participate in a study about how women make early breast cancer treatment decisions

Your doctor has given permission for his/her patients to participate in a study about how to better understand how women make decisions when selecting treatment for early breast cancer. This information will provide us with improved ways for nurses to help women when they are making these decisions. All the information gathered in the study would remain confidential and anonymous. No attempts will be made by the researchers to influence you when you are making decisions about your early breast cancer treatment.

Lea Budden who is an experienced Registered Nurse and a Senior Lecturer in Nursing Sciences at James Cook University is conducting the study as her PhD project. Another Registered Nurse (who has extensive experience working with women who have breast cancer) will be involved in collecting information for the study.

If you are interested in being part of the study please let your doctor's secretary know, or contact Lea directly. You will be given a questionnaire and a consent form to fill out. We will also ask you to complete three other questionnaires over the next six months. There are no right or wrong answers to any of the questions asked. If you wish to participate in the study each questionnaire only takes about 15 minutes to complete. I am aware that this is a difficult time for you and if you become distressed in any way because of your participation in this study, I have attached a list of Queensland Cancer Fund Offices you may wish to contact for support. If you have any questions or concerns about the study please do not hesitate to contact me. I will be happy to assist you in any way that I can. Thank you, Lea Budden.

For further information about the study please contact:

Lea Budden

Senior Lecturer
School of Nursing Sciences
James Cook University, Qld 4811
Townsville: 07 47816411 or 07 47815354
E-mail: Lea.Budden @jcu.edu.au
Facsimile: 07 47814026

Dr Barbara Hayes

Professor of Nursing
School of Nursing Sciences
James Cook University, Qld 4811
Townsville: 07 47815340
E-mail: Barbara.Hayes @jcu.edu.au
Facsimile: 07 47814026

Appendix 9- Participant's eligibility sheet

Lea Budden's Breast Study

Does this woman have a diagnosis of early breast cancer (Stage I & IIA)?
Yes/No

If so, does the pathology form identify;

- A primary breast tumour is >5cm (on palpation or imaging)
  Yes/No
- A tumour invasion into chest wall/skin
  Yes/No
  (i.e. ulceration, peau 'orange skin, satellite nodules, inflammatory carcinoma)
- Palpable FIXED axillary nodes
  Yes/No
- Distant metastases
  Yes/No

If any of these are mentioned, the woman will be excluded from this study. If all the answers are NO then is the woman:

- Unable to speak and read English
  Yes/No