This file is part of the following reference:


Access to this file is available from:

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

Lea Margaret Budden MNsg BaHlthSc (Nurs) GradDipEd (Tert)

DipHlthSc (NEd) RN FRCNA

for the Degree of Doctor of Philosophy in the School of Nursing, Midwifery & Nutrition

James Cook University in February 2008

Thesis Supervisors
Barbara A. Hayes, DNSc, R.N. (James Cook University)
Petra G. Buettner, PhD, M.Sc (James Cook University)
Penny F. Pierce, PhD, R.N. (University of Michigan)
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.
STATEMENT OF ACCESS

I, the undersigned, the author of this thesis, understand that James Cook University Library, by microfilm or by other means, allows access to users in other approved libraries. All users consulting this thesis will have to sign the following statement:

“In consulting this thesis, I agree not to copy or closely paraphrase it in whole or part without the consent of the author; and to make proper written acknowledgement for any assistance, which I have obtained from it”.

Beyond this, I do not wish to place any restriction on access to this thesis.

(Lea Budden)  (Date)
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 coastal 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.
ACKNOWLEDGEMENTS

I would like to acknowledge and thank the doctors and nurses who championed the project. Namely, to doctors Cherrell Hirst, Boris Chern, Richard Tuner, Peter Donnelly who supported the project and rallied the interest from other doctors for the study. Also to the research nurses, Shloeh, Judy, Sue and Marilyn who assisted in recruiting participants and collecting the data, your commitment to the project will never be forgotten.

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).
TABLE OF CONTENTS

CHAPTER 1- OVERVIEW OF STUDY ............................................................ 1

INTRODUCTION ................................................................................................. 1
BACKGROUND ................................................................................................... 1
RESEARCH PROBLEM .......................................................................................... 4
HYPOTHESES AND QUESTIONS ........................................................................ 6
Hypotheses ........................................................................................................ 6
Research questions ......................................................................................... 6
SIGNIFICANCE OF RESEARCH STUDY .............................................................. 7
CONCEPTUAL MODEL ....................................................................................... 9
Decision Styles ................................................................................................ 9
Deferrer ........................................................................................................... 11
Delayer ............................................................................................................ 11
Deliberator ..................................................................................................... 12
MICHIGAN ASSESSMENT OF DECISION STYLES (MADS) ......................... 12
ETHICAL CONSIDERATIONS .......................................................................... 13
METODOLOGY .................................................................................................. 13
STATISTICAL DATA ANALYSIS ...................................................................... 14

CHAPTER 2- LITERATURE REVIEW .............................................................. 21

INTRODUCTION ................................................................................................ 21
SCOPE AND LIMITATIONS OF REVIEW .......................................................... 21
INCIDENCE OF BREAST CANCER IN AUSTRALIA ........................................ 21
OVERVIEW OF EARLY BREAST CANCER TREATMENT ................................ 23
PSYCHOLOGICAL IMPACT OF BREAST CANCER ............................................. 28
THEORETICAL APPROACHES TO DECISION SCIENCE .................................. 40
Historical Background .................................................................................... 40
Normative Decision-making ........................................................................... 43
Prescriptive Decision-making ......................................................................... 44
Descriptive Decision-making ........................................................................ 46
Naturalistic Decision-making ......................................................................... 50
BREAST CANCER TREATMENT DECISION-MAKING ................................... 53
TREATMENT DECISION SATISFACTION ......................................................... 71

CHAPTER 3-METHODS .................................................................................... 84

OVERVIEW OF STUDY ..................................................................................... 84
PARTICIPANTS ................................................................................................ 85
Setting ............................................................................................................. 85
Health Region A .............................................................................................. 85
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision Treatment Process</td>
<td>167</td>
</tr>
<tr>
<td>Michigan Assessment of Decision Styles (MADS)</td>
<td>183</td>
</tr>
<tr>
<td>Qualitative Dimensions at Baseline</td>
<td>198</td>
</tr>
<tr>
<td>Follow-Up at Three to Four Months</td>
<td>201</td>
</tr>
<tr>
<td>Psychological Distress at Three to Four Months (BSI-18)</td>
<td>204</td>
</tr>
<tr>
<td>Qualitative Dimensions</td>
<td>233</td>
</tr>
<tr>
<td>Decision Satisfaction (PTDS)</td>
<td>236</td>
</tr>
<tr>
<td>Comparison across Pre- and Post-Treatment</td>
<td>259</td>
</tr>
<tr>
<td>Michigan Assessment of Decision Styles</td>
<td>259</td>
</tr>
<tr>
<td>Decision Satisfaction</td>
<td>262</td>
</tr>
<tr>
<td>Hypotheses Testing</td>
<td>264</td>
</tr>
<tr>
<td>CHAPTER 5-DISCUSSION</td>
<td>276</td>
</tr>
<tr>
<td>Introduction</td>
<td>276</td>
</tr>
<tr>
<td>Michigan Assessment of Decision Styles (MADS)</td>
<td>277</td>
</tr>
<tr>
<td>MADS Factors</td>
<td>280</td>
</tr>
<tr>
<td>Avoidance</td>
<td>280</td>
</tr>
<tr>
<td>Deferring Responsibility</td>
<td>283</td>
</tr>
<tr>
<td>Information Seeking</td>
<td>287</td>
</tr>
<tr>
<td>Deliberation</td>
<td>292</td>
</tr>
<tr>
<td>Decision Satisfaction</td>
<td>294</td>
</tr>
<tr>
<td>Limitations</td>
<td>297</td>
</tr>
<tr>
<td>Clinical Implications</td>
<td>300</td>
</tr>
<tr>
<td>Future Research</td>
<td>303</td>
</tr>
<tr>
<td>Contribution to the Discipline of Nursing</td>
<td>303</td>
</tr>
<tr>
<td>Conclusions</td>
<td>305</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>308</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>308</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1 Summary of empirical indicators of three decision styles .......................................................... 10
Table 2 Definitions of key terms. ........................................................................................................... 16
Table 3 Studies using the BSI-53 ........................................................................................................ 38
Table 4 Studies using the Control Preference Scale ............................................................................ 59
Table 5 Studies measuring breast cancer satisfaction ........................................................................ 73
Table 6 Reliability internal consistency coefficients for the BSI-18 instrument ................................... 99
Table 7 Statistical data analysis principles ............................................................................................ 111
Table 8 Re-coding of socio-demographic profile variables ................................................................. 113
Table 9 MADS items recoded into decision style factors ..................................................................... 116
Table 10 Patient Treatment Decision Satisfaction items re-coded variables ..................................... 118
Table 11 BSI-18 dimension items re-coded variables .......................................................................... 122
Table 12 Decision Treatment Process items re-coded variables ....................................................... 124
Table 13 Patient Treatment Decision Satisfaction Items re-coded ................................................... 126
Table 14 Women’s highest level (%) of completed education and employment status at baseline .... 133
Table 15 Women’s occupation and total annual household income (%) at baseline ......................... 134
Table 16 Women’s reported (%) previous history or contact with cancer at baseline ....................... 135
Table 17 Women’s responses (%) to the baseline BSI-18 items at baseline ..................................... 136
Table 18 Positive cases and descriptive analyses of women on the BSI-18 at baseline .................... 139
Table 19 BSI-18 Somatization median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline ........................................... 141
Table 20 BSI-18 Depression median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline ........................................... 148
Table 21 BSI-18 Anxiety median standardised scores and positive cases of women correlated with their socio-demographic characteristics at baseline ........................................... 155
Table 22 BSI-18 Global Severity Index (GSI) median standardised scores and positive cases of women correlated with their socio-demographic characteristics ........................................... 162
Table 23 Women’s responses (%) to the Decision Treatment Process statements regarding factors considered important when making the treatment decision .................................................. 168
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 ........................................................................................................... 175
Table 25 Women’s agreement (%) to Michigan Assessment of Decision Styles (MADS) factor items ........................................................................................................................................... 184
Table 26 Percentage of women who agreed or strongly agreed with all the items in each MADS factors ...................................................................................................................................... 188
Table 27 Michigan Assessment of Decision Styles (MADS) median values and interquartile ranges stratified by the women’s socio-demographic characteristics at baseline ........................................... 190
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 ................................................................. 198
Table 29  Women’s responses to the question “What nurses should know to help women make decisions ................................................................. 199
Table 30  Women’s responses to the questions “What advice do you have for other women who are facing this decision?” ......................................................... 200
Table 31.................Type of treatment received (%) by women at 3 to 4 months (n = 103). ................................................................. 202
Table 32  Percentage of treatment across each Health Region at 3 to 4 months (n = 104).......................... 203
Table 33  Women’s levels of psychological distress (%) as measured by BSI-18 scores (%) at 3 to 4 months after initial surgery ................................................................. 205
Table 34  Positive cases of women on the BSI-18 scores at follow-up 3 to 4 months after initial surgery ..................................................................................................... 208
Table 35  Relationships between women’s BSI-18 Somatization scores at 3 to 4 months after initial surgery and their socio-demographic characteristics ................................................................. 210
Table 36................. ................................................................. 216
Table 37  Relationships between women’s BSI-18 Depression scores at 3 to 4 months after initial surgery and their socio-demographic characteristics ................................................................. 216
Table 38  Relationships between women’s BSI-18 Anxiety scores at 3 to 4 months after initial surgery and their socio-demographic characteristics ................................................................. 222
Table 39  Women’s responses (%) to the question “What nurses should know to help women make decisions?” ................................................................. 233
Table 40  Women’s responses (%) to “What advice do you have for other women who are facing this decision?” ................................................................. 235
Table 41  Women’s agreement (%) with Patient Treatment Decision Satisfaction (PTDS) items 3 to 4 months after initial surgery ................................................................. 237
Table 42  Percentage of women who agreed or strongly agreed with all the items of decision satisfaction (PTDS) dimensions at 3-4 months ................................................................. 241
Table 43  Descriptive statistics of women’s Patient Treatment Decision Satisfaction (PTDS) scores at 3 to 4 months after initial surgery ................................................................. 242
Table 44  Relationships between women’s decision satisfaction (PTDS) scores at 3 to 4 months after initial surgery and their breast cancer treatment ................................................................. 243
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 ................................................................. 246
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 ................................................................. 254

Table 47 Women’s reported satisfaction (%) with the types of support they received (%) 3 to 4 months after the initial surgery ................................................................................................................... 255

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 ................................................................. 258

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. .............................................................................................................................. 258

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 ................................. 260

Table 51 Percentage of women identified as positive cases for BSI at baseline and 3-4 months. ........ 261

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 ........................................................................................................ 264

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 ................................................................................................................ 266

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 .................................................. 268

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 .................................................. 269

Table 56 Model 3: Avoidance (MADS) and women’s Global Decision Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months ............................................................................... 270

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 .................................................. 271

Table 58 Model 5: Deliberation (MADS) and women’s Decision Outcome Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months .................................................. 272

Table 59 Model 6: Avoidance (MADS) and women’s Decision Outcome Satisfaction (PTDS). Result of multiple linear regression analysis at 3 to 4 months .................................................. 274
LIST OF FIGURES

Figure 1  Diagram of data collection sites ................................................................. 88
Figure 2 Instruments contained in the baseline data collection. ............................... 93
Figure 3 Instruments contained in the follow-up data collection questionnaire at three to four months. ................................................................. 101
Figure 4 Outline of the data collection times ............................................................. 105
Figure 5 Overview of study ....................................................................................... 107
Figure 6 Histogram (%) of age of participants (years) ............................................... 132