

**ALTERNATIVE AND COMPLEMENTARY THERAPY USE BY  
WOMEN LIVING WITH BREAST CANCER: A TEST OF THREE MODELS**

by

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## Abstract

The overall aim of this study was to enhance knowledge of the experience of alternative and complementary therapy (ACT) use in women living with breast cancer. This was achieved by developing and testing three cognitive models of the causal relationships between selected health beliefs, sociobehavioural factors, demographic characteristics, and ACT utilization among women with breast cancer. The prevalence and patterns of ACT use were also examined.

A retrospective, correlational survey design was used in this study. A random sample of 650 women with stage I or II breast cancer was selected from the British Columbia Cancer Registry, of which 577 women were eligible for study participation. Completed self-report questionnaires were received from 334 women. The survey included questions to assess perceived risk of breast cancer recurrence, symptom distress, perceived efficacy of ACTs, barriers to ACT use, perceived control, and ACT utilization. Descriptive statistics were used to describe ACT utilization. Structural equation modelling was used to test the three models of ACT use across the contexts of preventive, ameliorative, and restorative health behaviour.

A substantial proportion of women with breast cancer was found to be using a variety of ACTs. Vitamin/mineral supplements, herbal remedies, and spiritual therapies were the most commonly reported ACTs, with the majority of women using fewer than five therapies following their breast cancer diagnosis and spending under \$50.00 a month on ACTs. Women most often sought information about ACTs from lay sources, including family and friends and print media. The majority of women had disclosed their use of ACTs to at least one of their conventional health care provider(s). Women who had used ACTs prior to their breast cancer diagnosis and had received encouragement from significant others to use ACTs were found to have greater commitment to ACTs. Health beliefs were found to explain a minimal amount of variances in women's commitment to ACTs. Exceptions included perceived efficacy of ACTs with regards to restoring well being and perceived control over well being. Women who believed ACTs to be efficacious in improving physical and mental well being and perceived themselves to be responsible for their well being were more likely to be committed to ACTs.

The study findings suggest that ACT use is a widespread phenomenon in breast cancer populations that is influenced most strongly by past health behaviour and the norms and preferences that exist within women's social groups. These findings also contribute to our understanding of ACT use by women with breast cancer as being a reflection of their commitment to self-care and wellness. The need for further research that explores the roles of family members and health care providers in treatment decisions related to ACTs and educational and counseling strategies that support informed treatment decision making are implications of this study.

## Table of Contents

Abstract .....	ii
Table of Contents.....	iii
List of Tables .....	ix
List of Figures .....	xii
Acknowledgements.....	xiii
 CHAPTER ONE – INTRODUCTION.....	 1
Background to the Study .....	1
Conceptual Issues .....	3
Defining Alternative/Complementary Therapies .....	3
Classifying Alternative/Complementary Therapies .....	6
Why Study Alternative/Complementary Therapy Use in Women with Breast Cancer? .....	6
Research Purpose .....	9
Summary .....	9
 CHAPTER TWO – LITERATURE REVIEW.....	 11
Alternative and Complementary Therapy Use in General and Cancer Populations .....	11
Prevalence of Alternative/Complementary Therapy Use in the General Population.....	12
Assessment of Alternative/Complementary Therapy Use.....	12
Sampling Issues .....	12
Retrospective Self-Report Measures .....	13
Alternative/Complementary Therapy Utilization Patterns .....	13
Prevalence of Alternative/Complementary Therapy Use in Cancer Populations .....	16
Alternative/Complementary Therapy Use by Women Living with Breast Cancer .....	22
Characteristics of Consumers of Alternative/Complementary Therapies.....	24
Demographic Profile within General Populations .....	25
Demographic Profile within Cancer Populations.....	26
Previous Health Experiences .....	27
Health Beliefs and Alternative/Complementary Therapy Use .....	27
Health Beliefs within General Population .....	28
Health Beliefs within Cancer Populations.....	33
Health Beliefs within the Breast Cancer Population.....	35
Perceptions of Need for Care.....	36
Summary of the Role of Health Beliefs.....	37



Other Factors Associated with Alternative/Complementary Therapy Use .....	38
Social Support .....	38
Control .....	40
Treatment Decision Making by Women Living with Breast Cancer .....	42
Conventional Treatment Decision Making .....	42
Treatment Decision Making and Alternative/Complementary Therapies .....	45
Chapter Summary .....	47
 CHAPTER THREE – THEORETICAL MODELS .....	50
Models of Health Behaviour .....	50
Behavioural Model of Health Care Utilization .....	51
Health Locus of Control .....	51
Theory of Reasoned Action .....	52
Summary .....	52
The Health Belief Model .....	52
Theoretical Models of Commitment to Alternative/Complementary Therapies .....	55
The Preventive Model of Alternative/Complementary Therapy Use .....	55
The Ameliorative Model of Alternative/Complementary Therapy Use .....	61
The Restorative Model of Alternative/Complementary Therapy Use .....	65
Chapter Summary .....	71
 CHAPTER FOUR – METHODS AND PROCEDURES .....	72
Research Design .....	72
Sample .....	72
Setting and Participants .....	72
Sample Size .....	73
Recruitment of Participants .....	77
Survey Completion Rates .....	78
Data Collection .....	81
Modified Total Design Method .....	81
Pilot Testing .....	82
Operationalization of Study Constructs .....	83
Demographics .....	84
Encouragement to Use Alternative/Complementary Therapies .....	84
Perceived Likelihood of Recurrence .....	85
Perceived Symptom Distress .....	86

Perceived Risk of Harm .....	87
Perceived Severity of Harm .....	87
Perceived Efficacy of Alternative/Complementary Therapies .....	88
Perceived Barriers to Alternative/Complementary Therapy Use .....	89
Perceived Control .....	90
Commitment to Alternative/Complementary Therapies .....	92
Data Analysis .....	101
Missing Data .....	101
Structural Equation Modelling .....	101
Ethical Considerations .....	102
 CHAPTER FIVE – DESCRIPTIVE FINDINGS .....	105
The Sample .....	105
Demographic, Disease, and Treatment Characteristics of Non-Respondents .....	105
Demographic Characteristics of the Respondents .....	105
Disease Characteristics of the Respondents .....	106
Conventional Cancer Treatment History of the Respondents .....	106
Differences between the Respondents and Non-Respondents .....	109
Use of Alternative/Complementary Therapies by Women with Breast Cancer .....	110
Prevalence of Alternative/Complementary Therapy Use .....	110
Prevalence of Alternative/Complementary Therapy Use by Therapy Type .....	112
Effect of Demographic Characteristics on Alternative/Complementary Therapy Use .....	113
Patterns of Alternative/Complementary Therapy Use .....	114
Number of Alternative/Complementary Therapies Used .....	114
Prior Experience with Alternative/Complementary Therapies .....	115
Initiation of Alternative/Complementary Therapy Use .....	115
Current Use of Alternative/Complementary Therapies .....	117
Frequency of Alternative/Complementary Therapy Use .....	118
Effort Involved in Using Alternative/Complementary Therapies .....	118
Cost of Alternative/Complementary Therapy Use .....	119
Sources of Information about Alternative/Complementary Therapies .....	120
Disclosure of Alternative/Complementary Therapy Use .....	121
 CHAPTER SIX – MODEL PREPARATION .....	122
Preventive Model of Alternative/Complementary Therapy Use .....	122
Examination of Missing Data .....	122

Tests of Normality .....	126
Univariate Normality.....	126
Bivariate Normality.....	128
Confirmatory Factor Analysis of the Measurement Model.....	131
Inclusion of Women with Breast Cancer Recurrence and Other Cancer Diagnosis....	132
Measurement Scaling and Reliabilities .....	134
Summary of the Preparation of the Preventive Model of Alternative/Complementary Therapy Use.....	137
Ameliorative Model of Alternative/Complementary Therapy Use.....	137
Examination of Missing Data .....	139
Tests of Normality .....	140
Univariate Normality.....	140
Bivariate Normality.....	142
Confirmatory Factor Analysis of the Measurement Model.....	143
Inclusion of Women with Breast Cancer Recurrence and Other Cancer Diagnosis....	146
Measurement Scaling and Reliabilities .....	148
Summary of the Preparation of the Ameliorative Model of Alternative/Complementary Therapy Use.....	148
Restorative Model of Alternative/Complementary Therapy Use .....	151
Examination of Missing Data .....	151
Tests of Normality .....	153
Univariate Normality.....	153
Bivariate Normality.....	155
Confirmatory Factor Analysis of the Measurement Model.....	156
Inclusion of Women with Breast Cancer Recurrence and Other Cancer Diagnosis....	157
Measurement Scaling and Reliabilities .....	159
Summary of the Preparation of the Restorative Model of Alternative/Complementary Therapy Use.....	160
CHAPTER SEVEN – STRUCTURAL EQUATION MODELLING RESULTS.....	162
Preventive Model of Alternative/Complementary Therapy Use.....	162
Structural Model 1a .....	162
Model Modifications to Model 1a.....	164
Structural Model 1b.....	165
Model Modifications to Model 1b.....	165
Structural Model 1c.....	166
Model Modifications to Model 1c.....	166

Structural Model 1d .....	166
Model Modifications to Model 1d .....	166
Structural Model 1e .....	167
Model Modifications to Model 1e .....	167
Structural Model 1f .....	167
Model Modifications to Model 1f .....	168
Bootstrapping of Model 1f .....	168
Direct and Indirect Effects in Structural Model 1f .....	170
Summary of Model Testing of the Preventive Model of Alternative/Complementary Therapy Use .....	173
Ameliorative Model of Alternative/Complementary Therapy Use .....	174
Structural Model 2b .....	174
Model Modifications to Model 2b .....	176
Structural Model 2c .....	176
Model Modifications to Model 2c .....	177
Structural Model 2d .....	177
Model Modifications to Model 2d .....	177
Structural Model 2e .....	178
Model Modifications to Model 2e .....	178
Bootstrapping of Model 2e .....	178
Direct and Indirect Effects in Structural Model 2e .....	181
Summary of Model Testing of the Ameliorative Model of Alternative/Complementary Therapy Use .....	183
Restorative Model of Alternative/Complementary Therapy Use .....	183
Structural Model 3a .....	183
Model Modifications to Model 3a .....	185
Structural Model 3b .....	185
Model Modifications to Model 3b .....	186
Structural Model 3c .....	186
Model Modifications to Model 3c .....	186
Structural Model 3d .....	187
Model Modifications to Model 3d .....	187
Bootstrapping of Model 3d .....	188
Direct and Indirect Effects in Structural Model 3d .....	189
Summary of Model Testing of the Restorative Model of Alternative/Complementary Therapy Use .....	192

CHAPTER EIGHT – DISCUSSION AND IMPLICATIONS .....	193
Discussion of the Findings .....	193
Alternative/Complementary Therapy Use by Women Living with Breast Cancer .....	193
Prevalence of Alternative/Complementary Therapy Use .....	194
Commonly Used Therapies .....	195
Patterns of Use .....	197
Cost of Alternative/Complementary Therapy Use .....	199
Sources of Information about ACTs and Disclosure of Use .....	200
The Role of Health Beliefs in Alternative and Complementary Therapy Use .....	202
Preventive Model of Alternative and Complementary Therapy Use .....	203
Ameliorative Model of Alternative and Complementary Therapy Use .....	207
Restorative Model of Alternative and Complementary Therapy Use .....	209
Comparison of the Three Models of Alternative/Complementary Therapy Use .....	212
Contributions and Strengths of the Study .....	215
Theoretical Considerations .....	215
Methodological Considerations .....	216
Limitations of the Study .....	217
Study Design .....	217
Retrospective Data .....	217
Measurement Issues .....	218
Generalizability .....	221
Implications for Practice .....	222
Recommendations for Future Research .....	224
Conclusion .....	229
REFERENCES .....	230
APPENDICES .....	248
Appendix 1 – Family Physician Letter .....	248
Appendix 2 – Letter of Invitation .....	249
Appendix 3 – Consent Form .....	250
Appendix 4 – Questionnaire Cover Letter .....	252
Appendix 5 – Study Questionnaire .....	253
Appendix 6 – Follow-up Letter .....	279
Appendix 7 – Survey Assessment Form .....	280
Appendix 8 – Complete Alternative/Complementary Therapy List (Liberal Definition) .....	281
Appendix 9 – Covariance Matrices for Models of Alternative/Complementary Therapy Use .....	283

## List of Tables

1.	Classification of Alternative/Complementary Therapies .....	7
2.	Summary Data from Prevalence Studies of ACT Use in Cancer Populations .....	18
3.	Survey Completion Rates .....	78
4.	Reasons for Ineligibility .....	78
5.	Inclusion and Exclusion Selection Criteria .....	79
6.	Reasons for Non-Participation of Eligible Women .....	79
7.	List of Scales/Items in Final Study Questionnaire .....	95
8.	Study Constructs and Associated Instruments in the Preventive, Ameliorative, and Restorative Models .....	100
9.	Demographic Characteristics of the Respondents .....	107
10.	Conventional Cancer Treatment History of the Respondents .....	108
11.	Discrepancies between Respondents' Self-Report and BC Cancer Registry Data on Conventional Treatment History .....	109
12.	Demographic and Disease Characteristics of Respondents and Non-Respondents ..	110
13.	Prevalence of Alternative/Complementary Therapy Use .....	111
14.	Most Frequently Reported Alternative/Complementary Therapies .....	112
15.	Prevalence of Alternative/Complementary Therapy Use by Therapy Type .....	113
16.	Association of Demographic Characteristics with Alternative/Complementary Therapy Use .....	114
17.	Number of Alternative/Complementary Therapies Used .....	115
18.	Association between Prior Alternative/Complementary Therapy Use and the Use of Alternative/Complementary Therapies Following Breast Cancer Diagnosis ....	116
19.	Alternative/Complementary Therapy Initiation by Therapy Type .....	116
20.	Comparison of Therapy Initiation by Therapy Type .....	117
21.	Association between Therapy Initiation and Current Use of Alternative/ Complementary Therapies at Time of Survey Completion .....	118
22.	Frequency of Alternative/Complementary Therapy Use .....	118
23.	Effort Involved in Using Alternative/Complementary Therapies by Therapy Type .....	119
24.	Reported Sources of Information about Alternative/Complementary Therapies .....	121
25.	Summary of Missing Data in the Preventive Model of Alternative/Complementary Therapy Use .....	124

26.	Frequency of Imputed Missing Data for Alternative/Complementary Therapy Use Variables by Therapy Type.....	125
27.	Univariate Statistics for Exogenous Variables (Preventive Model – Model 1a).....	126
28.	Univariate Statistics for Endogenous Variables (Preventive Model – Model 1a) .....	127
29.	Bivariate Normality Violations for Exogenous and Endogenous Variables in the Preventive Model (Model 1a) Following Transformations .....	129
30.	Univariate Statistics for Revised and New Variables (Preventive Model – Model 1a). .....	130
31.	Bivariate Normality Violations for Exogenous and Endogenous Variables in the Preventive Model (Model 1a) Following Transformations .....	131
32.	Goodness-of-Fit Indices for the Measurement Model of the Preventive Model (Model 1a) .....	132
33.	Factor Loadings and <i>t</i> -Values for the Measurement Model of the Preventive Model..	133
34.	Mean Differences between Women with and without Breast Cancer Recurrence on Preventive Model (Model 1a) Variables .....	134
35.	Mean Differences between Women with and without Other Cancer Diagnosis on Preventive Model (Model 1a) Variables .....	135
36.	Summary of Missing Data in the Ameliorative Model of Alternative/Complementary Therapy Use (Model 2a).....	140
37.	Univariate Statistics for Exogenous Variables (Ameliorative Model – Model 2a).....	141
38.	Univariate Statistics for Endogenous Variables (Ameliorative Model – Model 2a).....	142
39.	Bivariate Normality Violations for Exogenous and Endogenous Variables in the Ameliorative Model (Model 2a) Following Transformations.....	143
40.	Goodness-of-Fit Indices for the Measurement Model of the Ameliorative Model (Model 2a and Model 2b).....	144
41.	Factor Loadings and <i>t</i> -values for the Measurement Model of the Ameliorative Model (Model 2a and Model 2b). .....	145
42.	Mean Differences between Women with and without breast cancer recurrence on the Ameliorative Model (Model 2b) Variables.....	146
43.	Mean Differences between Women with and without other cancer diagnosis on the Ameliorative Model (Model 2b) Variables .....	147
44.	Error Variances in the Ameliorative Model of Alternative/Complementary Therapy Use.(Model 2b).....	149
45.	Summary of Missing Data in the Restorative Model of Alternative/Complementary Therapy Use (Model 3a).....	152
46.	Univariate Statistics for Exogenous Variables (Restorative Model – Model 3a) .....	153
47.	Univariate Statistics for Endogenous Variables (Restorative Model – Model 3a) .....	154

48.	Bivariate Normality Violations for Exogenous and Endogenous Variables in the Restorative Model Following Transformations .....	156
49.	Goodness-of-Fit Indices for the Measurement Model of the Restorative Model (Model 3a) .....	156
50.	Factor Loadings and <i>t</i> -values for the Measurement Model of the Restorative Model (Model 3a) .....	157
51.	Mean Difference between Women with and without Breast Cancer Recurrence on the Restorative Model (Model 3a) Variables .....	158
52.	Mean Difference between Women with and without Other Cancer Diagnosis on the Restorative Model (Model 3a) Variables .....	159
53.	Error Variance in the Restorative Model of Alternative/Complementary Therapy Use (Model 3a) .....	160
54.	Goodness-of-Fit Indices for Sequential Modifications of the Preventive Model of Alternative/Complementary Therapy Use .....	165
55.	Parameter Estimates for Model 1f (Preventive Model) .....	171
56.	Direct and Indirect Effects from Structural Model 1f (Preventive Model) .....	171
57.	Goodness-of-Fit Indices for Sequential Modifications of the Ameliorative Model of Alternative/Complementary Therapy Use .....	174
58.	Parameter Estimates for Model 2d (Ameliorative Model) .....	179
59.	Direct and Indirect Effects from Structural Model 2d (Ameliorative Model) .....	182
60.	Goodness-of-Fit Indices for Sequential Modifications of the Restorative Model of Alternative/Complementary Therapy Use .....	186
61.	Parameter Estimates for Model 3d (Restorative Model) .....	188
62.	Direct and Indirect Effects from Structural Model 3d (Restorative Model) .....	190
63.	Major Study Findings and Implications .....	225



## List of Figures

1.	Preventive Model of Alternative/Complementary Therapy Use by Women Living with Breast Cancer .....	56
2.	Ameliorative Model of Alternative/Complementary Therapy Use by Women Living with Breast Cancer .....	63
3.	Restorative Model of Alternative/Complementary Therapy Use by Women Living with Breast Cancer .....	67
4.	Flow Diagram of the Development of the Final Dataset prior to Randomization.....	74
5.	Flow Diagram of the Recruitment Process.....	80
6.	Transformation of Perceived Control Items.....	91
7.	Total Monthly Cost of Current Alternative/Complementary Therapy Use (Liberal Definitions .....	120
8.	Model 1a – Preventive Use of Alternative/Complementary Therapies .....	138
9.	Model 2b – Ameliorative Use of Alternative/Complementary Therapies.....	150
10.	Model 3a – Restorative Use of Alternative/Complementary Therapies .....	161
11.	Structural Model 1a – Preventive Use of Alternative/Complementary Therapies .....	163
12.	Structural Model 1f – Preventive Use of Alternative/Complementary Therapies .....	172
13.	Structural Model 2b – Ameliorative Use of Alternative/Complementary Therapies.....	175
14.	Structural Model 2d – Ameliorative Use of Alternative/Complementary Therapies.....	180
15.	Structural Model 3a – Restorative Use of Alternative/Complementary Therapies .....	184
16.	Structural Model 3c – Restorative Use of Alternative/Complementary Therapies .....	191

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## Chapter 1

### Introduction

In recent years, there has been a remarkable increase in interest and use of therapies that are considered to be beyond the realm of conventional medical care. In a recent survey conducted by the Fraser Institute (Ramsay, Walker, & Alexander, 1999), nearly three quarters of Canadians surveyed had used treatment that was alternative or complementary to their allopathic care at some point in their lives. One group that has been vocal in its support and advocacy of alternative and complementary therapies (ACTs) has been women with breast cancer. In a document recently published by the BC/Yukon Chapter of the Canadian Breast Cancer Foundation (Trussler, 2001), consumers identified ACTs as playing a central role in the supportive breast care strategy. With women with breast cancer comprising one of the largest categories of cancer survivors in Canada (National Cancer Institute of Canada [NCIC], 2001), the impact of ACTs on provincial health care systems may be significant. As the movement towards integration of ACTs into conventional cancer care has gained momentum, researchers have focussed on determining what social and behavioural factors influence the treatment decisions of individuals living with cancer. While much has been uncovered by this research, what remains to be developed is a comprehensive, theoretical model of ACT utilization.

### Background to the Study

Interviews with women living with breast cancer have revealed ACTs to be integral to their experiences with this life-threatening disease (Boon et al., 1999; Gray et al., 1997; Truant, 1998). For some women, ACTs are a means of preserving hope when faced with the uncertainty of their prognosis (Truant & Bottorff, 1999). For others, the decision to use ACTs reflects a desire to regain control over their health and to assert their independence within the biomedical health-care system (Montbriand, 1995a). Women with breast cancer who choose ACTs have also been motivated by specific goals related to their disease and recovery,

including the improvement of their immune system, the management of adverse effects of conventional cancer treatments, and the restoration of their physical and emotional well being (Crocetti et al., 1998). Despite the limited number of women who have reported using ACTs in the hope of curing their breast cancer (Morris, Johnson, Homer, & Walts, 2000) and as a replacement for conventional cancer care (Burstein, Gelber, Guadagnoli, & Weeks, 1999), conventional health professionals and researchers have expressed concern regarding the use of these therapies (Beyerstein, 1997; Damkier, Elverdam, Glasdam, Jensen, & Rose, 1998; Davidoff, 1998; Durant, 1998). Their concern is not without justification because there has been limited study of the efficacy and safety of ACTs in relation to cancer care (Tagliaferri, Cohen, & Tripathy, 2001) and some suggestion that potentially harmful interactions with conventional treatments may exist (Decker, 2000; Jacobson & Verret, 2001). A recent study of women with early-stage breast cancer (Burstein et al., 1999) raised additional concerns when women using ACTs were found to report higher levels of psychological distress and anxiety than non-users. Researchers have been cautious in relating ACT use to increased psychological morbidity (Holland, 1999), instead suggesting that cancer patients may turn to ACTs to treat the distress that has been not addressed by the conventional health-care system. With nearly one half of women with breast cancer choosing not to discuss their treatment decisions about ACTs with their conventional health-care providers (Adler & Fosket, 1999; Balneaves, Kristjanson, & Tatarzyn, 1999), opportunities to discuss concerns about ACTs and satisfaction with conventional care are often not realized in clinical settings.

Concerns about the safety of ACTs and the possibility that ACT use may function as a marker for distress and dissatisfaction with care have resulted in a large body of research focussed on determining which individuals are most likely to utilize ACTs. In both the general population (Eisenberg, 1997; Kelner & Wellman, 1997a; Millar, 1997) and across cancer diagnoses (Crocetti et al., 1998; Downer et al., 1994; Ernst & Cassileth, 1998), a distinct profile of ACT consumers has been revealed. Sociodemographic factors, such as age, gender, education, income, and a history of chronic illness, have been associated with ACT utilization (Blais, Maiga, & Aboubacar, 1997; Eisenberg et al., 1998; Lerner & Kennedy, 1992). Research has also examined the role of cognitive factors and belief systems in the decision to use ACTs. Most striking has been the association between beliefs about health and illness and treatment decisions related to ACTs (Furnham & Bond, 2000; Furnham & Kirkcaldy, 1996; Kelner & Wellman, 1997a; Risberg, Wist, & Bremnes, 1998; Vincent & Furnham, 1996). Recent work with women with breast cancer has revealed the importance of these beliefs, in addition to such sociobehavioural factors as perceived control, social support, previous use of ACTs, and perceptions of need (Balneaves et al., 1999; Boon et al., 2000; Crocetti et al., 1998; Truant & Bottorff, 1999). While this research has provided a preliminary and descriptive understanding of

ACT use in the context of breast cancer, what remains unanswered is how beliefs and sociobehavioural variables interrelate and motivate individuals' treatment decisions related to ACTs. This gap in knowledge underscores the need for innovative research that moves beyond the descriptive level and results in the development and testing of comprehensive theories of ACT use. The recent emphasis on the association between health beliefs and ACT use (Blais et al., 1997; Boon, Brown, Gavin, Kennard, & Stewart, 1999; Furnham & Kirkcaldy, 1996; McGregor & Peay, 1996; Millar, 1997; Vincent & Furnham, 1996; Yates et al., 1993) points towards the possible relevance of social cognitive theories in explaining ACT utilization.

## Conceptual Issues

### Defining Alternative/Complementary Therapies

Studies exploring the prevalence and motivations of ACT use have been marked by a lack of consensus with regards to the manner in which therapies are described, defined, and categorized. A variety of labels has been applied to ACTs, including *alternative*, *complementary*, *adjunctive*, *unproven*, *unconventional*, *unorthodox*, *questionable*, and *quackery*. The language used to describe ACTs has been described as reflective of the cultural or political position of these therapies within a society's health care system rather than a description of the care provided (Turner, 1998). Lerner (1994) further suggested that the terminology used relates primarily to the degree to which a therapy has achieved "acceptability" within the medical establishment. As such, the language used to describe ACTs is by no means benign in intent or meaning. Care is needed in selecting nomenclature that accurately and appropriately describes ACTs and the positions these therapies hold within the cultural, economic, medical, and educational domains of a society (Eskinazi, 1998).

At the beginning stages of ACT research, the term "alternative medicine" gained prominence within the biomedical community, most notably because of its use in two national surveys on ACT use conducted in the United States (Eisenberg et al., 1998; Eisenberg et al., 1993). This term was used to describe the following:

- Interventions neither taught widely in medical schools, nor generally available in US hospitals (Eisenberg et al., 1998; Eisenberg et al., 1993),
- Therapies used instead of Western medicine (Spiegel, Stroud, & Fyfe, 1998),
- Therapies characterized by their sociopolitical marginality (i.e., lack of support from medicine and/or government) (Kelner & Wellman, 1997b), and
- Therapies that are physiologically active, potentially harmful, and in conflict with mainstream care (Cassileth, 1998).

These descriptions of "alternative medicine" were problematic in several ways. Foremost, in placing "alternative medicine" at the margins of conventional medicine, there existed an underlying assumption that the therapies were used solely within a culture in which the biomedical paradigm was dominant. This assumption failed to consider health care practices on a worldwide basis where other distinct belief and practice systems exist. Secondly, the way in which "alternative medicine" was defined suggested that any therapy or intervention not claimed by conventional Western medicine would be classified as alternative (Wardell, 1994). With physicians and other health care professionals beginning to incorporate ACT content within their curricula, which therapies should be included under the rubric "alternative medicine" becomes increasingly difficult to determine. The use of the term "medicine" within this description is also of concern because it lacks neutrality and juxtaposes these therapies with a paradigm focussed on disease rather than well being. There also has been the suggestion that "alternative medicine" is representative of the co-optation of selected therapies by the conventional medical community.

Another popular label used to define ACTs has been "complementary" therapies or medicine (Ernst, 1995; Fairfield, Eisenberg, Davis, Libman, & Phillips, 1998; Furnham, Vincent, & Wood, 1995; Pietroni, 1994; Truant & Bottorff, 1999). Considered to be more respectful than "alternative medicine" (Turner, 1998), "complementary" therapies have been described in numerous ways:

- Therapies that complement the intelligent use of conventional approaches deemed scientifically to be efficacious (Lerner, 1994),
- Therapies that involve cooperative effort between biomedicine and alternative practitioners (Nienstedt, 1998),
- Therapies used in addition to and to balance the shortcomings of mainstream medicine (Spiegel et al., 1998),
- Therapies that are adjunctive to medical care (Kelner & Wellman, 1997b), and
- Therapies that are pleasant, non-toxic, and beneficial to quality of life (Cassileth, 1998).

Special emphasis has been placed on the distinction in meaning between "alternative" and "complementary" therapies and the coexistence of both kinds of therapies (Cassileth, 1998; Spiegel et al., 1998). Complementary therapies, for the most part, are considered to be more adjunctive and supportive than alternative therapies. In particular, Milton (1998) suggested that within cancer care, complementary therapies are used to manage cancer symptoms and the side effects of conventional treatment. Accordingly, when complementary therapies are used to promote healing and quality of life, they are believed to work in tandem with conventional

medicine. The use of the complementary therapy term as a descriptor of ACTs, however, does not encompass those therapies that are used in place of conventional medicine.

Most recently, a movement towards terminology that encompasses both alternative and complementary approaches to health care has occurred. In 1998, the US National Institutes of Health (NIH) Office of Alternative Medicine was re-established as the National Center for Complementary and Alternative Medicine (NCCAM). The following definition and description of complementary and alternative medicine (CAM) is used by the NCCAM:

A broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well being. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp and defined. (Anonymous, 1997, p. 50)

CAM has also been defined by Ernst and Cassileth (1998) as the:

Diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy, or by diversifying the conceptual frameworks of medicine. (p. 777)

Together, these definitions position CAM within a social, political, and cultural context and acknowledge the holistic nature putatively embodied by many traditional healing systems. However, concerns have been raised regarding the broadness of the term CAM and its application to therapies that have been accepted as adjunctive interventions within conventional medicine (e.g., group therapy, relaxation techniques) (Cassileth, 1998). Determining what therapies are accepted and by whom continues to be an elusive task because beliefs, attitudes, and knowledge surrounding ACTs continue to unfold within medical and lay communities.

Although the use of the term CAM represents a progressive step towards a comprehensive and contextual definition of therapies not traditionally included within a society's dominant health care system, a medical bias in language is still evident. Balneaves (1996) attempted to avoid this bias by developing the acronym ACTs (alternative and complementary therapies). This terminology not only considers therapies that are used to supplement or replace treatments offered by the dominant health care system, but also symbolizes choice and action on the part of health care consumers. In addition, the term ACTs allows both alternative

systems of healing (e.g., Traditional Chinese Medicine) and individual therapies (e.g., acupuncture) to be included under one appellation and acknowledges the intervention of practitioners other than physicians. Which therapies are considered to be alternative, complementary, or conventional, however, is dependent upon the relative hegemony of the biomedical paradigm within the society under study and the personal experiences of health care consumers. Notwithstanding this ambiguity, the ACT terminology is used in this study.

### **Classifying Alternative/Complementary Therapies**

A variety of strategies have been proposed to organize and classify the hundreds of existing ACTs. The most often quoted method is the seven category approach recommended by the NCCAM (Nienstedt, 1998), which includes the following: diet, nutrition, and lifestyle changes; mind/body interventions; alternative systems; bioelectromagnetic interventions; manual healing; pharmacological and biological therapies; and herbal medicine. These categories, however, have been criticized as being too broad and ambiguous to permit definitive classification (Nienstedt, 1998). For example, although relaxation and meditation techniques are traditionally classified under the rubric of mind/body interventions, they may also play an integral role within lifestyle changes, such as stress reduction. A more specific categorization system has been proposed by the Ontario Breast Cancer Information Exchange Project (1994) and consists of 15 distinct classes of ACTs (see Table 1). This classification is particularly useful within the context of this dissertation research, because it was developed specifically to inform Canadian women living with breast cancer<sup>1</sup>. Being able to classify therapies into their respective traditions allows ACT use to be explored in a more refined manner and acknowledges the range of therapies that exists.

### **Why Study Alternative/Complementary Therapy Use in Women with Breast Cancer?**

The utilization of ACTs has been examined across general and disease-specific populations, with cancer (Boon et al., 2000; Downer et al., 1994; Montbriand, 1995a; Yates et al., 1993), multiple sclerosis (Fawcett, Sidney, Hanson, & Riley-Lawless, 1994), and HIV/AIDS (Pawluch, Cain, & Gillett, 1994; Singh et al., 1996) being a few examples. That ACTs are being used to address a variety of life-threatening and chronic conditions, in addition to general well being, is apparent. The development and testing of cognitive models of ACT use could occur in populations other than women living with breast cancer and provide important insights into the underlying health beliefs and sociobehavioural factors that influence treatment choice. Testing the application of the developed models within these populations is an important future research endeavour, however, for the purposes of this study, women with breast cancer are the focus.

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<sup>1</sup> This classification system includes therapies that are of particular interest to women living with breast cancer and, as such, is not a comprehensive list of ACT therapies. For example, spiritual therapies, such as prayer and laying on of hands, were not included.



**Table 1. Classification of Alternative/Complementary Therapies**

Category	Therapies	
Natural Health Practices	Aromatherapy Ayurvedic medicine Herbalism Naturopathy	Homeopathy Native North American healing Traditional Chinese medicine
Herbal Therapies	Aloe Carnivora Coffee enema Essiac	Hoxsey method Pau d'Arco Isadora Ginseng
Dietary Therapies	Alkaline/acid cleansing diet Gerson therapy	Grape cure Metabolic therapy Macrobiotic diet
Vitamins	Vitamin A B vitamins Beta-carotene Vitamin C	Vitamin D Vitamin E Megavitamin therapy
Minerals	Calcium Selenium	Zinc
From Earth and Sea	Alkylglycerols Canthaxanthin Evening primrose	Mushrooms Seaweed Shark Cartilage
Energy Life Force Therapies	Acupuncture/acupressure Reiki	Polarity therapy Therapeutic touch
Movement Therapies	T'ai Chi	Yoga
Physical Therapies	Chiropractic Massage	Reflexology
Psychological Therapies	Hypnosis Imagery/Visualization Meditation	Psychotherapy and counselling Relaxation
Expressive Arts Therapies	Art therapy	Music therapy
To and From the Body	Cell extraction therapy Colonic irrigation	Urea
Oxygen Therapies	Ozone	Hydrogen Peroxide
Drugs	714-X Aspirin DMSO	Enzyme therapy Benzaldehyde Chelation therapy
Immune Boosters	Bestatin Chondriana Coley's toxins	Immuno-augmentative therapy Isoprinosine

*Note.* Adapted from Ontario Breast Cancer Information Exchange Project (1994). A guide to unconventional cancer therapies. Toronto, ON: Author.

This population has been chosen as a starting point to test models of ACT utilization for several reasons.

Foremost, breast cancer is a pervasive disease in Canadian society. In the past decade, the incidence of breast cancer has risen steadily. One in nine women is now expected to develop this disease at some point in her lifetime, with approximately 19,500 new cases of

breast cancer being diagnosed in 2001 (NCIC, 2001). While breast cancer mortality has declined slightly in recent years, breast cancer remains the second leading cause of cancer death for Canadian women. In British Columbia, approximately 2,500 women were diagnosed in 2001 (NCIC, 2001). These statistics suggest that a significant number of women in Canada are living with, and dying from, this disease.

Secondly, the effects of breast cancer on women and their families are extensive and profound. For many women, living with breast cancer is a traumatic, life-altering experience. The time from diagnosis to survival is fraught with uncertainty, dramatic physical changes, and emotional upheaval (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Pelusi, 1997; Wainstock, 1991). The side effects of conventional cancer treatments experienced by some women contribute to these feelings of distress. Breast cancer patients are also faced with existential issues, such as ascribing meaning to their illness (Luker, Beaver, Leinster, & Owens, 1996) and confronting a terminal prognosis (Wainstock, 1991).

Given the psychosocial distress and potential mortality associated with breast cancer, women may seek treatment options other than those offered by conventional medicine. Recent prevalence studies have confirmed that ACTs are used by women living with breast cancer, with reported prevalence rates between 17% to 67% (Balneaves et al., 1999; Boon et al., 2000; Burstein et al., 1999; Crocetti et al., 1998; Morris et al., 2000; Moschèn et al., 2001; Rees et al., 2000; Salmenperä, 2002; VandeCreek, Rogers, & Lester, 1999). Compared to patients with other forms of cancer, women with breast cancer are significantly more likely to use some form of alternative or complementary treatment (Morris et al., 2000). With such a substantial number of women using ACTs, the breast cancer population offers an interested, willing, and relevant milieu in which to conduct research examining the role of health beliefs and sociobehavioural factors associated with ACT use.

Another reason for researching ACT use in women with breast cancer is because they have demanded it. At the National Breast Cancer Forum in 1993, breast cancer survivors and advocates rated ACTs as one of the top priorities in terms of both efficacy studies and behavioural research (National Forum on Breast Cancer, 1994). A recent inquiry into the state of breast cancer care in British Columbia has given further support to the importance of ACTs to women living with this disease (Trussler, 2001). Recent initiatives through the National Cancer Institute of Canada's Canadian Breast Cancer Research Initiative (CBCRI) have also emphasized the relevance and importance of research exploring ACT use within the Canadian breast cancer community (Jacobson, 1996).

## Research Purpose

The main purpose of this research study was to develop and test three cognitive models of ACT utilization in women living with breast cancer. In testing these models, the influence of selected health beliefs (including perceived risk, perceived efficacy of ACTs, perceived barriers to ACT use, and perceived control) and sociobehavioural factors (including previous ACT use, encouragement to use ACTs, sociodemographic characteristics) on women's treatment decisions related to ACTs was explored. Guided by the theoretical underpinnings of the Health Belief Model (Janz & Becker, 1984; Rosenstock, 1974b), the three models tested in this research allowed women's use of ACTs to be examined across three different health contexts: prevention, amelioration, and restoration. In developing three unique models, the relevance of health beliefs and sociobehavioural factors within different contexts of ACT use was explored and the intent of therapy use was investigated. A secondary aim of the study was to determine the types of therapies used by women with breast cancer and the degree of commitment extended towards ACTs. The following research questions were addressed in the study:

- *How are health beliefs and selected sociobehavioural factors associated with the use of ACTs by women living with breast cancer within preventive, ameliorative, and restorative health contexts?*
- *To what extent do the preventive, ameliorative, and restorative models explain ACT use in a breast cancer population?*
- *What are the prevalence, pattern, and financial cost of ACT use by women living with breast cancer in British Columbia?*

## Summary

As the prevalence of and interest in alternative and complementary therapies (ACTs) have grown within general and cancer populations, it has become increasingly important to understand why individuals make such choices and what underlying beliefs influence their treatment decision making. Such knowledge will inform future research priorities in ACTs, assist in the development of appropriate counselling and educational strategies for patients and conventional health-care providers, and improve the clinical care of people using ACTs. Focussing on the experience of women living with breast cancer, this research study was undertaken to develop and test three cognitive models that examined the effects of selected health beliefs and sociobehavioural factors on women's decisions to use ACTs. In the following chapter, an overview of the literature pertaining to ACT use in general and cancer populations, including the characteristics of ACT users and motivating factors of ACT use, is provided. Later chapters review the theoretical framework guiding the development of the three cognitive

models, the design and procedures of the study, and the descriptive and structural modelling research findings. The final chapter provides a concise discussion of the results and implications of the study.

## Chapter 2

### Literature Review

The first section of this review provides a summary of the diverse literature on alternative and complementary therapy (ACT) use. This section focusses on recent sociobehavioural research that has examined ACT use within the general, breast cancer and other cancer populations. Research findings related to the prevalence of ACT use within general and cancer populations, the demographic and other predisposing characteristics of ACT consumers within general and cancer populations, and the motivations underlying the decision to use ACTs by individuals with cancer and within the general population are discussed. In the second section, a concise review of research examining treatment decision making in women with breast cancer is presented. Together, these two sections provide the substantive foundation for the development and testing of three cognitive models of ACT use within a sample of women living with breast cancer.

The majority of literature reviewed was drawn from a search of the research literature published in the past two decades, encompassing the fields of nursing, medicine, psychology, and sociology, (i.e., CINAHL, Medline, PsychLit, and Sociofile). Excluded from this review, for the most part, are non-English and unpublished literature. Non-research articles (e.g., editorials, letters to the editors, opinion articles) included in the review consist primarily of discussion pieces that provide a theoretical or social context to the research exploring the use of ACTs.

### Alternative and Complementary Therapy Use in General and Cancer Populations

The following section provides a detailed review and critique of sociobehavioural ACT research. The main areas of discussion include the prevalence of ACT use across general and cancer populations, the personal and social characteristics of ACT consumers, the influencing role of health beliefs in determining treatment choice, and other motivators of ACT use.

## **Prevalence of Alternative/Complementary Therapy Use in the General Population**

Previous epidemiological research has revealed that between 15% to 68% of the general population in North America, Europe, and the Middle East have used at least one type of ACT in their lifetime (Angus Reid Group, 1997; Bernstein & Shuval, 1997; Eisenberg et al., 1998; Eisenberg et al., 1993; Grenfell, Patel, & Robinson, 1998; MacLennan, Wilson, & Taylor, 1996; Millar, 1997; Murray & Shepherd, 1993; Ramsay et al., 1999). Despite the wide variation in utilization estimates, this research suggests that the use of ACTs is a substantial health care phenomenon within industrialized countries. The disparity among utilization estimates can be attributed, in part, to several methodological issues, including the methods of assessment of ACT use (Harris & Rees, 2000), sampling issues, and the retrospective nature of the studies. Each of these issues is discussed, followed by a comparison of ACT utilization patterns in the general population.

## **Assessment of Alternative/Complementary Therapy Use**

There has been a lack of consensus among researchers about how ACT use should be assessed. For some researchers, the use of therapies that are marginal to conventional medical treatment and that are generally unavailable within the majority of mainstream health-care institutions has been considered to be indicative of ACT use (Eisenberg, 1997; Eisenberg et al., 1993; Murray & Shepherd, 1993; Ramsay et al., 1999). In contrast, others researchers have used only consultations with alternative/complementary practitioners as being representative of ACT use (Millar, 1997). With over 50% of ACT consumers using treatments without consulting an alternative/complementary practitioner (Eisenberg et al., 1998), examining only the use of alternative/complementary practitioners may significantly underestimate the actual use of ACTs. Further, there has been variation in the way in which individuals are asked about ACT use. Although the majority of researchers have used pre-determined lists of ACTs and alternative practitioners to uncover ACT use (Eisenberg et al., 1998; Eisenberg et al., 1993; Millar, 1997; Murray & Shepherd, 1993; Ramsay et al., 1999), researchers have also used open-ended questions about treatment choices (Grenfell et al., 1998). This diversity in data collection methods limits comparisons across studies and biases participants' responses.

### **Sampling Issues**

Several issues arise related to the sampling methods used in previous surveys of ACT use. While random sampling was employed in the majority of prevalence studies examining ACT use in general populations (Angus Reid Group, 1997; Bernstein & Shuval, 1997; Eisenberg et al., 1998; Eisenberg et al., 1993; Ramsay et al., 1999; Thomas, Carr, Westlake, & Williams, 1991), some researchers (Grenfell et al., 1998; Kristof, Schlumpf, Wyss, & Saller, 1998; Murray & Shepherd, 1993) used convenience samples to determine the pervasiveness of ACT use in the general public. The latter sampling strategy raises concerns regarding the generalizability of

the findings. Further, the reliance on convenience samples to determine prevalence rates of ACT use, coupled with the identification of ACT use as being the subject of interest of the research, may have resulted in an over-representation of individuals who had used ACTs. Eisenberg et al. (1998, 1993) attempted to avoid this bias by making no mention of ACTs in their initial recruitment of participants.

Another methodological issue is the recruitment methods used in some of the prevalence studies. The use of telephone and/or household interviews that were limited to those participants able to speak English may have restricted the participants recruited in terms of socioeconomic status, ethnicity, and residency. As a consequence, the study findings may have limited generalizability to disadvantaged and ethnic populations (Eisenberg et al., 1998; Eisenberg et al., 1993; Millar, 1997; Ramsay et al., 1999). Further, the recruitment of participants through conventional or alternative health-care systems (Grenfell et al., 1998; Kristof et al., 1998; Murray and Shepherd, 1993; Thomas, et al., 1991) may have potentially under- or over-represented the prevalence of ACT use within general populations. For example, it is not surprising that Kristof et al. (1998) found over 96% of attendees at an alternative health fair had used ACTs at some time in their lives.

A final sampling issue that has not been addressed well in past prevalence studies has been whether the sample size was adequate to produce prevalence rates of ACT use that could be applied with confidence to the general population. Sample size calculations or confidence intervals are provided in only a few of the research articles reviewed (Eisenberg et al., 1998; Eisenberg et al., 1993; MacLennan et al., 1996)

#### Retrospective Self-Report Measures

The use of retrospective self-report measures in the majority of ACT survey research may have limited the validity of the findings. For example, Murray and Shepherd (1993) asked participants recruited from a general medical practice about the ACTs they had tried in the previous 10 years. Such a lengthy time span increases the possibility of memory distortion (i.e., recall bias) and inaccurate reporting of ACT use. A further limitation of retrospective studies on ACT use has been the cross-sectional approach of the research, which limits causal interpretations of the data and prevents cohort effects from being clearly identified. Prospective research on ACT use is needed to capture the dynamic nature of ACT use and to provide more precise measures of prevalence and incidence rates.

#### Alternative/Complementary Therapy Utilization Patterns

Given the methodological limitations of past prevalence research, Eisenberg et al.'s (1998, 1993) nationally-representative household telephone surveys in the United States have been the most scientifically rigorous investigations to date. Using random-digit sampling and the random selection of one household member over the age of 18 years, Eisenberg et al. (1993)

conducted telephone interviews with 1,539 participants about their use of ACTs. One in three participants was found to have used at least one type of ACT (selected from a pre-determined list of 16 ACTs) in the past 12 months. The most commonly used ACTs included relaxation techniques (13%), chiropractics (10%), and massage (7%). Of those using ACTs, 64% did so without consulting an alternative/complementary practitioner (e.g., over-the-counter herbal products) and 72% chose not to inform their primary care physician about their use of ACTs. Overall, Eisenberg et al. (1993) estimated out-of-pocket expenditures for therapies and practitioner visits in the United States to total \$13.7 billion (US funds).

In a similarly designed survey conducted in 1997, Eisenberg et al. (1998) found that ACT use increased by 25% since 1990, with 42% of participants over the age of 18 years (N = 2,055) reporting the use of ACTs in the previous 12 months. The most frequently reported ACTs included relaxation techniques (16%), herbal medicine (12%), massage (11%), and chiropractics (11%). The total number of visits to an alternative/complementary practitioner increased by 47%, with 46% of ACT consumers reporting consultations with an alternative/complementary practitioner. No difference was noted in the follow-up study with regards to disclosure of ACT use to conventional health-care providers. Expenditures for ACTs were found to have increased by 45% since 1990, with an estimated \$21.2 billion (US funds) being spent on therapies and practitioners.

Research conducted in Canada has found prevalence rates similar to Eisenberg et al. (1998). In 1997, the Angus Reid Group released to the public the findings of a nation-wide telephone survey of 1,200 Canadian adults 18 years and older (Angus Reid Group, 1997).<sup>2</sup> Over four in ten (42%) Canadians reported using ACTs, with British Columbia residents being most likely to report ACT use (56%). Chiropractics (59%), herbology (23%), acupuncture (22%), and homeopathy (18%) were the most commonly reported ACTs. Further information on the design of the study, particularly related to sampling procedures, would have been helpful to further evaluate the scientific merit of this survey.

In a similar study, the Fraser Institute conducted 1,500 telephone interviews with a randomly selected sample of Canadian adults in 1997 (Ramsay et al., 1999). Households were selected using random-digit dialing, with respondents being randomly selected based on the "birthday method" in which the person with the most recent birthday was interviewed. The interview was structured similar to Eisenberg's (1998, 1993), surveys with respondents being asked to choose the therapies they had used in the past 12 months and in their lifetime from a randomized list of 22 ACTs. Nearly three quarters of the respondents indicated that they had

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<sup>2</sup> While specifics were not provided in the press release related to the sampling procedure, the data were weighted statistically to ensure the sample's age/sex composition reflected that of the actual Canadian population based on the 1996 Census. The researchers reported that with the Canadian-wide sample of 1,200, surveys such as this were accurate within +2.8 percentage points, 19 times out of 20.



used at least one ACT in their lifetime, with British Columbians (85%) being the most likely to report the use of ACTs. Chiropractic care was the most frequently reported therapy (36%), followed by relaxation and massage (23%), prayer (21%), and herbal remedies (17%). The findings of this survey were compromised by a low response rate (25.7%). A comparison between respondents and non-respondents on selected demographic, behavioural, and attitudinal characteristics was conducted and no selection bias was observed, however, this comparison must be considered with caution as less than 4% of non-respondents took part in the follow-up interview.

Highlighting the discrepancies in prevalence rates as a result of study design issues, Millar (1997) found that only 15% of Canadians 15 years and older reported consulting an alternative/complementary practitioner in the previous year. Using data from the National Population Health Survey (1994-1995) (Catlin & Will, 1992; Tambay & Catlin, 1995), Millar (1997) assessed the use of practitioners such as massage therapists, homeopaths, naturopaths, acupuncturists, and chiropractors. Regional differences in the use of alternative/complementary practitioners were apparent, with only 5% of respondents living in the Atlantic provinces reporting alternative practitioner consultations compared to 12% of respondents in Ontario, and 21% of respondents in both the prairie provinces (Manitoba, Saskatchewan and Alberta) and British Columbia. The discrepancy in prevalence rates found in this study compared to Eisenberg et al.'s studies (1998, 1993), the Angus Reid Group poll (1997), and the Fraser Institute survey (Ramsay et al., 1999) can be attributed to differences in how ACTs were assessed (i.e., practitioner vs. therapies). In assessing only the use of alternative/complementary practitioners, Millar (1997) may have substantially underestimated the use of ACTs in Canada.

Although the ACT prevalence rates obtained by Murray and Shepherd (1993) from a nonrandom convenience sample (N = 233) in the United Kingdom must be viewed with caution, the percentage of individuals who had used ACTs was similar to rates reported in the United States (Eisenberg et al., 1998; Eisenberg et al., 1993) and Canada (Angus Reid Group, 1997; Ramsay et al., 1999). Just over one third of men (34%) and 46% of women reported trying at least one form of ACT in the past 10 years, with manipulative treatments (i.e., massage), homeopathy, and acupuncture being the most commonly reported therapies.

Despite being limited by a nonrandom, convenience sample of patients (N = 300) attending three outpatient medical clinics (diabetes, rheumatology, and chest), Grenfell et al.'s (1998) study of ACT use in the United Kingdom provides further insight into the use of ACTs within the general population. Approximately 68% of respondents were found to have used at least one type of ACT in the past 12 months, with acupuncture, homeopathy, herbal therapies, osteopathy, and Ayurvedic remedies being the most popular therapies. Prevalence of ACT use

varied by ethnicity, with Black (*sic*) (78%) and Asian (77%) patients reporting higher use of ACTs than White (*sic*) patients (53%). Caucasian patients were found to prefer acupuncture and homeopathy, while Blacks and Asians used more herbal therapies. The high prevalence of ACT use reported by participants was attributed to the population studied, which consisted of the chronically ill and had a high proportion of ethnic minorities. Further information about the number of recent immigrants within the sample would have been helpful in evaluating the high prevalence of ACT use.

Despite numerous methodological limitations, past prevalence research has revealed ACT use to be a clinically significant occurrence within the general population. Use of therapies that are situated outside of the conventional medical system appears to be increasing, with physical therapies being most prominent within North American populations.

### **Prevalence of Alternative/Complementary Therapy Use in Cancer Populations**

Compared to general populations, greater divergence in the prevalence of ACT use has been found in people living with cancer, with estimates ranging between 7% to 81% (Boon et al., 2000; Coss, McGrath, & Caggiano, 1998; Crocetti et al., 1998; Downer et al., 1994; Eidenger & Schapira, 1984; Ernst & Cassileth, 1998; Feigen & Tiver, 1986; Goldstein, Chao, Valentine, Chabon, & Davis, 1991; Lerner & Kennedy, 1992; M. Miller et al., 1998; Montbriand, 1995a; Oneschuk, Fennell, Hanson, & Bruera, 1998; Rees et al., 2000; Risberg, Kaasa, Wist, & Melsom, 1997; Risberg, Lund, Wist et al., 1995; Salmenperä, 2002; Swisher et al., 2002; Yates et al., 1993). This variability can be attributed, in part, to the methodological limitations previously outlined, including measurement and sampling issues. More specifically, Ernst and Cassileth (1998) cited the lack of specificity and inconsistent definitions of ACTs used by cancer patients and researchers as "contributing significantly to this variability" (p. 780). For example, by labelling all therapies that are received outside of conventional health-care settings as ACTs (e.g., self-help groups, counselling, home remedies, folk practices, and wellness regimens), prevalence rates of ACT use within cancer populations may have been artificially inflated (e.g., Montbriand, 1995a; Risberg, Lund, Wist et al., 1995; Risberg, Lund, Wist, Kaasa, & Wilsgaard, 1998). Conversely, defining ACTs as only those treatments used specifically to cure cancer (e.g., Cassileth, Lusk, Strouse, & Bodenheimer, 1984) may have significantly underestimated the prevalence rate. A further criticism of ACT use research within cancer populations has been the lack of differentiation between ACTs that are used as adjuncts to conventional cancer care and those that are used for curative purposes and in the place of conventional cancer treatment (Ernst & Cassileth, 1998). The latter type of ACTs are most often used by individuals who have removed themselves from the conventional health-care system, and as such, are rarely represented within prevalence statistics developed from clinically-situated samples.

Concern has been raised about the choice of study samples and the potential for selection bias within research exploring ACT use by individuals with cancer. The inclusion and exclusion of participants based on specific cancer diagnoses, stage of disease (i.e., palliative), and treatment experience (i.e., conventional vs. alternative/complementary) provides only a limited view of ACT use by individuals with cancer and restricts the generalizability of the findings. Further, the reliance on convenience samples within this area of research has made it difficult to reach conclusions about the prevalence of ACT use in cancer populations.

Recently, Ernst and Cassileth (1998) attempted to provide a summary of existing prevalence data on ACT use within cancer populations. Table 2 represents a modified version of the published table that excludes non-English articles and pediatric research. Several recent studies not included in Ernst and Cassileth's (1998) review have been added.

Very few of the prevalence studies conducted in the 1990s utilized random sampling techniques, the exceptions<sup>3</sup> being Coss et al.'s (1998) survey of cancer patients in California and Lerner and Kennedy's (1992) national telephone survey of cancer patients in the United States. Similar prevalence rates were reported in both studies (6% and 9%, respectively), however, closer examination reveals several methodological limitations. Foremost, Coss et al. (1998) examined only the use of alternative/complementary practitioners, and as such, may have grossly under-estimated the use of ACTs implemented independently by individuals living with cancer. Secondly, the inclusion of proxy respondents, both friends and family members, in Lerner and Kennedy's (1992) survey raises questions regarding the accuracy of the findings, more so considering the potentially covert nature of ACT use (Balneaves et al., 1999; Eisenberg et al., 1998). Further, the terminology used by Lerner and Kennedy (1992) to describe ACTs (i.e., "questionable treatment methods") may have introduced a pejorative bias to the survey, resulting in the under-reporting of ACT use. More recent prevalence studies on ACT use in cancer populations have addressed some of the sampling concerns that have plagued studies in this area by employing random sampling techniques (Boon et al., 2000; Rees et al., 2000).

Within Canada, the prevalence rate of ACT use within cancer populations has been reported to range from 7% to 81% (Boon et al., 2000; Eidenger & Schapira, 1984; Montbriand, 1995a; Oneschuk et al., 1998). Eidenger and Schapira (1984) conducted interviews with a volunteer sample of 315 cancer patients about whether unconventional treatments such as Laetrile, vitamins, or special diets could cure cancer. Only 7% of participants reported using "medications to treat their cancer other than those prescribed by their physicians" (p. 2739); however, given the question wording (i.e., "cure") used to assess ACT use, the estimated

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<sup>3</sup> Crocetti et al. (Crocetti et al., 1998) recruited women with breast cancer through the archives of the Tuscany Cancer Registry. Details regarding the recruitment and sampling procedures, however, are not sufficient to determine if random sampling was utilized.

**Table 2. Summary Data from Prevalence Studies on ACT Use in Cancer Populations**

<b>Authors (Year)</b>	<b>Sample (Country)</b>	<b>Method</b>	<b>Most Commonly Used ACTs</b>	<b>Prevalence</b>
Arkko, Arkko, Kari-Koskinen, & Taskinen (1980)	151 consecutive outpatients with cancer (Finland)	Personal interviews	Herbs, vitamins, diets	56% of female and 30% of male patients had used ACTs
Balneaves et al. (1999)	Convenience sample of 54 women with breast cancer (Canada)	Personal interviews with questionnaire	Relaxation, meditation, vitamins/tonics, spiritual therapies	67% had used at least one ACT since diagnosis
Begbie, Kerestes, & Bell (1996)	507 outpatients with cancer (Australia)	Questionnaire	Diets, psychological methods	22% had used some form of ACT
Boon et al. (2000)	Random sample of 422 women with breast cancer (Canada)	Mailed questionnaire	Vitamins/mineral, herbal products, green tea, special diet or foods	66.7% had used at least one ACT once in their life.
Burke & Sikora (1993)	100 new consecutive patients with various cancers (UK)	Personal interviews	Counseling, meditation, relaxation, visualization	32% had used some form of ACT
Cassileth et al. (1984)	304 inpatients with a variety of cancer diagnoses and 356 cancer patients of ACT practitioners (US)	Personal interviews	Metabolic treatments, diets, megavitamins, imagery, spiritual healing, immune stimulants	54% of patients receiving conventional medical treatment used ACTs
Clinical Oncology Group (Anonymous, 1987)	463 outpatients with cancer (New Zealand)	Personal Interviews	Diets, vitamins, herbal products, laetrile	37% had sought advice about ACTs
Coss et al. (1998)	503 randomly selected patients with a variety of cancer diagnoses (US)	Telephone interviews	Nutritionists, counselors, herbalists, massage therapists	6% had seen an alternative/complementary practitioner
Crocetti et al. (1998)	473 women with breast cancer identified through a cancer registry (Italy)	Mailed questionnaire	Homeopathy, manual healing, herbalism, and acupuncture	16.5% began using ACTs after diagnosis. 8.7% had used ACTs previously
Downer et al. (1994)	600 patients with a variety of cancer diagnoses (UK)	Mailed questionnaire and face-to-face interviews	Relaxation, visualization, diets, homeopathy, vitamins, herbalism	16% had used or were using ACTs

**TABLE 2. Summary Data from Prevalence Studies on ACT Use in Cancer Populations (cont.)**

<b>Authors (Year)</b>	<b>Sample (Country)</b>	<b>Method</b>	<b>Most Commonly Used ACTs</b>	<b>Prevalence</b>
Eidenger & Schapira (1984)	315 consecutive patients with a variety of cancer diagnoses (Canada)	Personal interviews	Interview questions focussed on Laetrile, vitamins, diets	7% had tried some type of ACT
Feigen & Tiver (1986)	202 consecutive patients with a variety of cancer diagnoses (Australia)	Questionnaire	Vitamins, herbalism, protein supplements, naturopathy, faith healing, meditation	13% had used diet supplements; 13% had consulted ACT practitioners
Goldstein et al. (1991)	Convenience sample of 40 radiation cancer patients with a variety of diagnoses (US)	Personal interviews	Diets, metabolic therapy, mental imagery	12% were using ACTs while receiving treatment
Lerner & Kennedy (1992)	5047 cancer patients (2855 of which were proxy interviews) (US)	Telephone interviews	Imagery, hypnosis, psychic therapy, diets, alternative drugs	9% had used at least one ACT in their lifetime
Liu et al. (1997)	100 consecutive Chinese patients with advanced cancer (Taiwan)	Questionnaire	Chinese medicine	81% were using ACTs along with conventional medical treatment
Montbriand (1995b)	Convenience sample of 48 patients and 252 randomly selected patients with respiratory/digestive system cancers (Canada)	Personal interviews	Vitamins, minerals, herbal products	64% used ACTs
Oneschuk et al. (1998)	143 consecutive patients with a variety of cancer diagnoses (Canada)	Personal interviews	Herbalism, vitamins, minerals	37% using ACTs
Rees et al. (2000)	Random sample of 714 women with breast cancer (UK)	Mailed questionnaire	Massage, aromatherapy, chiropractics, osteopathy, relaxation/meditation, spiritual healing	31.5% had used at least one ACT since diagnosis

**TABLE 2. Summary Data from Prevalence Studies on ACT Use in Cancer Populations (cont.)**

<b>Authors (Year)</b>	<b>Sample (Country)</b>	<b>Method</b>	<b>Most Commonly Used ACTs</b>	<b>Prevalence</b>
Risberg, Lund, & Wist (1995)	252 patients with a variety of cancer diagnoses (Norway)	Questionnaire	Laying on of hands, homeopathy, herbalism, vitamins, diets	19.6% had used ACTs for their cancer
Risberg, Lund, Wist, et al. (1995)	642 patients with a variety of cancer diagnoses (Norway)	Questionnaire	Laying on of hands, homeopathy, zone therapy, herbalism, diets, Nitter therapy, Isador	20% had used one or more ACTs
Risberg et al. (1998)	252 patients with a variety of cancer diagnoses. 60 month follow-up with 110 patients. (Norway)	Questionnaire with follow-ups at 4, 12, 24, 60 months and telephone interviews	Faith healing, laying on of hands, homeopathy, zone therapy, bergs, vitamins, diets, Isadore, Nitter therapy	Prevalence increased over follow-up: 26% at 4 months, 24% at 12 months, 18% at 24 months, and 27% at 60 months.
Salmenperä (2002)	229 women with breast cancer and 209 men with prostate cancer (Finland)	Mailed questionnaire	Vitamins/minerals, diets, natural health products, spiritual healing	30% and 28% of women and men, respectively, had used ACTs following diagnosis.
Swisher et al. (2002)	113 women with gynecologic cancers seen in an outpatient clinic (US)	Questionnaire	Faith healing, therapeutic touch, imagery, meditation/ relaxation, herbal products, vitamins/ minerals	49.6% reported using ACTs since diagnosis; 46% of users ingested some type of ACT; 79% of users used a psychological or spiritual therapy
Yates et al. (1993)	Convenience sample of 152 patients with a variety of meta- static cancer diagnoses (Australia)	Questionnaire	Vitamins/tonics, meditation, relax- ation, special foods, faith healing	40% had used at least one ACT or consulted at least one ACT practi- tioner for their cancer

*Note.* Modified from Ernst, E. & Cassileth, B.R. (1998). The prevalence of complementary/alternative medicine in cancer: A systematic review. *Cancer*, 83:777-782.

prevalence rate may have been biased downward. Sampling has also been problematic in Canadian prevalence studies, with convenience sampling (Oneschuk et al., 1998) or mixed convenience and random sampling approaches (Montbriand, 1995a) being used to recruit

participants. An exception has been Boon et al.'s (2000) survey of breast cancer survivors in Ontario, which is described in greater detail in the following section on prevalence of ACT use in breast cancer populations.

Risberg et al.'s (1998) study of ACT use in Norway is worthy of mention because of the longitudinal nature of the research. Two hundred and fifty-two individuals, with a variety of cancer diagnoses, were followed over a 5-year period to assess how ACT use changes over the cancer trajectory. Reported prevalence at each data collection time varied between 17.4% and 27.3%. The estimated cumulative risk of being a consumer of ACTs over a 5-year period was 45%. This research illustrates the potential limitations of cross-sectional studies of ACT use and suggests that prevalence rates of ACT use may fluctuate depending on the disease status of the population and the stage of the cancer trajectory. Further, Risberg et al. (1998) demonstrated that the majority of users (61%) started using ACTs three to four months following their cancer diagnosis. This finding emphasizes the importance of allowing several months to elapse after diagnosis prior to estimating prevalence rates within cancer populations. Longitudinal research is of particular interest in relation to ACT use because it provides information about the long-term implications of cancer patients' alternative or complementary treatment decisions on their health and the conventional and alternative health-care systems.

Earlier work by Cassileth et al. (1984) has provided additional evidence of the impact of the cancer trajectory on ACT use. Of the 660 cancer patients interviewed from across the US, 64% sought conventional medical treatment first, 18% received conventional treatment and ACTs simultaneously, and 18% began using ACTs before accessing conventional medical care. Moreover, 77% reported using ACTs prior to beginning chemotherapy or radiotherapy. With 24% of the sample using metabolic therapies and 20% undertaking major dietary changes, the potential for interactions between conventional treatment and ACTs is of significant concern. Also of interest in this study was the fact that 43% of participants did not begin using ACTs until distant spread of their disease occurred, suggesting that individuals with advanced cancer may be a unique population with regard to attitudes and treatment behaviour. These findings, however, must be considered with caution because of the use of grouped data, in which patients from both conventional (N = 304) and alternative/complementary health-care systems (N = 356) were included in the study.

Slight geographical differences in ACT use among cancer patients are apparent from previous prevalence research. In North America, metabolic therapies, special diets, and vitamins are the most commonly reported ACTs (Boon et al., 2000; Cassileth et al., 1984; Coss et al., 1998; Goldstein et al., 1991; Lerner & Kennedy, 1992). One exception is Montbriand's (1995a) study, in which the majority of cancer patients (71%) reported using physical alternative practices. A preference for physical ACTs was also reported in two Australian studies (Feigen &

Tiver, 1986; Yates et al., 1993). In contrast, research from Norway (Risberg, Lund, & Wist, 1995; Risberg, Lund, Wist et al., 1995; Risberg, Lund et al., 1998), the United Kingdom (Downer et al., 1994; Rees et al., 2000), and Italy (Crocetti et al., 1998) revealed a preference for spiritual healing, mind-body therapies (i.e., visualization), and traditional systems of healing (i.e., homeopathy, herbalism). For example, in Downer et al.'s (1994) exploration of ACT use by cancer patients receiving conventional treatment (N = 415), 65% of those individuals using ACTs practiced healing therapies and 25% used homeopathy remedies. Geographical differences in ACT use may reflect philosophical and health-care funding disparities between North American and European health-care systems. While the allopathic tradition has gained dominance within North America, many European countries have retained a pluralistic view of medicine (Lerner, 1994). Individuals from these countries may have better access to therapies from many traditions and may experience greater acceptance of their use of therapies that address more than physical needs. Such differences, however, may also reflect the lack of an internationally agreed upon definition of ACTs and should be interpreted with caution.

#### **Alternative/Complementary Therapy Use by Women Living with Breast Cancer**

While there is some evidence that the type of cancer has limited influence on the prevalence of ACT use (Lerner & Kennedy, 1992; Oneschuk et al., 1998; Risberg, Lund et al., 1998), the use of ACTs by women with breast cancer has been the subject of six recent studies (Balneaves et al., 1999; Boon et al., 2000; Crocetti et al., 1998; Gray et al., 1997; Rees et al., 2000; VandeCreek et al., 1999).

In Crocetti et al.'s (1998) study of 473 women with breast cancer selected from a population-based Italian cancer registry, just over 16% of the participants reported using ACTs following diagnosis. The ACTs most commonly used were homeopathy (24%), manipulative therapies (i.e., massage) (16%), herbalism (14%), and acupuncture (7%). The majority of women reported using ACTs either independently of conventional treatment (30%) or following conventional treatment (30%), with 17% reporting simultaneous use of ACTs with conventional treatment. The women who used ACTs were found to be significantly younger, better educated, and had a previous history of ACT use, with the latter characteristic being the only independent significant predictor of ACT use. These findings must be interpreted with caution, however, because the respondents were significantly younger than non-respondents.

Turning to the United Kingdom, Rees et al. (2000) undertook a population-based survey of 714 women who had been diagnosed with breast cancer between 1990 and 1996. Using a mailed questionnaire that had been pre-tested with outpatients at an alternative cancer therapy clinic, respondents were asked if they had ever visited or received therapy from one or more of a list of alternative practitioners. The women were also asked about their use of ACTs in the past 12 months and since their breast cancer diagnosis. Nearly 32% of the respondents had



consulted an alternative practitioner since diagnosis, with just over one half of these women reporting using more than one type of therapy. Over-the-counter ACTs (e.g., vitamins/minerals, herbal products) had been used by 33.2% of the women, with 14.8% using these ACTs since their breast cancer diagnosis. The most commonly used therapies in the previous year were massage/aromatherapy, chiropractics/osteopathy, relaxation/yoga/meditation, and spiritual healing.

Turning to North America, Balneaves et al. (1999) explored the health beliefs and treatment practices of a convenience sample of 54 women living with breast cancer in Manitoba, Canada. In marked contrast to the findings of Crocetti et al. (1998) and Rees et al. (2000), over 67% of the participants reported using at least one ACT since being diagnosed with breast cancer. This discrepancy was attributed to several factors, including differences in ACT definitions, instrument design, and sample selection methods. The use of face-to-face interviews may have also facilitated rapport between the participants and the researcher and, as a consequence, increased women's willingness to report ACT use. The most frequently reported ACTs were meditation/relaxation therapies (60%), vitamins/tonics (57%), and spiritual/faith healing (53%). This research provides preliminary insight into the use of ACTs by Canadian women with breast cancer.

In another Canadian study, Boon et al. (2000) used the Ontario Cancer Registry to obtain a random sample of 422 women who were diagnosed with breast cancer in either 1994 or 1995. Nearly 40% of the respondents reported visiting an ACT practitioner and an additional 62% reported using at least one ACT at sometime. Overall, 66.7% of women with breast cancer reported using some type of ACT at least once in their life.<sup>4</sup> Interestingly, statistics specific to the use of ACTs following breast cancer diagnosis were not provided. Only 16.4% of ACT users in this sample reported that they were currently adhering "completely" to an ACT treatment regimen. Vitamins and minerals were the most commonly used therapy, with 13.4% of respondents reporting these supplements as being the only ACT they had ever used. Other common therapies included herbal products (including green tea, Essiac), special diets or foods, bodywork, and meditation.

Additional support for the high prevalence rates reported by Balneaves et al. (1999) and Boon et al. (2000) was provided by VandeCreek, Rogers, and Lester (1999), who examined ACT use within 112 breast cancer outpatients randomly selected from a breast cancer clinic in the Midwestern United States. Using a pre-determined list of ACTs developed by Eisenberg et al. (1993), 91% of the sample reported using at least one of 18 therapies.<sup>5</sup> The most frequently

<sup>4</sup> Boon et al. (Boon et al., 2000) noted that the therapies reported by the women were "not necessarily in an attempt to treat their cancer" (p. 2517).

<sup>5</sup> The researchers noted that in contrast to previous prevalence studies (e.g., Eisenberg et al., 1993), prayer and exercise were included as ACTs in the analysis.

reported therapies included prayer (84.5%), exercise (75.8%), and other spiritual therapies (48.3%). While researchers have questioned the inclusion of prayer within the alternative health-care paradigm (Eisenberg et al., 1998; Eisenberg et al., 1993), the authors of this study suggested that the morbidity and mortality associated with breast cancer may increase the importance of spirituality in women's response to their disease. Similar findings related to the use of spiritual therapies have been reported in other cancer populations (Risberg, Lund et al., 1998). Overall, women spent approximately \$42 per visit, with the mean number of visits reported to be 5.3.<sup>6</sup>

Similar to the research conducted in general populations, exploration of ACT use in cancer populations has been hindered by inconsistent conceptualization of ACT use, convenience samples, and selection biases. Accordingly, wide ranges of prevalence rates and therapies have been reported. Some evidence suggests the ACT use within cancer populations fluctuates across the cancer trajectory and is influenced by geographical location. While prevalence studies of ACT use in breast cancer populations have, in general, been better designed with regards to sampling and measurement issues, a variety of prevalence rates have been reported. In addition, the lack of distinction between women at different stages of the cancer trajectory (i.e., newly diagnosed, undergoing conventional cancer treatment, survivorship, and palliative) may have influenced the estimation of the prevalence of ACT use and the types of therapies reported.

### **Characteristics of Consumers of Alternative/Complementary Therapies**

As the use of ACTs has become more prevalent within general and cancer populations, researchers have been interested in identifying those individuals most likely to use these types of therapies. In the following sections, the broad range of literature that describes the personal and social characteristics of ACT consumers within general and cancer populations, including the demographic profile of ACT users, and the influence of previous health experiences on ACT use, is discussed.

#### **Demographic Profile within General Populations**

Past empirical research has provided a consistent profile of ACT consumers. Sociodemographic factors found to be associated with complementary therapy use include age, gender, level of education, income, and health status (Eisenberg et al., 1998; Eisenberg et al., 1993; Murray & Shepherd, 1993; Thomas et al., 1991). The typical consumer of ACTs within the general population has been identified as female, under the age of 65 years, and with a high socioeconomic status. A similar profile has been found within the Canadian general population

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<sup>6</sup> The time period in which ACT use was assessed was not reported.

(Angus Reid Group, 1997; Berger, 1993; Blais et al., 1997; Kelner & Wellman, 1997a; Millar, 1997; Ramsay et al., 1999). There has been evidence supporting an association between ethnicity and the prevalence of ACT use (Eisenberg et al., 1998; Eisenberg et al., 1993; Grenfell et al., 1998). Eisenberg et al. (1993, 1998) reported that ACT use in the United States was least prevalent within the African-American population. In contrast, Grenfell et al. (1998) found ACT use in the United Kingdom to be more prevalent within Black [sic] (78%) and Asian (77%) populations than in Caucasian populations (53%). Limited investigation into the impact of immigration history on ACT use has been conducted (Hilton et al., 2001; Ma, 1999). Further epidemiological research is needed to clarify the nature of the relationship between ethnicity, immigration, acculturation, and ACT use, particularly within multicultural societies where popular, folk, and professional sectors of health care may overlap (Kleinman, 1988).

While a demographic profile of ACT consumers has been revealed, recent evidence shows that the relationships between demographic characteristics and ACT use may be dissipating. In a secondary data analysis of Canada's National Health Population Survey 1994-1995 (Statistics Canada, 1995), Balneaves and Ratner (under review) found no significant relationships between gender, education, income, and ACT use. Both men and women from a variety of educational and socioeconomic backgrounds reported consulting alternative/complementary practitioners. The lack of a distinct demographic profile was attributed to the growing salience, availability, and acceptance of ACTs within the Canadian health-care system (Balneaves & Ratner, under review). The recent Fraser Institute survey of ACT use (Ramsay et al., 1999) also found no significant relationship between reported annual income and ACT use in Canada. This research suggests that as selected ACTs gain legitimacy through scientific research, education, or widespread use and if they become accessible through insurance funding, ACT use may become prevalent across all segments of society.

#### Demographic Profile within Cancer Populations

Contradictory evidence of a distinct profile of ACT users also exists within cancer populations. In the majority of research studies, the typical consumer of ACTs is female, under the age of 65 years, and from a high socioeconomic class (Cassileth et al., 1984; Coss et al., 1998; Downer et al., 1994; Lerner & Kennedy, 1992; Oneschuk et al., 1998; Risberg, Lund et al., 1998; Swisher et al., 2002; Yates et al., 1993). As well, there has been some evidence to suggest that individuals with advanced cancer are more likely to use ACTs than patients with less advanced cancer (Lerner & Kennedy, 1992; Risberg, Lund, Wist et al., 1995). Preliminary research has also revealed significant associations among ethnicity and the prevalence of ACTs (Maskarinec, Shumay, Kakai, & Gotay, 2000) and the types of therapies used (Alferi, Antoni, Ironson, Kilbourn, & Carver, 2001; Lee, Lin, Wrensch, Adler, & Eisenberg, 2000). Contradictory findings exist, however, that challenge the influence of demographic characteristics on cancer

patients' use of ACTs. In a multi-centre study of Norwegian cancer outpatients, Risberg, Lund, et al. (Risberg, Lund, Wist et al., 1995) found no significant differences between users and non-users of ACTs with regards to gender or education. Cassileth et al. (1984) also reported no significant associations between gender, education, marital status, ethnicity, or stage of disease at diagnosis and ACT use by patients attending a conventional cancer facility. These discrepancies underscore the need for further study of the relationships between ACT use and demographic characteristics within cancer populations.

Opposing views also exist regarding the underlying processes that explain the relationships between demographic characteristics and the use of ACTs by individuals living with cancer. For example, Lerner and Kennedy (1992) suggested that ACT use was more prevalent within higher income groups because of the out-of-pocket costs associated with ACT use in the United States. In contrast, Yates et al. (1993) attributed the effect of socioeconomic status on ACT use by Australian cancer patients to differences in health beliefs. Individuals situated in higher socioeconomic groups were found to hold more positive beliefs about alternative causes of cancer and the efficacy of ACTs than individuals reporting lower education and income levels. In addition, Yates et al. (1993) found younger cancer patients, who used ACTs more frequently than older individuals, to be more skeptical about conventional medical care. Thus, while the development of a profile of ACT consumers has been helpful in identifying potential users of ACTs in cancer populations, the demographic characteristics of ACT users may be more indicative of variations in health beliefs rather than treatment preferences. Further study is needed to clarify the associations between demographic characteristics, ACT use, and health beliefs.

Within the breast cancer population, preliminary work has revealed associations between ACT use and selected demographic characteristics. In their study of 242 Italian women with breast cancer, Crocetti et al. (1998) found that women using ACTs were significantly younger, better educated, and had used ACTs prior to their breast cancer diagnosis. This study is unique compared to other epidemiological research on ACT use because it recognizes the inter-relationship among demographic characteristics; the proportion of highly educated women was reported to be significantly greater among younger women, along with previous use of ACTs (Crocetti et al., 1998). Balneaves et al. (1999) also reported a significant relationship between education level and the use of ACTs by Canadian women with breast cancer. The lack of additional significant associations between demographic factors and ACT use in this study reflects the limited power of this study resulting from the restricted sample size ( $N = 54$ ). More recent studies of ACT use in breast cancer survivors have further supported the role of age, education, income, and cancer treatment history (Boon et al., 2000; Rees et al., 2000; Salmenperä, 2002). No theories regarding the cognitive or social processes through which

demographic characteristics influence treatment decisions specific to ACT use, however, have been put forth specific to women with breast cancer.

In summary, past epidemiological research within general and cancer populations has provided contradictory evidence regarding the demographic profile of ACT consumers. Additional research with larger populations is needed to clarify the relationship between gender, age, socioeconomic status, chronic illness and the decision to use ACTs, with a special emphasis on the interrelationships among demographic characteristics and health beliefs in relation to the use of ACTs by women living with breast cancer.

#### Previous Health Experiences

Beyond demographic characteristics, evidence exists of a relationship between chronic disease occurrence and the use of ACTs (Balneaves & Ratner, under review; Kelner & Wellman, 1997a; Millar, 1997; Murray & Shepherd, 1993; Ramsay et al., 1999). In a recent Canadian survey of ACT use (Ramsay et al., 1999), between 60% and 71% of individuals reporting a variety of chronic conditions (e.g., back problems, arthritis, lung problems) had used at least one ACT in the past year. Millar (1997) also observed a progressive trend in ACT use in relation to chronic illnesses, with 26% of individuals having three or more chronic conditions reporting ACT use in the previous 12 months. This trend is of significance given the increasing prevalence of chronic conditions in an aging Canadian population.

In addition to chronic illness being a potential predictor of ACT use, some support is found for an association between previous ACT use and the decision by individuals faced with cancer to use ACTs. For example, in Risberg, Lund, et al.'s (1995) exploration of ACT use among Norwegian cancer patients, individuals who had used ACTs prior to diagnosis were significantly more likely to use ACTs as part of their cancer care. Montbriand (1995b) also found previous use of ACTs to be predictive of ACT use by individuals with cancer, with 87% of patients with a high interest in ACTs reporting using ACTs prior to diagnosis. An association between ACT use and previous ACT use in women with breast cancer has been reported by Crocetti et al. (1998) and Rees et al. (2000). Additional research, however, is needed to understand the predictive value of illness history and previous ACT use with regard to the use of ACTs by cancer patients and the influence of health experiences on the treatment decision-making process.

#### **Health Beliefs and Alternative/Complementary Therapy Use**

One area of ACT research that has received much attention in recent years has been the role of cognition in the decision to use ACTs. Of particular interest has been the relationship between beliefs about health and illness and the use of therapies beyond the scope of conventional medicine. In the following section, the potential associations between health

beliefs and ACT use within both general and cancer populations is discussed, with special emphasis being placed on beliefs reflecting perceived need for care (i.e., perceived risk).

#### Health Beliefs within General Population

Researchers have expressed interest in uncovering not only the demographic characteristics of ACT consumers, but also the attitudes and beliefs of individuals within the general population who use ACTs. In particular, extensive research has been conducted on the effect of lay perceptions of health and illness on the decision to use ACTs. The most prominent program of research has been led by Furnham et al. (Furnham, 1994; Furnham & Beard, 1995; Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Kirkcaldy, 1996; Furnham & Smith, 1988; Furnham, Vincent, & Wood, 1995; Vincent & Furnham, 1996, 1997), who have explored the relationships among lay health beliefs and the use of ACTs in the United Kingdom.

Beginning in 1988, Furnham and Smith (1988) examined the health beliefs of a convenience sample of 87 individuals who were attending either a general practitioner or a homeopathic provider. Homeopathic patients were found to hold more negative beliefs about the efficacy of conventional medicine and more positive beliefs in the body's ability to heal. In contrast, patients receiving conventional medicine held more positive beliefs about the effects of conventional medicine therapies and, correspondingly, had more confidence in the care provided by general practitioners. No differences were found between the two patient groups with regard to perceived illness susceptibility. Although this research was limited in scope and could not be generalized to the larger population of ACT users, it provided preliminary support for health beliefs being antecedent variables associated with the decision to use ACTs.

A follow-up study of homeopathic and conventional medical patients (N = 160) by Furnham and Bhagrath (1993) examined a broader range of health beliefs and behaviour. Controlling for the effects of age and income, homeopathic patients were found to be highly skeptical of conventional medical care and to hold strong beliefs about the tenets of homeopathy. These individuals were also found to be more aware of health issues than were conventional medical patients and more likely to believe in the role of lifestyle in preventing illness (i.e., stress reduction, relaxation and meditation techniques). These findings led to the hypothesis that individuals who use homeopathy have an intrinsically greater interest in health care than individuals attending general practitioners. This interpretation, however, must be considered with caution because participants' past medical history and current health status and the extent to which participants had used practitioners from different health paradigms were not taken into account.

Furnham and Forey's (1994) research attempted to address, in part, these limitations by comparing the health beliefs of patients attending general practitioners and patients drawn from a variety of ACT providers (N = 160). ACT consumers were again found to be more cynical

about conventional medicine, perceived greater efficacy of ACTs, and had a higher health consciousness than individuals sampled from the offices of general practitioners. ACT and general practitioner patients, however, reported using treatments from both the conventional and alternative health-care systems. In both study groups, serious illnesses were brought first to the attention of conventional medical providers. This research is significant because it suggests that ACT users select therapies based on the nature of their illness and view ACTs as being on a continuum of care, which includes conventional medical care.

Extending previous work, Furnham, Vincent, and Wood (1995) examined the unique beliefs held by conventional medicine patients (N = 58) and three groups of ACT consumers, including osteopathic (N = 65), homeopathic (N = 76), and acupuncture (N = 57) patients. This research provided further support for the presence of a continuum in treatment choice and, correspondingly, in health beliefs. ACT consumers and conventional medicine patients were found to vary in their beliefs about the quality of the doctor-patient relationship, the efficacy of conventional medicine and ACTs, and the importance of a healthful lifestyle. Those patients using acupuncture were found to be the least satisfied with their relationships with conventional care providers, to be the most skeptical of the efficacy of conventional medicine, and to place the greatest emphasis on lifestyle as a change agent in health than other ACT users. Also of interest was the association between chronic illness and ACT use, with acupuncture patients being most likely to have a chronic illness in comparison to other patients. Unfortunately, this research was limited by significant crossover between study groups in terms of treatment history.

In a follow-up study, Furnham and Beard (1995) grouped study participants (N = 187) by therapy use rather than clinic attendance. Not only did this study explore the health beliefs of conventional, complementary, and alternative therapy patients, but also their general beliefs, such as coping styles<sup>7</sup> and "Just World" beliefs".<sup>8</sup> Although the sampling design (both convenience and random) and the restricted range of ACTs explored (acupuncture and shiatsu) limited the generalizability of the findings, this research is important because it revealed that health-specific beliefs discriminated more clearly between treatment choice than general beliefs. Furnham and Beard (1995) suggested that the lack of significant associations between coping styles, "Just World" beliefs and ACT use illustrated the irrelevance of personality factors in the

<sup>7</sup> Coping styles were measured using Miller's (1987) Behavioral Style Scale in which individuals are classified as being either monitors (actively seek information about a potential threat) or blunterns (avoid relevant threat information).

<sup>8</sup> "Just World" Beliefs were first introduced by Lerner (1965) and are based on the tendency of people to blame others for their own misfortunes. A 6-item scale, the "Just World" Beliefs measure assesses the extent to which individuals perceive the world to be orderly, stable, and just. In the context of Furnham and Beard's (1995) research, individuals who use ACTs are hypothesized to perceived the world as being less stable and just.

decision to use ACTs. However, they acknowledged that further research was needed to explore the relationship between trait characteristics and ACT use as well as the association between health beliefs and ACT use. It remains to be demonstrated if health beliefs not only lead to ACT use but are also a consequence of attending an ACT provider or independently using ACTs.

Vincent and Furnham (1996) examined the motivation of ACT consumers to use therapies that were not offered by conventional medicine. Two hundred and sixty-eight patients from three ACT practices (acupuncture, osteopathy, and homeopathy) were asked to rank 20 potential reasons for seeking ACTs. Following factor analysis, five factors were identified in order of importance: a) a positive valuation of complementary treatment, b) the ineffectiveness of orthodox treatment for their chronic illness, c) concern about the adverse effects of orthodox medicine, d) concern about communication with physicians, and e) the availability of complementary medicine. Vincent and Furnham (1996) concluded that ACT consumers were being both "pulled" towards ACTs through positive beliefs about the efficacy and nature of ACTs and "pushed" by the failure of conventional medicine to address their chronic illness and by inadequate doctor-patient relationships. With 82% of the sample initially consulting a physician about their complaint, these researchers concluded that a "wholesale disillusionment" about conventional medicine was not apparent on the part of ACT consumers; rather, the decision to use ACTs was a reflection of the inadequacy of conventional medicine in treating chronic conditions.

Vincent and Furnham (1997) have further explored beliefs about the efficacy of conventional medicine held by ACT consumers. Acupuncture patients (N = 82) were asked to complete a questionnaire about the perceived efficacy of selected ACTs for four categories of illness (major, minor, chronic, and psychological) and attitudes towards conventional medicine and health. Conventional medicine was seen by all participants as being more effective in treating major, life-threatening illness, such as heart disease and cancer. In contrast, ACTs were seen as being more effective in the treatment of chronic and minor illness. Not surprisingly, positive attitudes towards science were associated with a stronger belief in the efficacy of conventional medicine, while beliefs in the importance of psychological factors in health were associated with positive attitudes towards ACTs. Despite this research being limited to individuals undergoing acupuncture treatment, Vincent and Furnham (1997) suggested that health beliefs and their associated health behaviours were linked to wider beliefs about science and illness causation. More sophisticated research is needed, however, to examine not only the predictive power of health beliefs in relation to ACT use, but also the complex interactions among health beliefs, previous health experiences, demographic characteristics, and ACT use across a range of treatment options and within both general and disease-specific populations.



Influenced by the movement towards ACT effectiveness research that has pitted alternative paradigms against the biomedical hegemony present in Western health-care systems, Furnham has focussed his research program in recent years on the disparity in health beliefs between the two health-care systems. In a vignette-based study of the perceived efficacy of homeopathy and conventional medicine (Furnham & Bond, 2000), personal treatment history was found to play a significant role in how participants perceived the effectiveness of the different treatments. Those individuals with experience with ACTs perceived homeopathy to be more effective than conventional medicine, with the opposing trend found for individuals who attended a general practitioner. In a more recent study, Furnham (2002) examined the assertion that ACT use is representative, or an outcome, of an individual's rejection of empiricism and positivism (e.g., Beyerstein, 1997). Using beliefs about predicting the future<sup>9</sup> as a proxy for "non-proven" or postmodern belief systems, Furnham (2002) hypothesized that individuals interested and confident in the efficacy of ACTs would be more likely to believe in what he termed "future-ologies". Regression analysis revealed that attitudes towards and knowledge of ACTs were related to attitudes and knowledge about future-ologies, more so than attitudes towards science and conventional medicine. In other words, the higher the efficacy of ACTs was rated, the higher the efficacy of future-ologies was also rated. However, a factor analysis revealed that participants made clear distinctions between ACTs and future-ologies and were highly skeptical of the latter. Furnham (2002) concluded that individuals interested in ACTs might be more open and sympathetic to alternative belief systems than would be conventional medicine consumers. It could be argued, however, that the distinction between alternative and conventional health-care systems is becoming more blurred with the increasing use of ACTs. For example, in the Fraser Institute survey (Ramsay et al., 1999), the majority of individuals who used ACTs (72%) believed that alternative and conventional healthcare should be used concurrently rather than individually. Further research is thus needed to examine the predictive capacity of health and general beliefs in determining treatment choices.

The program of research developed by Furnham and colleagues has provided substantial evidence of the relationship between health beliefs and health behaviour within the general population. Individuals who used ACTs were found to be both pulled and pushed towards these therapies as a consequence of their positive valuation of ACTs and their dissatisfaction with conventional medicine. Being health conscious and placing greater emphasis on lifestyle and its influence on health was also found to be associated with the use of ACTs. ACT consumers, however, were not in a "flight from science," instead, ACTs were being used as part of a continuum of care that included both conventional and alternative health care.

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<sup>9</sup> Methods of predicting the future presented to participants included astrology, palmistry, tarot, clairvoyance, graphology, oriental astrology, dowsing, and necromancy.

In Canada, researchers also have examined the effect of health beliefs on ACT use within the general population. Using a comprehensive health care utilization model (Andersen, 1968; Andersen, 1995), Kelner and Wellman (1997a) interviewed 300 individuals attending five different practitioners: family physicians, chiropractors, acupuncturists, naturopaths, and Reiki practitioners. ACT users were found to not only share a unique demographic profile (female, younger, highly educated) and to have experienced more chronic illness, but they also had a greater sense of personal responsibility for their health. The association between health beliefs and ACT use was less clear. While some individuals using ACTs expressed confidence in the principles of ACTs, other individuals were motivated by more pragmatic reasons, including desperation. ACT consumers were found to use a mixture of treatments, both alternative and conventional. Kelner and Wellman (1997a) concluded that while some ACT consumers may ascribe to an "alternative ideology," others consider conventional medicine and ACTs to be part of a multidimensional health-care system.

The existence of a continuum of care, ranging from conventional to alternative, was further supported by Kelner and Wellman (1997b), who compared the characteristics of patients across the five modes of treatment (family physician, chiropractic, acupuncture, naturopathy, and Reiki). The heterogeneity of ACT consumers was revealed in this research, with the differences between patients who used conventional treatment and those who used ACTs becoming more pronounced as therapies became more alternative. For example, individuals who used Reiki were found to be more educated and had higher incomes in comparison to other conventional and ACT consumers. Conventional and ACT consumers were also found to differ in terms of health profile, with individuals further along the continuum of care using ACTs for a broader range of health issues (i.e., chronic pain, emotional health, health promotion). Kelner and Wellman (1997b) further suggested that the continuum not only existed in terms of the profile of consumers, but also with regard to public recognition and institutional legitimacy of treatments.

Researchers from the United Kingdom also have explored the association between health beliefs and ACT use within the general population (Murray & Shepherd, 1993). Despite its numerous design limitations, this research revealed the range in beliefs, health profiles and ACT use that exists in individuals attending ACT providers. Individuals who used ACTs were found to use a variety of ACTs for both minor ailments and for recurrent health problems, such as colds, headaches, and gastrointestinal disorders. Many ACT consumers expressed distrust of conventional medicine with regard to unknown long-term dangers and regarded ACTs as being "safe" and "non-invasive." However, it was interesting to note that non-users of ACTs reported lower consultation rates with general practitioners than ACT users. This finding provides further support for the proposition that the use of ACTs does not preclude conventional

medicine utilization but instead represents some of the many treatment options deemed appropriate and acceptable in today's health-care system.

### Health Beliefs within Cancer Populations

Turning towards ACT use within cancer populations, researchers have explored the motivations of ACT use, including the association between health beliefs and health behaviour. In a study of 660 cancer patients in the United States who were receiving conventional medical therapy and ACTs, Cassileth et al. (1984) found significant differences between study groups with regard to their beliefs about illness and treatment. The majority of participants receiving ACTs, with or without conventional treatment, believed that their cancer could have been prevented, primarily through diet, stress management, and environmental changes. These individuals also perceived conventional cancer treatment, including chemotherapy and radiotherapy, to be more harmful than helpful and ACTs to be beneficial. Conventional treatment patients held opposing beliefs. Due to the retrospective nature of the study, it is difficult to determine whether the beliefs of ACT consumers were established prior to their illness or treatment, were a consequence of their exposure to alternative and complementary practitioners, or were an attempt to reduce cognitive dissonance. However, this research provided preliminary evidence of the unique belief systems of ACT consumers within cancer populations.

Downer et al. (1994) interviewed 48 cancer patients in the United Kingdom who were using ACTs. When asked to explain their attraction to ACTs, over one half of the sample reported feeling more hopeful when using ACTs than when using conventional medicine alone. Forty-two percent were attracted to ACTs because of their belief in the non-toxic and "holistic" nature of the therapies. Twelve patients also reported that conventional medicine had been unable to offer any further treatment for their disease. This research points to the potential role of both positive beliefs in the efficacy of ACTs and hope in the decision to use ACTs. For some individuals living with cancer, ACTs may not only correspond to their health beliefs about treatment, but also may address a psychological need for optimism within their cancer care.

Drawing from the health behaviour theories of Fabrega (1974) and Becker (1974), Yates et al. (1993) explored the effect of selected health beliefs on cancer patients' treatment decisions related to ACTs. In a study of 152 Australians living with advanced cancer, significant predictors of ACT use included a belief in "alternative" causes<sup>10</sup> of cancer and being optimistic (operationalized as "will to live"). This research builds upon Cassileth et al.'s (1984) work and provides further empirical evidence of a relationship between beliefs about cancer etiology and treatment choice. The importance of maintaining hope in the face of a potentially life-threatening

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<sup>10</sup> Alternative causes of cancer included such statements as "My cancer was caused by pollution" and "My cancer was caused by stress".

illness was also emphasized as being a key motivator in the decision to use ACTs and points to a potential gap in the care provided to cancer patients through conventional medicine. Although this research was limited to individuals with advanced cancer, it provides preliminary evidence that ACT use within cancer populations may be unique with regard to the underlying motivations and health beliefs held by ACT consumers.

Research by Risberg and colleagues (Risberg, Lund, & Wist, 1995; Risberg, Wist et al., 1998) also highlights the unique experience of cancer patients relative to their use of ACTs. In a comparative study of Norwegian patients with non-malignant ( $N = 305$ ) and malignant disease ( $N = 252$ ), patients without cancer expressed more positive beliefs about the potential benefits of ACTs in cancer care than individuals living with cancer (Risberg, Lund, & Wist, 1995). It was postulated that because of the personal implication of such beliefs to patients with malignant disease, cancer patients might be more circumspect in their attitudes towards ACTs. Compared to the previous work of Yates et al. (1993), this finding creates an interesting paradox because it suggests that while cancer patients may use ACTs to foster hope, they may be unwilling to place too much confidence in the potential benefits of ACTs. This difference, however, may reflect the greater knowledge held by cancer patients with regard to treatment of their disease and the potential benefits of ACTs. The discrepancy between Yates et al.'s (1993) and Risberg, Lund, and Wist's (1995) findings may also highlight the differences in beliefs among patients with early-stage versus late-stage cancer.

Risberg, Wist et al. (1998) found additional evidence of a difference between cancer and non-cancer patients with respect to beliefs about the cause of cancer. Non-cancer patients were found to be more dogmatic in their beliefs about cancer etiology, expressing positive beliefs in the role of the environment and lifestyle in causing cancer. In contrast, cancer patients were more ambiguous in their beliefs about cancer etiology. This lack of certainty mirrors past research with cancer patients that has revealed similar ambiguity in ascribing meaning to and causation of cancer (Blaxter, 1983; Linn, Linn, & Stein, 1982; Yates et al., 1993). The uncertainty held by cancer patients about the cause of their disease may limit the explanatory power of beliefs about causation in predicting ACT use. Further research is needed to clarify the nature of the relationship between the use of ACTs and etiological beliefs.

With regards to Canadian research on the health beliefs of cancer patients using ACTs, few studies have focussed on a broad range of cancer diagnoses. Gray et al.'s (1997) study, however, did examine the beliefs and attitudes of 32 cancer survivors, of whom 35% had been diagnosed with a malignancy other than breast cancer. For many of the respondents, their interest in ACTs was motivated by their desire to make certain that they were not missing any treatments that could be important in their recovery. Some respondents reported using ACTs to prevent a recurrence and to increase the likelihood of a healthy future. For many respondents,

however, their use of ACTs following diagnosis was simply an extension of their existing health beliefs and practices.

#### Health Beliefs within the Breast Cancer Population

Limited research has been conducted on the health beliefs of ACT consumers within the breast cancer population. Boon et al.'s (1999) qualitative study of the health beliefs of breast cancer survivors using ACTs (N = 36) revealed four main themes: survival, reacting to a bad experience with conventional medicine, prevention of further illness, and a belief that there was "nothing to lose." Many of the women believed that ACTs could enhance their chance of survival by "boosting the immune system," stabilizing their current disease, or preventing a possible recurrence. Further, the women cited negative experiences with conventional medicine, including side effects, as motivating them to seek ACTs. It was concluded that rather than being pulled or pushed towards ACTs, women with breast cancer were simply "hedging their bets" in an attempt to facilitate their future survival.

A follow-up study by Boon et al. (2000) with 422 women diagnosed with breast cancer further revealed that ACT consumers were less likely to believe that conventional cancer treatments would cure their cancer, prevent a spread of disease, assist other treatments to work, boost their immune system, or be perfectly safe. Instead, women using ACTs expressed concern that conventional therapy had side effects and would weaken their bodies' natural reserves. In contrast, ACTs were perceived to be safer than conventional treatments and more likely to assist the body's natural forces to heal.

In contrast to Boon et al.'s (1999; 2000) findings, Balneaves et al. (1999) failed to find significant associations between ACT use and health beliefs in 54 women living with breast cancer. Irrespective of treatment choice, the majority of women held positive beliefs about the outcomes of conventional care and the supportive nature of ACTs. Although these beliefs did not appear to influence treatment decisions, their co-existence highlights the open-mindedness and flexibility with which women living with breast cancer consider multiple treatment options and choose those most relevant to their health care and support needs. However, the study by Balneaves et al. (1999) was limited by its sample size, making it difficult to generalize to the larger breast cancer population and to rule out a Type II error<sup>11</sup>.

Qualitative researchers have provided additional evidence of the consistency of health beliefs across treatment choices within the breast cancer population (Brown & Carney, 1996). In semi-structured interviews with 20 women with breast cancer who had used either conventional therapies alone or in conjunction with ACTs, women in both study groups

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<sup>11</sup> Type II error is defined as the failure to find a statistically significant association when one exists.

attributed their illness to environmental factors and believed recovery to be possible through healthful diets and lifestyle changes. Women using ACTs differed only in the emphasis they placed on stress as a causative factor in illness. Also of interest were the women's perceptions about the development of their health beliefs. Almost all of the women using ACTs described their health beliefs to be recently formed and perceived these beliefs to have been influenced by their experiences of having cancer. In contrast, women using only conventional medicine reported their beliefs to be "lifelong" and influenced primarily by family or religious experiences. This difference may be understood within the context that the women using ACTs had been living with cancer twice as long as women in the conventional medicine group, suggesting that beliefs about health and illness may change over time. Brown and Carney (1996) postulated that as cancer becomes a more permanent part of a person's life, beliefs may shift to assist in the development of meaning within the illness experience. Thus, in order to explicate the relationship between health and illness beliefs and treatment choice, research is needed that encompasses the breast cancer trajectory, from early diagnosis to survival (5 year or 10 year).

#### Perceptions of Need for Care

A special kind of health belief that has received minimal attention within general and cancer populations has been the impact of individuals' perceptions of need for care on the decision to use ACTs. Need for care has been defined as both a subjective perception of risk (e.g., risk of cancer recurrence, quality of life) and an objective perception of need (e.g., cancer staging information) (Andersen, 1968; Andersen, 1995). Only one study has examined the specific effect of need for care factors on ACT use. In their research on the motivations of Canadian patients using ACTs, Kelner and Wellman (1997a) found that the majority of ACT consumers perceived their health problems to be serious (83%) and disruptive to their daily functioning (89%). In comparison, 67% of conventional medicine patients believed their condition was negatively affecting their daily lives. These findings suggest that as individuals' perceived need for care increases, they may be more willing to use therapies that are outside the conventional medical system. How need for care factors interrelate with other elements of the treatment decision-making process, such as health beliefs, remains to be determined.

Further support for a potential link between ACT use and need for care has been provided by a number of studies that have reported a link between anxiety and ACT use. In particular, ACT consumers have been found to report higher levels of psychological distress than non-users (Burstein et al., 1999; Furnham & Bhagrath, 1993; Furnham & Smith, 1988). This difference has been attributed to ACT consumers' longer illness careers and greater physical dysfunction, resulting in more pronounced distress (Furnham & Smith, 1988). Montbriand (1995b) also reported an association between ACT use and anxiety, with those individuals expressing a high interest in ACTs being more likely to describe stress as a

response to their cancer diagnosis and treatment. A recent study of the psychological characteristics of 117 Austrian breast cancer outpatients using ACTs provided additional evidence of an association between distress and ACT use, with women using more than three ACTs tending to adopt a more depressive coping style than women who used fewer ACTs (Moschèn et al., 2001). High users of ACTs were also found to report poorer emotional functioning than low users. Researchers have been cautious, however, in suggesting that the use of ACTs be used as a screening test for clinically significant distress and have encouraged further prospective, longitudinal research to examine the relationship between treatment choice and psychological distress (Burstein & Weeks, 1999).

Contradictory evidence of the association between clinical evaluations and ACT use does exist, however, in the literature. For example, in Risberg et al.'s (1995) comparison of patients with malignant and non-malignant disease, cancer patients who used ACTs were more likely to be receiving palliative treatment than non-users, but their performance status<sup>12</sup> was not significantly associated with ACT use.

In conclusion, some empirical support exists for an association between perceived need for care and ACT use. In particular, perceived seriousness of a disease, chronicity of the illness, and anxiety have been implicated as motivating factors of ACT use within cancer and general populations. The lack of prospective research, however, has precluded researchers from conclusively determining the directionality of the relationship between psychological distress and ACT use. Possibly, commitment to a restrictive, detailed regimen of ACTs may result in excessive attention to illness and its outcomes, resulting in higher anxiety in high users of ACTs (Moschèn et al., 2001). Further research is warranted to examine the potential psychological side effects of ACT use.

#### Summary of the Role of Health Beliefs

There is preliminary evidence to suggest that individuals who use ACTs as part of their cancer care may hold specific beliefs about their disease and the benefits of ACTs. ACT consumers within cancer populations may use ACTs as a means of maintaining hope and optimism, particularly when faced with advanced or terminal cancer. ACT use by individuals living with cancer may also reflect their dissatisfaction with or concerns about conventional cancer treatments. What is striking is that, with the exception of studies by Kelner and Wellman (1997a) and Yates et al. (1993), the research conducted to explore the role of health beliefs in predicting ACT use has occurred without direction from an explicit theoretical framework. Given the many well-established theories of health behaviour, this gap is surprising and may account

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<sup>12</sup> Assessed by the ECOG (European Cooperative Oncology Group) Performance Scale, which is used to assess how a patient's disease is progressing and how the disease affects the daily living abilities of the patient, as well as to determine appropriate treatment and prognosis.

for the broad array of health beliefs that have been tested. Research informed by theory would allow treatment decisions related to ACTs to be examined within the general rubric of health behaviour and allow comparisons with conventional health behaviour. While there is a danger of oversimplifying reality in the development and testing of theoretical models (Weiss, 1995), the application of health behaviour theory in ACT research would provide a tentative foundation for the prediction and explanation of this complex phenomenon.

### **Other Factors Associated with Alternative/Complementary Therapy Use**

Beyond health beliefs, the role of other factors in the decision to use ACTs has been examined within both general and cancer populations. These factors include quality of life (Jordan & Delunas, 2001; Moschèn et al., 2001; Paltiel et al., 2001), personality characteristics (Owens, Taylor, & Degood, 1999; Sturm, 2000; Sugimoto & Furnham, 1999), coping styles (Moschèn et al., 2001), and conventional medicine utilization (Kaboli, Doebbeling, Saag, & Rosenthal, 2001). Two additional concepts that have received much attention within ACT research in cancer populations, and are the focus of discussion in this section, are social support and control.

#### Social Support

Within general populations, limited empirical work has explored the association between social support and ACT use. One exception has been Kelner and Wellman's (1997a) examination of the process through which ACT consumers gain information about therapies and practitioners. The majority of treatment and practice referrals were reported to be from family members, acquaintances, co-workers, and other ACT providers. Very few ACT consumers (3%) reported receiving a recommendation from their physician regarding ACTs. Overall, one half of all patients using ACTs cited referrals by others as the primary motivation underlying their choice in therapy. While treatment and practice referrals may be a questionable proxy measure of social support, this research points to the social context in which individuals make treatment decisions specific to ACTs.

Additional evidence of the social context of treatment decision-making in cancer populations is apparent in the literature. Qualitative work by Truant (1998), Gray et al. (1997), and Montbriand (1995a) has highlighted the influence of family members, friends, cancer survivors, co-workers, and health food store workers on treatment decisions made by women with breast cancer who use ACTs. In fact, many women reported feeling overwhelmed with the amount of information provided by well-meaning individuals about ACTs (Truant, 1998). Particularly persuasive in encouraging ACT use have been members of cancer support groups, with several studies reporting support group participation as being an important determinant of ACT use (Boon et al., 2000; Gray et al., 1997; Lee et al., 2000).



The possibility of cancer patients being burdened by an abundance of information on ACTs led Risberg, Kaasa, Wist, and Melsom (1997) to inquire about the referral patterns of 126 patients in Norway. The majority of ACT consumers received their primary information about therapies from relatives and friend (64%), with 5% stating that the media was their main referral system. Only 14% reported feeling some pressure from significant others to use ACTs, with those aged 30-45 years reporting the greatest sense of obligation. Risberg et al. (1997) suggested that for cancer patients and their family members, ACT use might be one way of coping with the uncertainty surrounding illnesses such as cancer.

Other researchers focussing on women with breast cancer have also found relatives and friends to be primary sources of information about ACTs (Crocetti et al., 1998), although how influential family and friends are on treatment decisions has been questioned (Salmenperä, Suominen, Lauri, & Puukka, 2001). Surprisingly, general practitioners were also identified as being an important source of knowledge regarding therapies not offered by conventional medicine (Crocetti et al., 1998). Earlier work by Lerner and Kennedy (1992) revealed the role of physicians in introducing the idea of ACTs to non-cancer and cancer patients, with 31% of participants identifying physicians as being their primary source of information about ACTs. This finding is surprising given the number of participants (61.5%) in Eisenberg et al.'s (1998) study who did not disclose their use of ACTs to their physician. These discrepancies point to the need for further research to make clear the distinction between social support and referral patterns.

Based on available knowledge, Yates et al. (1993) conducted one of the few studies that has attempted to directly study the effect of social support on ACT utilization rates within cancer populations. Describing social support as "encouragement to use," a significant association between encouragement and the use of ACTs was demonstrated. Those individuals who had received support in using ACTs were four times more likely to use ACTs than those who had received no encouragement. Further analysis, however, failed to confirm the independent effect of encouragement to use ACTs on utilization.

The limited research on the influence of social support on the decision to use ACTs by individuals with cancer provides contradictory evidence of an association between these two concepts. However, rich qualitative data have highlighted the involvement of significant others, especially family members, friends, and health professionals in treatment decisions, including the use of ACTs. Further study is required to elucidate the nature of the relationship between ACT use and social support and to determine the mechanism through which cancer patients learn about ACTs and make the decision to use these therapies. Exploration of the social and psychological consequence of giving and receiving encouragement to use ACTs is also warranted.

## Control

One variable that has attracted considerable interest as a potential motivator of ACT use within general and cancer populations has been the concept of control. Despite wide variation in conceptualization and instrumentation, the majority of research has supported a positive relationship between ACT use and the desire for control. How control is conceived or manifested by patients who use ACTs, however, has yet to be conclusively determined.

The most focussed program of research on the association between ACT use and control has been developed by Montbriand (1995a; 1995b; Montbriand & Laing, 1991). In an ethnographic study of ACT use by 75 acute care patients in Canada, Montbriand and Laing (1991) uncovered three themes of control: 1) perceived control; 2) internal-external control; and 3) illusion of control. The first theme encompassed patients who perceived themselves as having the ability to escape or regain freedom from the control of biomedicine. For these individuals, ACT use represented a strategy through which they recovered control of their health and covertly separated themselves from the conventional health-care system. ACT use was also examined through the lens of Rotter's (1966) internal-external locus of control theory. Individuals who used therapies that were more psychological in nature appeared to keep control to themselves, illustrating an internal orientation. In contrast, individuals who used physical and/or spiritual therapies gave away their control to practitioners or to a "Higher Being", representing an external locus of control. Control was also found to fluctuate as patients progressed through the disease trajectory, suggesting control to be a flexible, rather than static, entity. Lastly, Montbriand and Laing (1991) drew inspiration from gambling studies to present ACT use as being an illusion of control, in which patients discount the influence of chance on their health outcomes. Such conceptualization lends support to an additional theme, desire for control, which has been the subject of much research within cancer populations (Degner & Russel, 1988; Degner & Sloan, 1992; Degner, Sloan, & Venkatesh, 1997; Hack, Degner, & Dyck, 1994). In the face of an uncontrollable disease, such as cancer, individuals may seek to increase their chance of survival and control of their illness through the use of ACTs.

In considering the larger body of literature on ACT use within general and cancer populations, control has been linked consistently with the decision to use ACTs. In one of the first examinations of cancer patients using conventional medicine and ACTs, ACT consumers were found to be more likely to accept an active role in their health care than patients using only conventional medicine (Cassileth et al., 1984). The personal responsibility held by ACT consumers was reflected in their choice of therapies that were life-style oriented rather than practitioner-controlled. While this research did not specifically consider control as an intervening variable in the decision to use ACTs, it provided preliminary evidence of an association between desire for control and health behaviour.

In a survey of 125 outpatient oncology patients, Hiratzka (1985) found that individuals who held positive attitudes towards ACTs and had greater knowledge of ACTs scored higher on the internal locus of control subscale of the Multi-Dimensional Health Locus-of-Control Scale (Wallston, Wallston, & DeVellis, 1978). Despite the criticisms of this scale for it being too static and limiting (Furnham & Beard, 1995), Hiratzka (1985) concluded that individuals with an internal orientation were more likely to seek out and to use information about ACTs than individuals holding a "powerful others" or "chance" orientation. The implications of this research, however, are limited because only attitudes towards and knowledge about ACTs were examined rather than actual treatment utilization.

Furnham (Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Smith, 1988) extended Hiratzka's (1985) research by exploring the association between health locus of control and ACT use within the general population. Using Lau and Ware's (1981) health-specific locus of control scale, Furnham and Smith (1988) found homeopathic patients to have significantly lower scores on the provider control subscale than patients attending a general practitioner. This difference was attributed to homeopathic patients' general dissatisfaction with, and distrust of, conventional medicine. In a follow-up study of a larger sample of homeopathic and conventional medical patients, a significant difference between the two study groups on the health-specific locus of control scale was reported (Furnham & Bhagrath, 1993). This difference, however, was found on the internal locus of control subscale rather than the provider control scale. Homeopathic patients were found to believe more strongly in their ability to control their health than conventional medicine patients. This belief was attributed, in part, to homeopathic patients' disappointment with conventional medicine, which pushed them towards greater responsibility for their own health. Furnham and Forey (1994) provided further support for the association between ACT use and the desire for personal control over health decisions and less reliance on conventional medicine practitioners. More recent work, however, has challenged the hypothetical relationship between locus of control and ACT use, with significant differences among ACT and conventional medicine consumers being attributed to demographic differences (i.e., age and illness history) rather than control orientation (Furnham et al., 1995). This discrepancy emphasizes the need to consider the interactions among personal, social, and cognitive factors in conducting ACT utilization research.

Yates et al. (1993) improved on previous research by exploring the predictive value of the concept "need for control" with regards to ACT use by cancer patients. Need for control was conceptualized as being one's attitude towards having control over decisions about one's cancer and its treatment. ACT users were found to express a stronger desire for control over health-care decisions in comparison with individuals using only conventional treatments. In contrast to Furnham et al.'s (1995) findings, need for control was found to be an independent

predictor of ACT use within this population. The validity of Yates et al.'s (1993) findings, however, was tempered by the use of an investigator-developed measure of control.<sup>13</sup> Balneaves et al. (1999) addressed this limitation by using a validated measure of desired control (i.e., Control Preference Scale, Degner & Sloan, 1992; Degner et al., 1997)<sup>14</sup> in their study of ACT use in women with breast cancer. The findings of this research, along with Truant's (1997) ethnographic study of the decision-making process of women with breast cancer who use ACTs, are discussed in greater detail in the following section on treatment decision making.

In summary, research within general and cancer populations has provided preliminary evidence of an association between control and the use of ACTs. The lack of consistency in the definition and measurement of control has made comparisons across studies difficult and has highlighted the need for more definitive theory development. Determining whether control is best operationalized as a desire for control, an internal/external orientation, or an illusion of control will contribute significantly to research exploring the relationship between ACT use and control. Examination of the role of control in relation to other health beliefs would further current understanding of the complexities associated with treatment decisions specific to ACTs

## **Treatment Decision Making by Women Living with Breast Cancer**

This section provides a concise summary of research examining treatment decision making by women living with breast cancer. Women's experiences and preferences related to conventional treatment decision making are examined, focussing on women's preferred role in decision making, demographic and cognitive factors associated with treatment decision making, and the ways in which treatment decisions are made. The limited literature on treatment decision making within the context of ACT use also is examined.

### **Conventional Treatment Decision Making**

The majority of studies examining the conventional treatment decision-making process of women with breast cancer has focussed on what role women want to play in their treatment decisions (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner, Kristjanson et al., 1997; Degner & Sloan, 1992; Hack et al., 1994; Kenny, Quine, Shiell, & Cameron, 1999; Street & Voigt, 1997). The findings have been contradictory, with some researchers suggesting that women with breast cancer prefer to take on an active or collaborative role in their treatment decisions (Degner, Kristjanson et al., 1997; Keating, Guadagnoli, Landrum, Borbas, & Weeks,

<sup>13</sup> Yates expressed concern regarding the reliability of the 2-item Encouragement to Use ACT measure and suggested that a more reliable measure of control should be used in future ACT research. (P. Yates, personal communication, October 31, 1994)

<sup>14</sup> Degner & Sloan's (1992) Control Preference Scale has been well validated through a series of studies and across a range of populations (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner, Kristjanson et al., 1997; Degner & Sloan, 1992; Degner, Sloan et al., 1997).

2002; Mastaglia & Kristjanson, 2001) and other researchers suggesting that when faced with a life-threatening diagnosis such as breast cancer, many women prefer to defer treatment decisions to their physicians (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner & Sloan, 1992). This discrepancy, along with data that suggests that being offered an active role in treatment decision may either positively (Keating et al., 2002; Street & Voigt, 1997) or negatively (Fallowfield, Hall, Maguire, Baum, & A'Hern, 1994; Reaby, 1998) influence women's physical and psychological well being, has emphasized the importance of individualizing decision-making strategies.

The need for improved communication between health-care providers and women with breast cancer regarding expectations of the decision-making process has been further supported by research identifying discrepancies in women's preferred and actual role in treatment decisions (Bilodeau & Degner, 1996; Degner, Kristjanson et al., 1997; Keating et al., 2002). For example, in Bilodeau and Degner's (1996) survey of 74 women newly diagnosed with breast cancer, only 19% of women preferring a collaborative role were able to assume such a role in the clinical setting. While barriers to achieving a more active role in decision making have been identified (e.g., lack of information, lack of time, physical and mental distress, poor patient-provider communication skills (Reaby, 1998; Sainio, Eriksson, & Lauri, 2001), no known studies have examined the difficulties faced by women preferring a more passive role in treatment choice in achieving their desired level of involvement in treatment decisions.

Factors that have been significantly associated with the preferred decisional role of women with breast cancer include age, education, and income level (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner & Sloan, 1992; Hack et al., 1994; Pierce, 1993). In general, young women with a high socioeconomic status have been found to prefer active roles in treatment decisions. In contrast older women and those from lower socioeconomic groups have preferred less control in their treatment choices. The amount of variance in preferred decisional role explained by demographic factors, however, has been of limited clinical significance (Beaver et al., 1996).

Despite the controversy over the role of women with breast cancer in treatment decisions, researchers have developed some insights into the types of information women would like during the decision-making process. Hack et al. (1994) examined the information needs of 17 women diagnosed with stage I or II breast cancer who were two to six months post-diagnosis. Women who preferred an active role in choosing their breast cancer treatment were found to desire detailed information regarding their diagnosis, treatment alternatives, and treatment procedures. All women, notwithstanding their preferred decisional role, were found to want information about the side effects of treatment and their prognosis. The findings of this study, however, are limited by the small sample size. In a larger study of 74 women diagnosed

with breast cancer (Bilodeau & Degner, 1996), information needs included (listed in order of perceived relevance): stage of disease, likelihood of cure, treatment options, physical and emotional side effects, risk to relatives, impact on social activities, self-care issues, and sexuality. Women's ability to assimilate technical information about their diagnosis, treatment, and prognosis and physicians' ability to communicate such information in an understandable manner, however, has been questioned (Kenny et al., 1999).

In terms of the actual decision made with regards to breast cancer treatment, the majority of studies has focussed on women's decision to have either mastectomy or breast-conserving surgery (i.e., lumpectomy) (Graling & Grant, 1995; Mastaglia & Kristjanson, 2001; Stafford, Szczys, Becker, Anderson, & Bushfield, 1998; Street & Voigt, 1997; Ward, Heidrich, & Wolberg, 1989). The proportion of women choosing breast-conserving surgery over mastectomy has varied considerably in the literature. Factors found to discriminate between surgical choice include age, education, income level, geographic residency, and physician preference (Graling & Grant, 1995; Hughes, 1993; Mastaglia & Kristjanson, 2001; Stafford et al., 1998). Young urban women with high socioeconomic status were found to prefer lumpectomy to mastectomy. These differences raise interesting questions regarding women's perceptions of risk and the perceived availability of breast cancer treatment based on financial and travel considerations. Conflicting results have been found regarding the role of information and physician communication in women's surgery decisions (Hughes, 1993; Mastaglia & Kristjanson, 2001).

Few studies have examined the actual decision-making process of women with breast cancer. One exception is Pierce (1993), who used grounded theory to explore the decision-making experiences of 48 women newly diagnosed with early-stage breast cancer. Three patterns of decision making were uncovered: a) deferrer; b) delayer; and c) deliberator. Just over 40% of the women were classified as being "deferrers", which was defined by the women's lack of conflict over treatment options, their preference to defer to their physician, and limited deliberation. For many of these women, they did not perceive themselves as having a treatment choice. In contrast, 44% of the women were classified as "delayers", who vacillated between treatment options and had difficulty distinguishing between the benefits and costs of the different choices. These women often made a decision using the "first difference rule", in which the treatment option that had the first detectable benefit over the other treatments was chosen. For only 15% of the women, a "deliberator" role in decision making was identified. These women accepted a personal responsibility for their decision and developed a structured deliberation plan to sort through the available treatment options and to seek information. Although this latter pattern of decision making was closest to the normative models presented in the decision-making literature (Janis & Mann, 1977; Slovic, Fischhoff, & Lichtenstein, 1977; Tversky & Kahneman, 1981; Tversky & Shafir, 1992), women who were deliberators experienced the

greatest psychological distress in making their treatment decisions compared to women who used other decisional styles. Pierce (1993) was cautious in judging one decision-making style as being better and encouraged long-term follow-up to determine women's satisfaction or regret with their treatment decisions.

In summary, research on treatment decisions by women with breast cancer has revealed that while some women may prefer an active role in the decision-making process, other women may be more comfortable in being less involved in treatment choices. That the decision-making experience is stressful for all women, notwithstanding the preferred decisional role, is apparent and emphasizes the need for clear communication regarding treatment options and the decision-making process. Health-care providers must also provide sufficient information to allow those women interested in having more control over their treatment decisions to make informed choices. Although the role of control in treatment decision making has been well studied, further research is warranted on how women with breast cancer make decisions and what are other influencing factors.

### **Treatment Decision Making and Alternative/Complementary Therapies**

To date, few studies have been conducted on the decision-making process of consumers of ACTs, particularly individuals diagnosed with cancer. Exceptions include Montbriand (1995b), Truant (Truant, 1997; Truant & Bottorff, 1999), and Balneaves et al. (1999). Although much of this work appears to overlap the research previously discussed on the association between control and ACT use, these studies are discussed here in the context of treatment decision making. Given the body of research that has focussed on the role of control in the treatment decisions of women with breast cancer (Bilodeau & Degner, 1996; Degner, Kristjanson et al., 1997; Degner & Sloan, 1992; Hack et al., 1994; Mastaglia & Kristjanson, 2001), it is not surprising to find such commonality.

In the first study mentioned, Montbriand (1995a) found the theme of control interwoven throughout her examination of cancer patients' decisional strategies specific to ACTs. The first phase of her study involved the development of a decision tree based on interviews with 48 individuals diagnosed with respiratory or digestive system cancers. The decisional tree consisted of 21 questions that differentiated individuals who expressed high interest in ACTs, regular interest in ACTs,<sup>15</sup> or were interested in biomedical treatments only. The main themes of the decision tree included the following: (1) preferred treatment methodology, (2) secrecy about alternatives, (3) social group influence, (4) considerations of cost, (5) perceived stress, (6) desired decisional control, (7) judgements about cure, (8) change and searching, and (9) faith in

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<sup>15</sup> High and regular interest groups were differentiated by the high interest respondents intending on using ACTs as a consequence of their cancer diagnosis and regular interest respondents continuing to use those ACTs they had been using prior to diagnosis.

the practice. The decision tree's predictive value was tested in the second phase of the study, in which 252 cancer patients were interviewed. Overall, 90.4% of respondents were correctly classified using the decision tree, with 22% being high interest group members, 48% classified as regular interest group members, and 29.8% responding in a manner consistent with the biomedical only group. Those individuals included in the high interest group were more likely to be young and female, have a more severe cancer diagnosis, and report a higher level of education and income than those in the biomedical only group. High interest members were also more secretive about their use of ACTs, received support from their social group to use ACTs, wanted a high level of decisional control, and held health beliefs supportive of alternative treatment paradigms. Interestingly, high interest members perceived stress as being a motivating factor in their decision to use ACTs. With regards to control, Montbriand (1995a) found high interest members' desire for control over health care was associated with several factors, including social, cultural, and economical influences. She suggested that making the decision to use ACTs allowed some cancer patients to express their independence from the conventional health-care system. The amount of variance in ACT use explained by preferred role in treatment decisions, however, was not clear from the model developed by Montbriand (1995a). Further predictive work is needed to model the concept of control along with other health beliefs and sociobehavioural variables in relation to the decision to use ACTs.

Qualitative work by Truant (Truant, 1998; Truant & Bottorff, 1999) has provided further rich description of the dynamic nature of treatment decision making in women with breast cancer who use ACTs. Central to the decision-making process was the issue of control. The women (N = 16) who participated in this grounded theory study described their use of ACTs as being a means through which control could be regained. The motivations underlying the need to regain control, however, varied as women moved through the cancer trajectory. Newly diagnosed women expressed a desire to reduce their feelings of loss and to take action. These women reported making quick, and often uninformed, decisions about ACTs before beginning conventional treatment. For many women at this point in their disease, decisions related to conventional cancer treatments took precedence over decisions related to ACTs. Following surgery, a desire to take back control from the conventional health-care system and to increase control over the cancer and one's health became paramount. Women at this point in the trajectory experienced less anxiety and were able to take more time to research treatment options and to choose therapies that fit best with their lifestyle and belief systems. Beyond increasing a sense of control, ACTs were also used to manage the side effects of conventional cancer therapies, boost the immune system, promote well being, and prevent a recurrence of breast cancer. Once conventional treatment had ended and the women began to regain a sense of "normality" in their lives, they continued to use ACTs in an attempt to enhance their illusion or



perception of control. In using ACTs, women felt they were continuing to exert some measure of control over their cancer and general health. Although all women using ACTs reported taking an active role in their decisions related to ACTs, they described more passive roles in the treatment decision-making process within the conventional health-care system. This finding, in part, contradicts past research on women's preferred role in treatment decisions (Bilodeau & Degner, 1996; Degner & Sloan, 1992) and suggests that desire for control may fluctuate not only across the cancer trajectory but also across treatment decisions. The decision to use ACTs may be one way in which women with breast cancer are able to play a more active role in treatment decisions while maintaining their relationships with conventional health-care providers.

Balneaves et al. (1999) also examined ACT decision making from the perspective of control by using Degner and Sloan's (1992; 1997) Control Preference Scale to determine the preferred decisional role of women with breast cancer using ACTs. Of the 52 women interviewed, the majority of ACT users (94%) were found to prefer an active or collaborative role in treatment decision making, whereas only 56% of women using only conventional medicine were found to prefer similar roles. Similar to Truant and Bottorff (1999), Balneaves et al. (1999) concluded that the decision to use ACTs may be an important mechanism through which women with breast cancer gain control, knowledge, and responsibility over an illness that appears, at times, uncontrollable.

The research on treatment decisions related to ACT use in cancer populations has provided insight into the role of control as both a motivator and an outcome of the decision to use ACTs. The influence of other factors, including stage of disease and conventional treatment, psychological distress, and social support on ACT decisions has been also suggested. Additional decision-making research is needed, however, that examines the variability of ACT use beyond a "yes-no" dichotomy and the role of both social and cognitive factors in influencing the manner in which ACTs are used.

## **Chapter Summary**

This chapter has reviewed and critiqued the two main areas of literature: alternative and complementary therapy use in general and cancer populations and treatment decision making in women living with breast cancer.

With regards to the ACT literature, three major areas of ACT research within general and cancer populations were reviewed: the prevalence of ACT use, the characteristics of ACT consumers, and the social and cognitive motivations of ACT use. Although lacking in concise and consistent terminology, this body of literature suggests ACT use to be a growing health-care phenomenon within industrialized nations. The increase in the use of ACTs within general populations has been mirrored within cancer populations, with a limited body of literature

suggesting that ACTs play a significant and integral role in the experiences of women living with breast cancer. Further research is needed to develop more specific and reliable statistics on the prevalence of ACT use within breast cancer populations.

The literature on the characteristics of ACT consumers within general and cancer populations has provided inconclusive evidence of associations among personal and social factors and the use of ACTs. Gender, age, socioeconomic status, health experiences, and health beliefs have all been implicated as predisposing factors in the decision to use ACTs. The literature has also pointed towards potential associations between demographic characteristics, health beliefs, and the use of ACTs by individuals living with cancer. These preliminary findings underscore the importance of moving from descriptive research to inquiry that is grounded in theory to explain and understand the potential interrelationships among sociodemographic characteristics, personal belief systems, and ACT use within cancer populations. In particular, the research on ACT use by women with breast cancer has raised questions regarding the role of health and illness beliefs in the decision to use ACTs and the interactions among beliefs and sociodemographic factors, and ACT use.

Research on the utilization of ACTs has also revealed several factors that potentially motivate individuals to search for treatment alternatives outside of the conventional health-care system. Despite the lack of prospective, longitudinal research, strong associations have been identified between social support and control and the use of ACTs. The limited research exploring the motivations of ACT use in women with breast cancer has provided some support for these factors; however, further study is required to fully elucidate the nature and quality of the relationships among these concepts and women's use of ACTs. Greater specificity is also required regarding the context within which ACTs are used in breast cancer populations. While the majority of prevalence research has considered ACT use to be singular in purpose (i.e., curative), qualitative work has suggested that ACTs are used more discretely throughout the breast cancer trajectory (Truant, 1998).

Research on treatment decision making has shed further light on the way in which women with breast cancer make decisions and what social and cognitive factors may affect their treatment decisions. The desire for control has been found to be an important variable in women's decision-making process, with treatments such as ACTs representing a means of regaining control from the biomedical establishment and asserting one's independence. Much of the work on treatment decision making specific to ACTs has occurred, however, without a strong theoretical framework. By examining the treatment choices of women with breast cancer within an accepted and recognized cognitive framework, those factors associated with treatment decisions related to ACTs are uncovered.

In summarizing the literature, ACT use has been described as a consequence of sociobehavioural (i.e., demographic factors, previous experience, social support) and cognitive factors (beliefs about health, illness, and control). The descriptive nature of past research, however, has hindered attempts to test the interrelationships among these factors and ACT use, and examine ACT use within a recognized theory of health behaviour. The proposed research will address these limitation by developing and testing three causal models of ACT use by women with breast cancer, focussing on the personal, social and cognitive factors that have been implicated in the literature as being associated with ACT use. The following chapter delineates more fully the proposed models of ACT use and the theoretical underpinnings of the hypothesized relationships.

## Chapter 3

### Theoretical Models

Despite the existence of a vast body of literature describing the use of alternative/complementary therapies (ACTs) by general and cancer populations, few researchers have attempted to examine ACT use within the context of a theoretical framework of health behaviour. This has resulted in ACT use being presented in a disjointed and fragmented manner that has prevented the causal relationships between sociodemographic characteristics, attitudes, health beliefs, and the use of ACTs from being fully elucidated within a comprehensive theory. Without this knowledge, health professionals are unable to understand which individuals are most likely to use ACTs, their motivations for such health behaviour, and the context in which ACT use is most prevalent. The purpose of this study is to develop and test three hypothetical models of ACT use by women with breast cancer. Using key constructs derived from the Health Belief Model (Janz & Becker, 1984; Maiman & Becker, 1974; Rosenstock, 1974b), the use of ACTs by women who had been diagnosed and treated for breast cancer was examined within the context of preventive, ameliorative, and restorative health behaviour. In developing and testing three distinct models of ACT use, the purpose underlying women's use of therapies beyond conventional medicine and the role of health beliefs in motivating ACT use across a range of health contexts were examined. The following discussion provides an overview of the most well known models of health behaviour, including the Health Belief Model, as well as a detailed description of the three hypothetical models of ACT use that were tested in this study. Empirical support for the postulated models and structural relationships is also provided.

### Models of Health Behaviour

Since the 1960s, numerous sociobehavioural models have been developed in an attempt to further understanding of the decision-making process underlying the use of selected

health services. In this section, a brief outline of three of the most familiar models of health behaviour is provided, describing how each model conceptualizes health action. The advantages and disadvantages of each model also are presented.

### **Behavioural Model of Health Care Utilization**

One of the first models of health behaviour to be advanced was Andersen's (1968; 1995) behavioural model of health care utilization. Originally developed to explain the use of health services by families, the model has been applied across a variety of behaviours, including utilization of conventional health-care services (Barrilleaux & Miller, 1992; Bazargan, Bazargan, & Baker, 1998; Cohen, 1993; Potvin, Camirand, & Beland, 1995), self-care activities (Fleming, Giachello, Andersen, & Andrade, 1984; Fosu, 1989) and the use of ACTs (Kelner & Wellman, 1997a). The behavioural model conceptualizes health behaviour as being a product of complex interrelationships among predisposing (personal and social structures), enabling (resources and barriers to care), and need-for-care (perceived risk and need) factors (Andersen, 1968; Andersen & Newman, 1973; Andersen, 1995). Of these factors, perceived need-for-care has been found to be the strongest predictor of health behaviour (Andersen, 1995). While ambitious in its attempt to account for total health service utilization, Andersen's model has been described as a theoretical framework of personal and social factors rather than an actual theory of health behaviour (Kirscht, 1974). The model lacks specificity and is, therefore, restricted in its application to exploring the social cognitions (i.e., health beliefs) associated with health-care decisions.

### **Health Locus of Control**

In an attempt to better explain and predict health behaviour at the social cognitive level, several theories have been developed using the construct of locus of control. Defined as the degree to which individuals perceive events in their lives to result from their own actions and therefore controllable (internal control), or as being unrelated to their own behaviour and beyond their control (external control) (Lefcourt, 1976), locus of control originated within the traditions of social learning theory (Rotter, 1966; Wallston et al., 1978). Social learning theorists conceptualize behaviour, including health action, to be a function of both an individual's expectancies about the consequences of one's actions and ability to perform a behaviour and the value of the expected outcome (Oberle, 1991; Rosenstock, Strecher, & Becker, 1988). Wallston et al. (1978) further refined the locus of control construct by developing the multidimensional health locus of control (MHLC) scale, which measures the degree to which individuals perceive their health to be a consequence of their own action, the action of powerful others, or chance. Despite wide application to a variety of health behaviours (Rosenstock et al., 1988; Zindler-Wernet & Weiss, 1987), health locus of control theories have been able to explain only a minimal amount of variance in health behaviour (Conner & Norman, 1996). The theories

have been criticized for their lack of stability across health behaviours and their failure to incorporate perceived value of health.

### **Theory of Reasoned Action**

The theory of reasoned action, also known as the theory of planned behaviour, has extended the scope of social cognitive theories by examining not only personal beliefs and attitudes towards health, but also the social norms associated with health behaviours (Ajzen & Fishbein, 1980; Lauver, 1992). Within this model, health behaviour is proposed to be a consequence of one's intentions, or health motivations, which are in turn derived from beliefs about the perceived consequences of an action, the normative value of those consequences, and one's capacity to perform the action. Individuals are believed to engage in health behaviour if they perceive the action to result in an outcome that they value, if they believe that significant others desire they should act, and if they believe they have the needed resources to successfully perform the behaviour (Conner & Norman, 1996). The theory of reasoned action has been used in examinations of a variety of health behaviours, including smoking (Marin, Marin, Perez-Stable, Otero-Sabogal, & Sabogal, 1990), sexual behaviour (Chan & Fishbein, 1993), and health screening (Lauver & Angerame, 1993). The model and its associated propositions, however, have not received unequivocal support within the literature. Foremost, health beliefs and attitudes have been found to have direct, rather than indirect, effects on health behaviour (Pender & Pender, 1986). This finding calls into question the importance of intention in predicting health behaviour. The theory of reasoned action has also failed to consider the impact of factors such as previous experience with a behaviour, which has been shown to be predictive of health action (Lauver, 1992).

### **Summary**

The previous discussion provided a concise overview of selected theories that have been used in past research to examine the motivations and cognitions underlying the decision to engage in health behaviour. A wide variety of factors, including beliefs about expectancy, value, control, and self-efficacy have been implicated as being central to motivating health actions. Within the context of this study, however, the limitations of these models create doubt about the applicability of these theories in research examining the use of ACTs. Given the nascent stage of development of this field of study, a theory is needed that provides an elementary foundation for conceptualizing the social cognitions associated with ACT use. With health beliefs forming the most basic component of the above models, the Health Belief Model and its potential application in the present study is considered in the following section.

### **The Health Belief Model**

The Health Belief Model (HBM) arose in the 1950s in response to a series of research problems faced by researchers in the United States Public Health Services. Frustrated by their

inability to explain the failure of many preventive health services and screening programs, the HBM was developed as a means of predicting and modifying health behaviour. Drawing from Lewin's (1951) theory of valence, which considers actions to be determined by positive, negative, and neutral forces within the environment, the HBM hypothesizes that health behaviour is a consequence of an individual's evaluation of the perceived threat of an illness and the potential benefits and costs of a specific health action (Janz & Becker, 1984; Rosenstock, 1974b). Similar to other expectancy-value models (Slovic et al., 1977), the HBM conceptualizes health behaviour as arising from subjective perceptions of probability and utility and as being the consequence of an evaluative, decision-making process.

Within the HBM, the perceived threat of an illness is dependent upon two beliefs, *perceived susceptibility* to illness and the *perceived severity* of the consequences of an illness (Sheeran & Abraham, 1995). Perceived susceptibility is defined as "one's subjective perception of risk of contracting a condition" (Janz & Becker, 1984, p. 2) and captures an individual's sense of vulnerability to illness, resusceptibility, and belief in diagnosis. Perceived severity is defined as "feelings concerning the seriousness of contracting an illness" (Janz & Becker, 1984, p.2) and includes not only evaluations of the clinical consequences of illness (i.e., death, disability, and suffering), but also the social consequences of a condition (i.e., work, family life, and relationships). Together, perceived susceptibility and severity provide the force or motivation to act (Rosenstock, 1974b). The course of action that is taken is determined by two sets of beliefs about behaviour, including the *perceived benefits* or efficacy of a health behaviour and the *perceived barriers* to enacting a behaviour. Perceived benefits are defined as "beliefs regarding the effectiveness of the various health actions available in reducing the disease threat" (Janz & Becker, 1984, p. 2) and refer to a lessening in either perceived susceptibility to or perceived seriousness of an illness. In contrast, perceived barriers represent the "potential negative aspects of a particular health action" (Janz & Becker, 1984, p. 2) and include such factors as inconvenience, expense, pain, and effort. In considering which health behaviour to undertake, Janz and Becker (1984) suggested that a kind of "cost-benefit" analysis occurs, with individuals weighing the perceived efficacy of health behaviour against its associated costs.

While perceptions of susceptibility, severity, benefits, and barriers provide the motivation and direction underlying health behaviour, the HBM also proposes that a *cue to action* must be present to provoke an individual to act. Despite the limited research examining the role of cues to action in the HBM (Janz & Becker, 1984; Sheeran & Abraham, 1995), it is suggested that cues serve as instigating events that set behaviour in motion (Rosenstock, 1974b). Cues may be both internal (e.g., symptoms, pain) or external (e.g., encouragement from others, media) and vary in the level of intensity based on one's perceived susceptibility and severity. For those individuals with little acceptance of their susceptibility to, or the severity of an illness, an intense

cue to action would be needed to provoke behaviour. Individuals who perceive themselves as being highly vulnerable to a serious illness would require only a minor cue for action to engage in health behaviour.

The majority of studies utilizing the HBM have focussed on the applicability of the theory within the context of *preventive health behaviour*, which has been defined as behaviour that is undertaken in an attempt to prevent disease or to detect disease in an asymptomatic stage (Rosenstock, 1974a). Some researchers have confirmed, however, the relevance of the HBM to *sick role behaviour* and *illness behaviour* (Becker, 1974; Kirscht, 1974). Sick role behaviour has been described as those actions used by individuals who are *socially recognized as being ill* to restore health or to prevent the further progression of disease (e.g., compliance with a treatment regimen) (Janz & Becker, 1984). In contrast, illness behaviour refers to those activities undertaken by individuals *who feel ill* for the purposes of determining their health status and discovering possible remedies for their perceived distress (e.g., clinic utilization) (Kasl & Cobb, 1966). It has been acknowledged by some theorists that the line between sick role and illness behaviour is blurred and, at times, difficult to discern (Kirscht, 1974). The distinction between sick role and illness behaviour as operationalized in this study becomes apparent later in this chapter when the use of ACTs by women with breast cancer is considered from the context of symptom management (i.e., sick role behaviour) versus the response to ambiguous and ill-defined concerns related to general well being (i.e., illness behaviour).

Despite criticisms of the HBM as being insufficiently conceptualized and lacking clear and empirically supported relationships among the model constructs (Davidhizar, 1983; Mikhail, 1981; Sheeran & Abraham, 1995), the HBM has been used in a wide range of health research (Janz & Becker, 1984). The HBM has been particularly useful in cancer research, providing a means of exploring a variety of health behaviours, including breast self-examination (Calnan & Rutter, 1986; Champion, 1991; Champion & Miller, 1996; Rutledge, 1987; Stillman, 1977), cervical cancer screening (Burak & Meyer, 1997), and compliance with conventional cancer treatment (Newell, Price, Roberts, & Baumann, 1986). In addition, research comparing the predictive capacity and parsimony of a variety of health behaviour theories, has supported the use of a modified HBM in predicting health actions (Mullen, Hersey, & Iverson, 1987; Murray & McMillan, 1993). These studies offer support for the potential application of the HBM within research that explores the health behaviour of women living with breast cancer, including their use of ACTs. While the HBM is limited in its accounting for the variance in health behaviours explained by attitudes and health beliefs, the theory could potentially provide valuable insight into the motivations and beliefs that underlie breast cancer patients' commitment to using ACTs.



## **Theoretical Models of Commitment to Alternative/Complementary Therapies**

Previous research on the use of ACTs by cancer patients, including women living with breast cancer, has revealed numerous motivations underlying the decision to use therapies that are not offered as part of conventional medical care. For some individuals, ACTs are used to increase one's chances of survival and to prevent a recurrence of cancer (Downer et al., 1994; Millar, 1997; Truant, 1997). Other cancer patients find themselves struggling with the adverse effects of conventional cancer treatment and use ACTs as a means of coping with their physical, emotional, and spiritual distress (Crocetti et al., 1998; Furnham & Kirkcaldy, 1996). To capture the diverse health contexts in which individuals with cancer may use ACTs, three theoretical models of ACT use have been developed. These models, derived from the HBM (Janz & Becker, 1984; Rosenstock, 1974b), consider women's use of ACTs from a preventive, sick role, and illness behaviour perspective. While the three models of behaviour are not discontinuous (Rosenstock, 1974a), testing each of the models separately allows the health beliefs and attitudes underlying the decision to use ACTs to be most clearly conceptualized within an appropriate theoretical and contextual framework. The following discussion presents a theoretical description of each of the proposed models of ACT use, with the Preventive Model of ACT Use providing a template for the Ameliorative and Restorative Models of ACT Use. Empirical evidence supporting the postulated relationships among study constructs is also provided.

### **The Preventive Model of Alternative/Complementary Therapy Use**

Figure 1 illustrates the Preventive Model of ACT Use. Using key constructs from the HBM, as well as sociobehavioural variables identified in past research to be associated with preventive health behaviour, the Preventive Model of ACT Use explains ACT use within the context of preventing a recurrence of disease.

Previous research using the HBM has investigated such health behaviour as flu vaccination (Rundall & Wheeler, 1979), preventive dental behaviour (Chen & Land, 2002), breast self-examination (Champion & Miller, 1996; Champion, 1991), mammography screening (Clarke, Lovegrove, Williams, & Macpherson, 2000; Holm, Frank, & Curtin, 1999), genetic screening (Becker, Kaback, Rosenstock, & Ruth, 1975) and smoking cessation (Weinberger, Greene, Mamlin, & al., 1981). To date, this research has focussed on individuals who are not ill but who wish to avoid injury or disease. Kirscht (1983) acknowledged that preventive health behaviour is not limited to individuals who are well, but is also undertaken by those experiencing sickness. In this study, women who have been previously diagnosed and treated for breast cancer are the subjects of interest. Within this context, preventive health behaviour is not directed towards an initial diagnosis of breast cancer but is instead used in the prevention of a

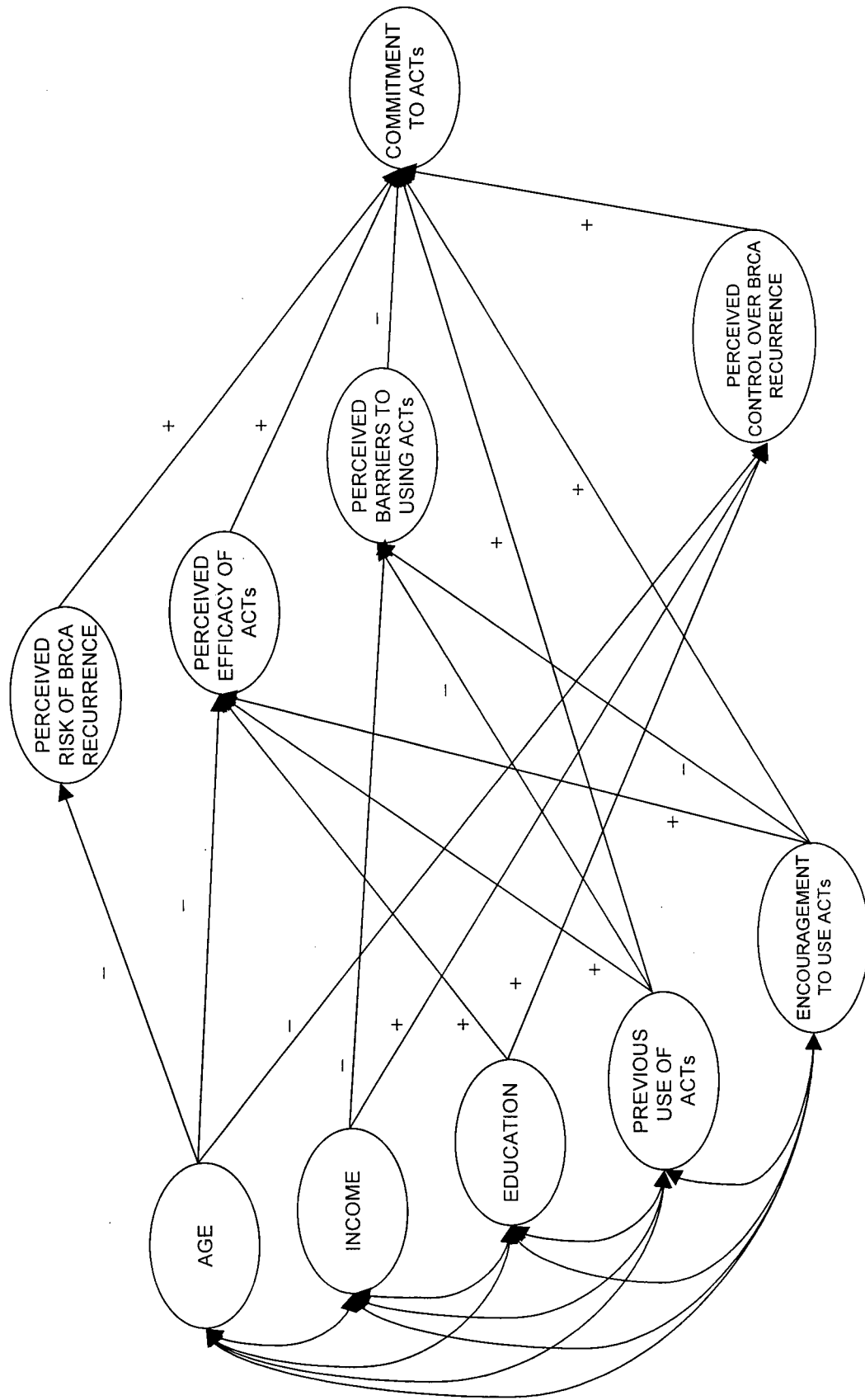


Figure 1. Preventive Model of Alternative/Complementary Use by Women Living with Breast Cancer (BRCA)

recurrence of breast cancer. Fear of recurrence has been reported to play a significant role in the emotional distress and uncertainty experienced by breast cancer survivors (Northouse, 1981; Pelusi, 1997; Wainstock, 1991). Such fear may motivate women to seek treatment alternatives that may increase the success of conventional cancer therapies and prevent a recurrence of breast cancer. In this sense, ACTs are used preventively to avoid disease.

The outcome construct, *Commitment to ACTs*, represents women's preventive use of ACTs within the context of breast cancer recurrence and is defined as the degree of effort and expense one is willing to extend in using ACTs. While the majority of past relevant research has examined behaviour deemed by the biomedical community to be efficacious in reducing or identifying the threat of disease, lay health practices, such as the use of ACTs, are important to study as they provide insight into the popular health beliefs held by the general public (Kirscht, 1983). In the Preventive Model, *Commitment to ACTs* is hypothesized to be a direct consequence of three key health beliefs, women's perceived control over recurrence, their prior history of ACT use, and the social support they received related to ACTs. The health beliefs include: (1) *Perceived Risk of Breast Cancer Recurrence*, (2) *Perceived Efficacy of ACTs*, and (3) *Perceived Barriers to ACT Use*. These beliefs are analogous to the HBM constructs of perceived susceptibility, perceived benefits, and perceived barriers, respectively. The HBM construct, perceived severity, has been omitted from the model because it is assumed that all women in the study will perceive a recurrence of breast cancer to be a serious health threat. The irrelevance of severity in models of preventive breast health behaviour has also been supported in the theoretical and empirical literature (Clark, Hill, Rassaby, White, & Hirst, 1991; Janz & Becker, 1984; Sheeran & Abraham, 1995; Stillman, 1977).

*Perceived Risk of Breast Cancer Recurrence* is defined as the degree to which one feels susceptible to a recurrence of breast cancer. A variety of beliefs have been used in prevention research to measure perceptions of susceptibility, including perceived likelihood of carrying the Tay-Sachs gene (Becker et al., 1975), perceived vulnerability for recurrent infections secondary to cystic fibrosis (Abbott, Dodd, & Webb, 1996), and perceived susceptibility to the side effects of hypertension (heart disease, stroke, and kidney disease) (Kirscht & Rosenstock, 1977). In research that has examined women's breast health practices (i.e., breast self-examination [BSE] and mammography utilization), perceived susceptibility has been measured by the subjective perception of breast cancer risk (Calnan & Rutter, 1986; Champion & Miller, 1996; Champion, 1999; Hyman, Baker, Ephraim, Moadel, & Philip, 1994; Stillman, 1977). Positive associations between women's perception of susceptibility and both BSE practice and mammography screening have been reported (Champion, 1991; Hallal, 1982; Stein, Fox, Murata, & Morisky, 1992; Stillman, 1977). These associations suggest that women who perceive themselves to be at high risk for breast cancer are more likely to engage in preventive health practices than

women who perceive themselves to be at low risk. Extending these findings to the Preventive Model of ACT Use, it is theorized that women who perceive their risk of recurrence to be high are more likely to commit to ACTs in the hope of increasing their chances of a cancer-free survival than women who perceive themselves to be at relatively low risk.

Significant associations between perceived benefits of and barriers to preventive health behaviour and cancer screening have also been identified (Burak & Meyer, 1997; Fulton et al., 1991; Hyman et al., 1994; Rutledge, 1987). In three studies of women's BSE practices, beliefs about the perceived benefits of BSE were found to be predictive of preventive health behaviour (Calnan & Rutter, 1986; Hallal, 1982; Rutledge, 1987). Women who considered BSE to be effective in the early detection of breast cancer were found to be more likely to engage in BSE than women who did not believe BSE to be beneficial. Mammography screening studies also have revealed negative associations between beliefs about perceived barriers to mammography and compliance with screening (Hyman et al., 1994; Stein et al., 1992). In a study that examined enrollment in a breast cancer prevention trial, non-participants were found to be more concerned about perceived barriers to participation (e.g., effects of tamoxifen, receiving a placebo) than women enrolled in the trial (Yeomans-Kinney et al., 1995).

Similar findings in relation to the influence of perceived benefits and barriers on the enactment of preventive health behaviour have been reported within the ACT cancer literature (Cassileth et al., 1984; M. Miller et al., 1998; Yates, 1991). In one study, nearly 60% of cancer patients using ACTs held the belief that their treatments would effect a remission or prevent metastatic growth (Cassileth et al., 1984). Kelner and Wellman (1997a) reported that healthy users of ACTs perceived few barriers to their use of alternative treatments. These findings lend support to the inclusion of perceived benefits and barriers within the Preventive Model of ACT Use. In this model, *Perceived Efficacy of ACTs* is defined as the degree of confidence one has in the ability of ACTs to prevent a recurrence of breast cancer. *Perceived Barriers to ACT Use* are defined as the negative deterrents associated with using ACTs. Together, it is hypothesized that women who hold positive beliefs about the effectiveness of ACTs in preventing a recurrence of breast cancer and perceive few barriers to accessing ACTs will demonstrate greater commitment to ACTs than women to whom these types of therapies are believed to be ineffective or inaccessible.

In response to past criticisms of the HBM that have decried the lack of consideration of such constructs as control and self-efficacy (King, 1983; Lauver, 1992; Rosenstock et al., 1988; Sheeran & Abraham, 1995), *Perceived Control over Recurrence* is included as a construct within the Preventive Model. Defined as the degree of control one has over the prevention of a recurrence of breast cancer, *Perceived Control over Recurrence* is hypothesized to positively influence *Commitment to ACTs*. Women who believe that they have some control over a

recurrence of breast cancer are more likely to take preventive action and commit to using ACTs than women who believe that they have limited control over their future prognosis. Support for this hypothesis has been provided within both the preventive health literature and previous ACT research (Abbott et al., 1996; Balneaves et al., 1999; Furnham & Bhagrath, 1993; Furnham & Smith, 1988; Hallal, 1982). For example, in Hallal's (1982) study of breast health practices, women who performed BSE were found to be less likely to have a locus of control that was dependent on powerful others than women who failed to practice BSE. Similarly, individuals who used homeopathic remedies reported greater perceived control over their health than individuals receiving only conventional medical care (Furnham & Bhagrath, 1993). Both these studies suggest that individuals who participate in preventive health behaviour accept greater responsibility for their health and perceive themselves as playing an active role in their health care.

Despite being equivocally conceptualized within the HBM, researchers have found sociodemographic characteristics to be significantly associated with preventive health behaviour (Kirscht, 1983; Sheeran & Abraham, 1995). In particular, education and income have been positively associated with such preventive health behaviour as immunizations (Cummings, Jette, & Brock, 1979), genetic screening (Becker et al., 1975), prenatal care (Stout, 1997), breast cancer screening (Champion & Miller, 1996; Fink, Shapiro, & Roester, 1972; Thomas, Fox, Leake, & Roetzheim, 1996), and ACT use (Balneaves et al., 1999; Cassileth et al., 1984; Downer et al., 1994; Lerner & Kennedy, 1992; M. Miller et al., 1998; Yates et al., 1993). In addition to socioeconomic factors, age has been negatively correlated with both breast health behaviour (Champion, 1994; Rutledge, 1987; Yeomans-Kinney et al., 1995) and ACT use in cancer populations (Crocetti et al., 1998; Downer et al., 1994; M. Miller et al., 1998; Yates et al., 1993). Although the inclusion of ethnicity and immigration history in the Preventive Model would have been informative, there was a lack of diversity in the study sample to ensure sufficient variability in these constructs. Over 89% of the respondents reported their ethnicity to be Caucasian, Canadian, or "nothing in particular".<sup>16</sup> In addition, more sophisticated and specific data (i.e., country of birth, number of years living in Canada, first language spoken) would have been required to determine the effect of acculturation on ACT use.

While the majority of past research has directly associated sociodemographic factors to preventive health behaviour, there has been some suggestion that age, education, and income may indirectly influence health behaviour through their effects on health beliefs (Sheeran & Abraham, 1995; Janz & Becker, 1984). For example, in Champion's (1984, 1994) studies on

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<sup>16</sup> The only feasible statistical comparison of ACT use across ethnic groups would have required ethnicity to be recoded as a binary variable (i.e., Caucasian/Canadian and other ethnic group). Comparing ACT use based on being Caucasian or not, however, does not have any substantive support in the literature.

BSE and mammography compliance, age was found to be inversely correlated with women's perceived susceptibility to breast cancer. Age also has been negatively associated with perceived efficacy of preventive practices, including the use of ACTs (Nakazono, Davidson, & Andersen, 1997; Yates et al., 1993). Significant associations have been identified between income and beliefs about perceived barriers and control (Stein et al., 1992; Yates et al., 1993), and between education and beliefs about perceived efficacy of health behaviour (Nakazono et al., 1997). These relationships suggest that the differences found across age cohorts and social classes in relation to preventive health practices may reflect the mediating influences of health beliefs on the performance of health behaviour.

Drawing from previous research that highlights the indirect relationships among sociodemographic variables and preventive health behaviour, the following relationships are proposed within the Preventive Model of ACT Use. Foremost, it is theorized that *Age* is inversely related to *Perceived Risk of Breast Cancer Recurrence*, *Perceived Efficacy of ACTs*, and *Perceived Control over Breast Cancer Recurrence*. Younger women are hypothesized to perceive themselves as having a higher risk of breast cancer recurrence, to perceive ACTs as more efficacious, and to perceive themselves as having greater control over breast cancer recurrence. In turn, younger women are postulated to be more committed to using ACTs. Secondly, *Income* is indirectly associated with *Commitment to ACTs* through its effects on *Perceived Barriers to ACT Use* and *Perceived Control over Breast Cancer Recurrence*. Women with higher socioeconomic status are predicted to confront few deterrents to using ACTs and to have access to resources that increase their sense of control over their health. Lastly, *Education* is proposed to positively influence *Perceived Efficacy of ACTs* and *Perceived Control over Breast Cancer Recurrence*. Women with higher educational attainment are hypothesized to have greater knowledge of the potential benefits of ACTs and to have greater access to health and informational resources that increase their sense of control over recurrence of breast cancer. In addition to the relationships among the sociodemographic variables and health beliefs, *Age*, *Income*, and *Education* are allowed to covary within the model.

Some theorists have further suggested that preventive health behaviour is influenced by past experiences with prevention activities (Sheeran & Abraham, 1995). While few HBM studies have included previous health behaviour as a study construct (some that have include Cummings et al., 1979; Fajardo, Saint-Germain, Meakem, Rose, & Hillman, 1992; Fulton et al., 1991), an association between past preventive health behaviour and utilization of preventive health services has been noted in the literature. For example, in Fulton et al.'s (1991) study of mammography utilization, women's past history of breast screening behaviour predicted mammography screening. Previous use of ACTs, prior to the diagnosis of cancer, has been positively associated with the use of ACTs following cancer diagnosis (Crocetti et al., 1998; M.

Miller et al., 1998). Similar to the associations among sociodemographic variables and preventive health practices, the influence of previous use on behaviour has been suggested to be a consequence of indirect effects on health beliefs, particularly perceived efficacy (Sheeran & Abraham, 1995). In the Preventive Model of ACT Use, *Previous Use of ACTs* is indirectly related to *Commitment to ACTs* through a positive effect on *Perceived Efficacy of ACTs*. Women who have used ACTs prior to their breast cancer diagnosis are hypothesized to be more confident in the outcomes of ACTs, thus increasing their commitment to ACTs. It is further theorized that previous experience with ACTs negatively influences how women perceive barriers to using ACTs. As the effect of previous use of ACTs on an individual's commitment to ACTs cannot be explained entirely through its influence on perceived efficacy and barriers, a direct positive relationship is also proposed. This relationship captures other factors potentially associated with previous use, including cultural traditions and habitual health behaviour. *Previous ACT use* is also permitted to covary with the sociodemographic variables.

Several cues to actions have been identified in previous research as being potential triggers of women's preventive health behaviour, including such factors as social support, physicians' recommendations, and health insurance (the latter being particularly relevant in the United States) (Burak & Meyer, 1997; Champion, 1991; Fulton et al., 1991; Stein et al., 1992). The effect of social influence on health behaviour has been of particular interest within the ACT literature, with numerous studies reporting encouragement from significant others as being an important motivator in the decision to use ACTs (Crocetti et al., 1998; Kelner & Wellman, 1997a; Truant, 1998; Yates et al., 1993). Based on this preliminary evidence, the construct *Encouragement to Use ACTs* was included in the Preventive Model of ACT Use. Defined as the social support received from significant others regarding the use of ACTs, *Encouragement to Use ACTs* is theorized to have both direct and indirect effects on *Commitment to ACTs*. Foremost, receiving support from significant others regarding ACTs is hypothesized to increase the perceived efficacy of ACTs and to reduce perceived barriers to using ACTs, resulting in a heightened commitment to ACTs. Secondly, *Encouragement to Use ACTs* is postulated to have a direct effect on *Commitment to ACTs*, reflecting the influence of social desirability on preventive health behaviour. *Encouragement to Use ACTs* and *Previous Use of ACTs* were permitted to covary with each other and with the sociodemographic factors in the model.

### **The Ameliorative Model of Alternative/Complementary Therapy Use**

The second theoretical model to be examined is the Ameliorative Model of ACT Use. This model incorporates key constructs of the HBM and related sociobehavioural variables and focusses on women's use of ACTs within the context of experiencing symptom distress as a consequence of conventional cancer treatments. The Ameliorative Model is most closely aligned to previous HBM research that has examined the impact of health beliefs on *sick role*

*behaviour*, which has been previously defined as any activity undertaken by an individual who is socially recognized as being ill, for the purposes of becoming well (Kasl & Cobb, 1966). Often, sick role behaviour occurs following the diagnosis of a disease or the prescription of conventional medical treatment. In this context, the Ameliorative Model examines how women with breast cancer respond to medically recognized side effects of conventional cancer therapies (e.g., fatigue, lymphadema) through the use of ACTs.

Although the majority of research that has utilized the HBM to examine sick role behaviour has focussed on individuals' compliance with conventional treatment recommendations (Abbott et al., 1996; Becker, 1974; Becker & Maiman, 1975; Kirscht & Rosenstock, 1977; Paskett, Carter, Chu, & White, 1990), the Ameliorative Model of ACT Use takes a less pejorative stance and examines the self-care activities of women who have chosen to use ACTs as a means of managing their symptom distress. Past research suggests that symptom distress is experienced by a considerable number of breast cancer survivors during and following their conventional cancer treatment (Cimprich & Ronis, 2001; Ehlke, 1988; Hoskins, 1997; Knobf, Cimprich, & Ronis, 2002; Love, Leventhal, Easterling, & Nerenz, 1989; Wainstock, 1991). Symptoms most prevalent within the breast cancer population include fatigue, nausea, vomiting, pain, and sleep disturbances (Ehlke, 1988; Hoskins, 1997; Lindley, Vasa, Sawyer, & Winer, 1998; Love et al., 1989; Oberst, 1991). Emotional distress has also been reported as being a serious consequence of the diagnosis and treatment of breast cancer (Mast, Lindley, Vasa, Sawyer, & Winer, 1998; Wainstock, 1991). These symptoms and distress are proposed within the Ameliorative Model to be motivating factors behind women's commitment to ACTs.

The Ameliorative Model of ACT Use and its related constructs are illustrated in Figure 2. While similar to the Preventive Model of ACT Use with regards to the inclusion of health beliefs and sociobehavioural variables, several key differences exist between the models. The following discussion focusses on these differences and provides empirical evidence of the specified causal relationships.

Foremost, the outcome construct within the Ameliorative Model, *Commitment to ACTs*, is hypothesized to be representative of women's ameliorative use of ACTs within the context of symptom distress secondary to conventional cancer treatment. Defined as the degree of effort and expense one is willing to extend in using ACTs, this construct reflects women's sick role behaviour following the diagnosis and treatment of breast cancer.

To capture the impact of symptom distress on women with breast cancer's commitment to ACTs, the central construct in the Ameliorative Model is the health belief, *Perceived Symptom Distress*. This construct, defined as the degree of discomfort felt in relation to the symptoms



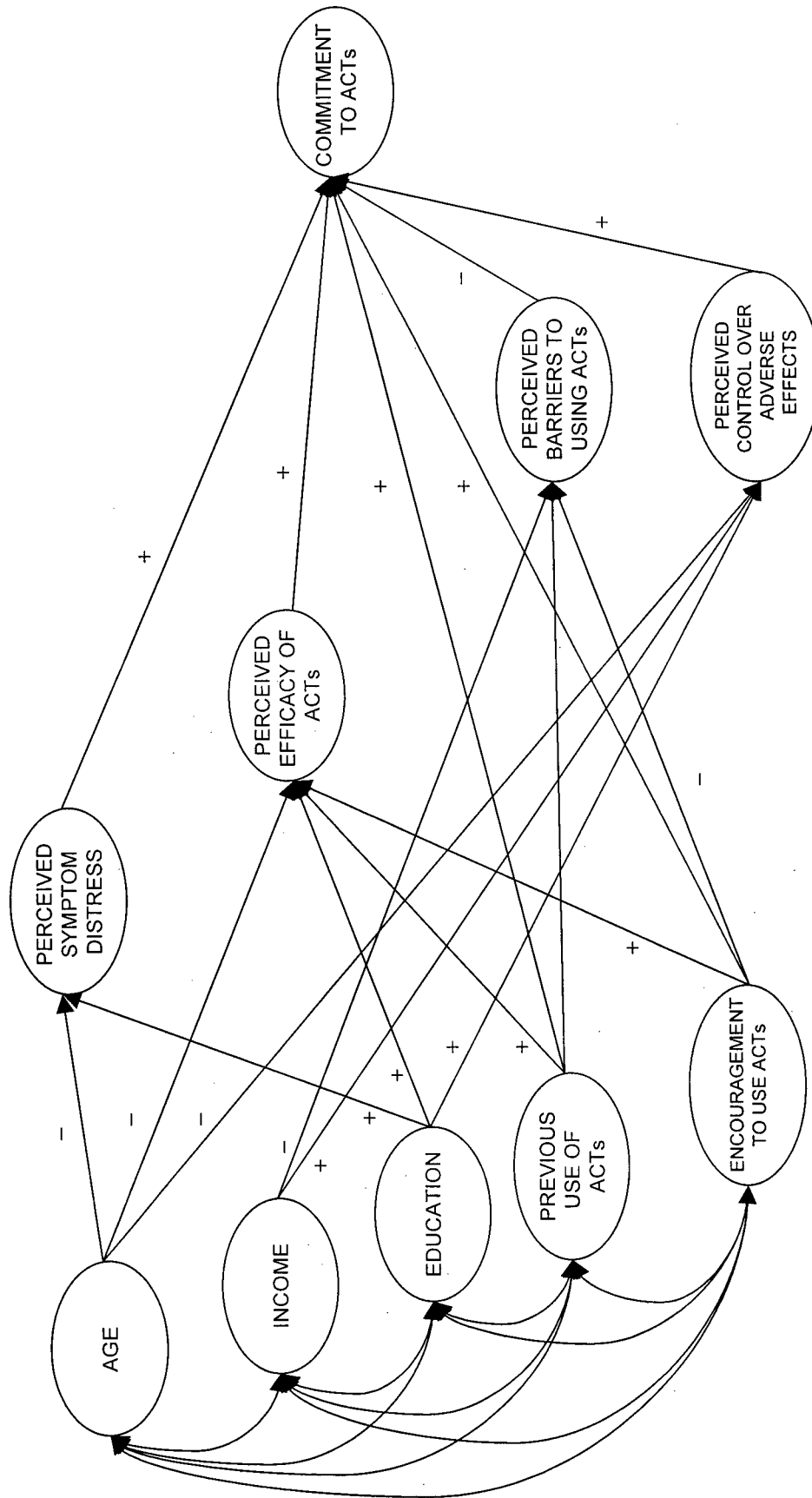


Figure 2. Ameliorative Model of Alternative/Complementary Therapy Use by Women Living with Breast Cancer

being experienced (McCorkle & Young, 1978), is analogous to the HBM concept of *Perceived Severity*. Previous research has suggested that perceived severity is a key predictor of sick role behaviour, more so than beliefs about perceived susceptibility (Sheeran & Abraham, 1995; Becker & Maiman, 1975; Kirscht, Becker, & Eveland, 1976). The importance of the perceived severity construct within models of sick role behaviour has been partially explained by individuals' ability to conceptualize the consequences of illness when they are experiencing symptoms (Janz & Becker, 1984). Perceived susceptibility may be of lesser importance within models of sick role behaviour because perceptions of risk become superfluous when individuals are confronted with symptoms or a disease. In other words, individuals who consider themselves to be sick and have been diagnosed with an illness may no longer perceive themselves to be at risk. Given these conjectures, the perceived susceptibility construct has been omitted from the Ameliorative Model of ACT Use.

Evidence for the potential relationship between *Perceived Symptom Distress* and *Commitment to ACTs* has been provided within the ACT cancer literature (Crocetti et al., 1998; M. Miller et al., 1998; Yates, 1991). For example, in one study of ACT use by breast cancer patients, physical and psychological distress was cited as the main reason for using ACTs (Crocetti et al., 1998). Recent intervention research on the effects of guided imagery on women's adjustment during conventional breast cancer treatment is also suggestive of a positive relationship between perceived symptom distress and commitment to ACTs (Kolcaba & Fox, 1999). As such, it is theorized within the Ameliorative Model of ACT Use that women who experience heightened perceptions of symptom distress are more likely to commit to ACTs than women experiencing few or no adverse effects from conventional breast cancer treatment.

Similar to the Preventive Model, *Commitment to ACTs* within the Ameliorative Model is hypothesized to be a consequence of two other health beliefs, *Perceived Efficacy of ACTs* and *Perceived Barriers to Using ACTs*. However, in the Ameliorative Model of ACT use, *Perceived Efficacy of ACTs* is defined as the degree of confidence one has in the ability of ACTs to address the adverse side effects of conventional treatment. The construct, *Perceived Barriers to ACT Use*, is defined as the deterrents of ACT use. The relevance of these constructs within models of sick role behaviour has been illustrated in a meta-analysis conducted by Janz and Becker (Janz & Becker, 1984), who found that perceived benefits and barriers were significant predictors of sick role behaviour in the majority of past research (Janz & Becker, 1984). Research on the use of ACTs within the general population has also revealed significant associations among the *Perceived Efficacy of ACTs* and *Perceived Barriers* constructs and the use of ACTs in the management of such symptoms as anxiety, headaches, and dermatitis (Furnham & Forey, 1994; Furnham & Smith, 1988). Given this evidence, it is theorized that women who consider ACTs to be effective in managing the side effects of conventional cancer

treatment and who perceive few barriers to ACT use are more likely to commit to ACTs than women who do not hold these beliefs.

Researchers have also implicated perceived control as being influential in decision making related to sick role behaviour, including the use of ACTs (Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Kirscht & Rosenstock, 1977). Within the Ameliorative Model of ACT Use, the control construct, *Perceived Control over Adverse Effects* is defined as the degree of control one has over the adverse effects of conventional cancer treatment. It is postulated that women who believe in their ability to control the side effects of cancer therapies and their subsequent symptom distress are more committed users of ACTs than women who do not consider symptom management to be within their control.

Like the Preventive Model of ACT use, health beliefs are postulated to mediate the effect of the sociobehavioural constructs of *Age*, *Education*, and *Previous Use of ACTs* on women's commitment to ACTs. Based on past breast cancer research, younger women are hypothesized to experience greater symptom distress than older women, hence motivating them to seek out alternative forms of symptom management (Love et al., 1989; Pozo et al., 1992; Wainstock, 1991). Younger women are also hypothesized to perceive ACTs as being more efficacious and to perceive greater control over the adverse effects of conventional cancer treatment. The remaining relationships among *Income*, *Education*, *Previous Use of ACTs*, and the HBM constructs are identical to those proposed within the Preventive Model, with the exception of the effect of *Education* on *Perceived Symptom Distress*. Previous research on the effect of education on symptomatology and distress in cancer patients has suggested that individuals who report a high level of education experience significantly greater levels of distress and difficulty as a consequence of their cancer treatment (Love et al., 1989). Given this finding, women with a higher level of education are predicted to experience greater perceived symptom distress than women reporting less education. The latent constructs of *Age*, *Income*, *Education*, and *Previous Use of ACTs* also are allowed to covary within the Ameliorative Model.

The last construct in the Ameliorative Model, *Encouragement to Use ACTs*, functions in the same manner as in the Preventive Model. The support received from significant others regarding the use of ACTs is hypothesized to affect women's perceptions of the efficacy of ACTs and perceived barriers to ACT use. As well, social influence is suggested to directly influence commitment to ACTs through the desire to meet the expectations of one's social network. The *Encouragement to Use ACTs*, sociodemographic factors, and the *Previous Use of ACTs* construct were permitted to covary.

### **The Restorative Model of Alternative/Complementary Therapy Use**

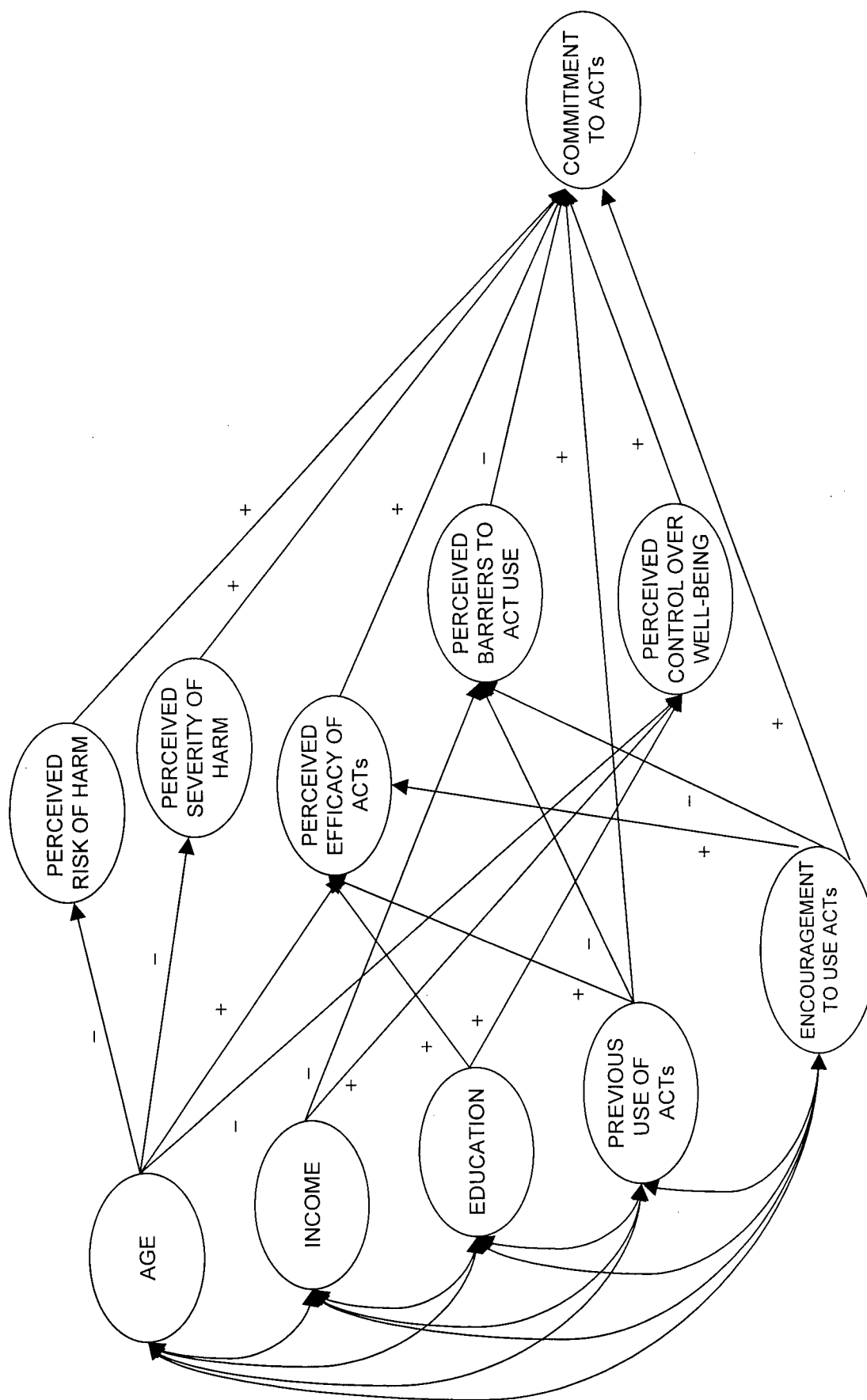
The final model to be tested in this study is the Restorative Model of ACT Use, which examines women's use of ACTs within the context of addressing non-specific concerns about

the state of their general well being following their breast cancer diagnosis. This model is closest in theory to past HBM research that has examined illness behaviour. As previously mentioned, illness behaviour refers to those actions undertaken in response to vague symptoms or health concerns of illness for the purposes of determining one's health status and identifying possible remedies for perceived distress (Kirscht, 1974). While the boundary between illness and sick role behaviour has been acknowledged to be indistinct at times, illness behaviour is specific to those situations in which the nature of the perceived symptom or health threat is ambiguous or the cause is unknown (Kirscht, 1974).

The HBM has been used sparingly in exploring illness behaviour, with the exception of research on clinic utilization (Berkanovic, Telesky, & Reeder, 1981; Kirscht et al., 1976; Leavitt, 1979). However, Kirscht (1974) recommended using the HBM to examine additional illness behaviour, including promptness or delay in seeking care and the use of "non-medically approved remedies". It is the latter issue that is of interest within the context of the Restorative Model of ACT Use.

In comparison to the Preventive and Ameliorative Models, the Restorative Model of ACT Use is unique in that it considers how women define their general well being following the diagnosis and treatment of breast cancer. Rather than reflect definitive perceptions of risk or symptom distress that are specific to the disease process, the Restorative Model examines the ambiguous threat of the cancer experience on well being. In contrast to previous research that has examined health behaviour from the perspective of illness (Kirscht et al., 1976; Leavitt, 1979), perceived threat to well being may occur in the absence of well-defined symptomatology. Previous research has shown cancer patients to be concerned about the generalized effect of cancer and conventional treatment on physical, emotional, and spiritual well being (Boon et al., 1999; Cassileth et al., 1984; Crocetti et al., 1998; Downer et al., 1994). According to Cassileth et al. (1984), individuals with cancer are particularly fearful of the effect of conventional cancer therapies on the "body's reserve" or immune system. In fact, using ACTs to "boost the immune system" is frequently cited by cancer patients as being one of the main reasons for using these types of therapies (Cassileth et al., 1984; Downer et al., 1994; Risberg et al., 1997; Yates, 1991). Research specific to women with breast cancer has also revealed concerns about the failure of conventional medicine to provide holistic care that considers not only the disease, but also emotional and spiritual well being (Boon et al., 1999; Brown & Carney, 1996). Given this context, the Restorative Model attempts to explain those actions undertaken by women in response to the perceived threat of the breast cancer experience to their general well being.

Figure 3 illustrates the Restorative Model of ACT Use. Similar to the Preventive and Ameliorative Models, the Restorative Model considers commitment to ACTs to be a consequence of key constructs from the HBM as well as selected sociobehavioural variables.



**Figure 3. Restorative Model of Alternative/Complementary Therapy Use by Women Living with Breast Cancer**

However, the Restorative Model is unique in several important ways. The following discussion highlights these differences and provides, where possible, empirical evidence of the specified causal relationships. Due to the limited number of studies that have tested the illness behavioural model, evidence is drawn primarily from the care-seeking literature.

As in the previous two models of ACT use, the outcome construct *Commitment to ACTs* is defined as the degree of effort and expense one is willing to extend in using ACTs. This construct, however, is operationalized within the context of women's illness behaviour following the diagnosis and treatment of breast cancer. Specifically, women's commitment to ACTs in the Restorative Model reflects women's attempts to define and restore their health in the face of a cancer experience.

Previous research examining women's care-seeking behaviour in response to breast symptoms has suggested that a variety of cognitive factors are associated with the intent to seek care. These factors include fear related to breast symptom discovery, perceived seriousness of symptoms, and knowledge of cancer (Facione, Dodd, Holzemer, & Meleis, 1997; Facione & Giancarlo, 1998; Lauver & Angerame, 1993; Worden & Weisman, 1975). Anxiety has also been positively associated with prompt care-seeking behaviour in women who have detected breast abnormalities, with women reporting a high level of anxiety being more likely to seek care than women with minimal anxiety (Lauver & Angerame, 1993). These findings are suggestive of a positive association between perceptions of threat and care-seeking behaviour. Some support for the role of perceived threat of illness in seeking care has been also provided by the limited research that has used the HBM to explore illness behaviour (Kirscht et al., 1976; Leavitt, 1979).

Given this evidence, the constructs *Perceived Risk of Harm* and *Perceived Severity of Harm* are included in the Restorative Model of ACT Use. Analogous to the HBM constructs of perceived susceptibility and perceived severity, these constructs reflect women's perceptions of harm resulting from their experiences with breast cancer. *Perceived Risk of Harm* is defined as the degree to which one believes it is likely that their well being has been, or will be, harmed by their breast cancer experience. The concept of "harm" is derived from stress and coping theory, where harm is conceptualized as being either damage or loss (Lazarus & Folkman, 1984). Not only is physical well being affected by the breast cancer experience, but so too is a woman's psychological, social, and spiritual well being. Implicit within the concept of harm is the notion of threat, reflecting the future implications of the losses in one's life (Lazarus & Folkman, 1984). In the Restorative Model of ACT Use, women who feel it is very likely that their well being has been, or will be, harmed by their cancer experience are theorized to use ACTs as a means of restoring or reducing the risk of harm to their well being. Accordingly, women who perceive

themselves to be at high risk of harm will demonstrate greater commitment to ACT than will women with low perceived risk of harm.

*Perceived Severity of Harm* is defined as the perceived degree of personal threat felt in relation to one's well being as a consequence of the breast cancer experience. This construct represents women's evaluations of how seriously their physical, psychological, social, and spiritual well being has been harmed by their diagnosis and conventional cancer treatment. Women who believe that their well being has been, or will be, seriously damaged by their breast cancer experience are postulated to use ACTs as a means of restoring or protecting their well being. A positive, direct relationship between *Perceived Severity of Harm* and *Commitment to ACTs* is thus theorized within the Restorative Model of ACT Use.

Research exploring illness behaviour also has demonstrated the significant influence of both beliefs about efficacy of treatment and barriers to care on the decision to seek conventional medical care (Kirscht et al., 1976; Leavitt, 1979). For example, in Kirscht et al.'s (1976) examination of the use of medical services by low-income mothers, beliefs about the efficacy of medical care were positively related to clinic utilization. Within the literature examining women's responses to breast symptoms, beliefs about the effectiveness of cancer treatment and barriers to care are also associated with care-seeking behaviour (Facione & Dodd, 1995; Facione et al., 1997; Worden & Weisman, 1975). In light of this research, it is probable that these beliefs may also influence decisions to use ACTs. The constructs *Perceived Efficacy of ACTs* and *Perceived Barriers to ACT Use* are therefore included in the Restorative Model of ACT Use. Within this model, *Perceived Efficacy of ACTs* is defined as the degree of confidence one has in the ability of ACTs to enhance or protect one's physical, psychological, social, and spiritual well being. *Perceived Barriers to ACT Use* is defined as the negative costs and constraints associated with using ACTs. It is postulated that women who hold positive beliefs in the efficacy of ACTs to address their concerns about well being and who perceive few barriers to accessing these types of therapies are more committed to using ACTs in comparison to women who hold opposing beliefs.

Few studies in the care-seeking literature have examined the potential relationship between control and the decision to seek conventional medical attention. One exception has been Timko (1987), who used the theory of reasoned action to examine women's intentions to delay seeking care in response to a hypothetical breast symptom. Women who perceived themselves as having greater control over their own health and lives were found to have greater intention to delay than women who believed that they had less control. While this relationship appears to contradict the positive associations proposed in previous models of ACT use between perceived control and health behaviour, this finding must be considered within the context of the conventional health-care system. Delay to seek care in Timko's (1987) study

referred to accessing conventional medical care and did not encompass therapies that might be obtained from other sources or self-care activities. For example, in Facione and Giancarlo's (1998) narrative analysis of women's care-seeking behaviour following detection of a breast symptom, some women used ACTs rather than consult a conventional medical provider. Given that a positive relationship between *Perceived Control* and *Commitment to ACTs* may exist within the context of illness behaviour, the construct *Perceived Control over Well Being* is included in the Restorative Model of ACT Use. Defined as the degree of control one has over the maintenance and improvement of well being, women who believe that they have control over their well being are theorized to have greater commitment to ACTs than women who perceive themselves to have little control. This relationship suggests that individuals who believe that they can influence their well being are more likely to enact health behaviours, such as using ACTs.

The indirect relationships among sociobehavioural variables and women's commitment to ACTs are similar to those discussed in the Preventive and Ameliorative models. Due to the paucity of research examining the associations among health beliefs and personal characteristics within the context of illness behaviour, the proposed relationships are primarily drawn from previous preventive and sick role behaviour research (Champion, 1994; Nakazono et al., 1997; Stein et al., 1992; Wainstock, 1991). The assumption is thus made that the effects of *Age*, *Income*, and *Education* on health beliefs are consistent across the Preventive, Ameliorative, and Restorative Models. Younger women are proposed to feel more threatened by the breast cancer experience, to perceive ACTs as being more effective in addressing their concerns about well being, and to consider themselves as having greater control over their well being. Women with a high level of income are also hypothesized to perceive fewer barriers to accessing ACTs and to experience greater perceived control over well being. Educational level is further postulated to be positively related to perceived efficacy of ACTs and perceived control over well being. Overall, women who are young, educated, and affluent are committed to ACTs in an attempt to restore their well being following the diagnosis and treatment of breast cancer. The constructs of *Age*, *Income*, and *Education* are also permitted to covary in the model.

Also included in the Restorative Model of ACT Use are the constructs *Previous Use of ACTs* and *Encouragement to Use ACTs*. Some evidence exists in the care-seeking literature to support potential associations between prior experiences, social support, and illness behaviour (Bottorff et al., 1998; Facione & Dodd, 1995; Facione et al., 1997; Facione & Giancarlo, 1998; Lauver & Angerame, 1993). For example, Facione et al. (1997) found that health care utilization habits are significantly related to help-seeking intentions related to breast symptoms. The importance of receiving social sanctions from significant others prior to seeking care for breast symptoms has also been highlighted within specific cultural groups (Bottorff et al., 1998). Direct



effects are thus proposed within the Restorative Model between *Previous Use of ACTs* and *Encouragement to Use ACTs* and *Commitment to ACTs*. Women who have used ACTs prior to diagnosis and who have received support from family and friends to pursue ACTs are presumed to be more committed to ACTs, more so than women without previous experience or support. The previous use and encouragement constructs are also proposed to have similar indirect effects on selected health beliefs (i.e., perceived benefits and barriers), as proposed in the preventive and ameliorative models. *Previous Use of ACTs* is allowed to covary with the demographic characteristics, as well as with the *Encouragement to Use ACTs* construct.

## **Chapter Summary**

This chapter has described in detail the three proposed models of ACT use by women with breast cancer. Using the HBM as a guiding theoretical framework, these models conceptualize ACT use within the context of preventive, ameliorative, and restorative health behaviour and as a consequence of key health beliefs, sociobehavioural factors, and demographic characteristics. The following chapter provides a discussion of the research methods, the instrumentation of the study constructs, and the data analyses.

## Chapter 4

# Methods and Procedures

### Research Design

This research study utilized a retrospective, correlational survey design to collect data on the use of alternative/complementary therapies (ACTs) by women living with breast cancer. Self-report questionnaires were mailed to a random sample of women with breast cancer living in British Columbia. Structural equation modelling (SEM) was used to test three proposed theoretical models of ACT utilization. In the following sections, a description is provided of the sampling and recruitment strategies, operationalization of the constructs of interest, and data collection and analysis methods. A discussion of the ethical considerations of the study concludes this chapter.

## Sample

### Setting and Participants

The population of interest in this study was women living in British Columbia that had been recently diagnosed with breast cancer and were 18 years or older. The sample was limited to women who had been diagnosed with stage I or II breast cancer and excluded women who had experienced a recurrence of breast cancer.<sup>17</sup> Individuals with advanced cancer were ineligible because of the possible introduction of bias or unmeasured sources of confounding effects in relation to their use of ACTs (Cassileth et al., 1984; Truant & Bortoff, 1999). In addition, only women diagnosed between July 1, 1997 and December 31, 1998 (9 to 29 months

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<sup>17</sup> Because the BC Cancer Registry does not record all cancer diagnoses (i.e., skin cancer) and is limited to British Columbia residents, women who had been diagnosed with other forms of cancer were not excluded from the initial sampling frame. Instead, women were asked in the questionnaire to indicate if they had ever been diagnosed with another type of cancer other than breast cancer.

after diagnosis at time of sampling) were recruited to limit recall bias and to access women when they were most likely to be using ACTs (Truant & Bottorff, 1999). To prevent too much research burden for the potential participants, women who had participated in a national complementary therapy survey of individuals living with cancer (undertaken by the National Cancer Institute of Canada's Sociobehavioural Cancer Research Network [SCRN]) and a genetic testing for breast cancer risk study (Bottorff et al., 2002) were also excluded from the sampling frame.<sup>18</sup>

Women were recruited through the British Columbia Cancer Registry, a provincial registry that records approximately 95% of all new cancer diagnoses (excluding non-melanoma skin cancer) in British Columbia. Because staging information was complete for only those women referred to a British Columbia Cancer Agency centre or clinic, sample selection was further limited to women who had received conventional cancer treatment and were referred to the British Columbia Cancer Agency.<sup>19</sup> A small subset of women were found to fit the eligibility criteria but had been entered twice in the Registry because of having more than one breast cancer diagnoses (i.e., bilateral breast cancer diagnosed on the same and different dates). For women diagnosed with bilateral breast cancer on the same date, the case that was entered first in the registry was used. For women with bilateral breast cancer diagnosed on different dates, the case with the earliest diagnosis date was used in the dataset. A total of 1,997 women met the eligibility criteria and comprised the population from which the random sample was generated (see Figure 4 for further details of the development of this final dataset). Additional inclusion and exclusion criteria that could not be determined prior to the random selection are provided on Table 5.

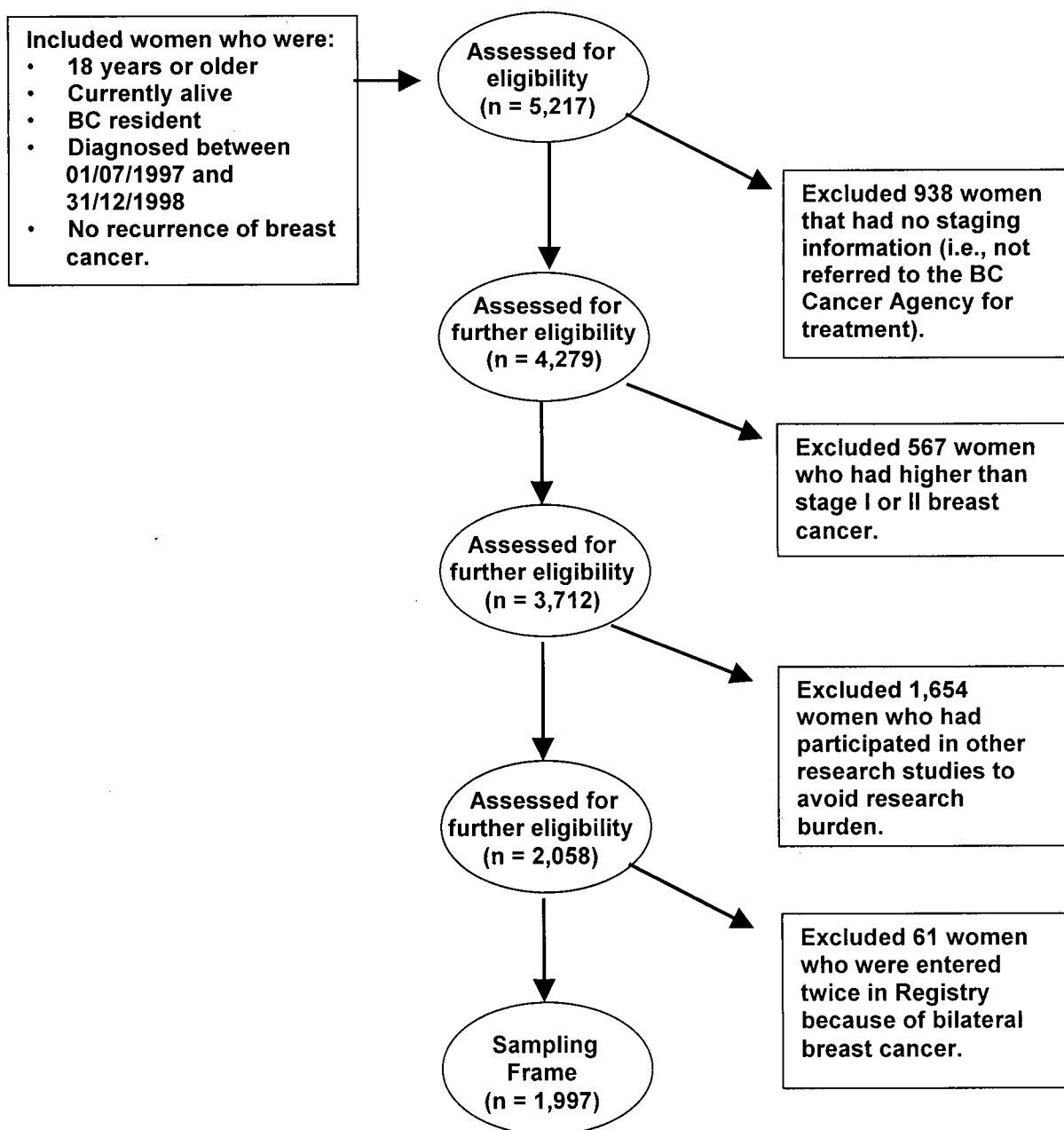
### **Sample Size**

Decisions related to sample size are important to researchers who must balance limited resources against findings that accurately represent the population of interest. Too small a sample may result in questionable conclusions while too large a sample causes unnecessary waste and subject burden. Unlike multivariate statistical tests, there are no satisfactory approaches for determining an adequate sample size for research using SEM techniques. The following discussion provides a brief overview of current trends in sample size estimation within

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<sup>18</sup> 1,654 women with breast cancer had been randomly selected from the BC Cancer Registry and recruited for the Sociobehavioural Cancer Research Network (SCRN) and Bottorff et al. (2002) studies and were excluded from this study's sampling frame. It is important to note that the SCRN survey was not limited to breast cancer but included other cancer diagnoses.

<sup>19</sup> The BC Cancer Registry estimates that between 70% to 90% (depending on stage of disease) of women diagnosed with breast cancer in British Columbia are referred to the BC Cancer Agency for treatment (W. Robb, personal communication, July 24, 2001; T. G. Hislop, personal communication, July, 26, 2002).



**Figure 4. Flow diagram of the development of the final dataset prior to random selection**

SEM research. Given the design of this study, sample size calculations for sample survey research provided preliminary estimates of the necessary sample size.

In survey research, a sample size is sought that provides an estimate of a population value (e.g., means, proportions) within a certain degree of precision. Typically, the degree of precision expected within survey research is within  $\pm 5\%$  or less of population estimate. Despite this margin of error, a sample may be selected that is in error by more than the specified level of precision. Researchers are thus compelled to state how confident they are that a sample

estimate falls within the selected margin of error of the true population parameter. In survey research, confidence levels ranging from 95% to 99% have been accepted as illustrating reasonable confidence in the data (Lemeshow, Hosmer, & Lwanga, 1990). More specifically, a 95% confidence interval would suggest that there is only a 5% probability that a sample estimate is beyond  $\pm 1.96$  standard errors of the population parameter, or alternatively, a 95% probability that the sample estimate is within  $\pm 1.96$  standard errors of the population parameter.

For survey research concerned with population proportions, the standard error is approximately equal to the standard deviation of the proportion ( $\sqrt{pq/n}$ , where  $p$  is the population parameter,  $q$  is  $1-p$ , and  $n$  is the sample size). If, for example, we wanted the sample estimate to fall within  $\pm 5\%$  of the population proportion with 95 percent probability, then:

$$[1] \quad 0.05 = 1.96 \sqrt{pq/n}$$

This leads to the following equation to solve for  $n$ :

$$[2] \quad n = \frac{1.96^2 pq}{.05^2}$$

When  $p$  is unknown, which frequently occurs in studies exploring innovative areas of research, a population estimate of maximum variability should be used (Kalton, 1983; Lohr, 1999). Because  $pq$  reaches its maximal value when  $p = .50$ , this value will provide a conservative estimate of sample size. Given this, we can solve equation 2, with  $n = 384$ .

Equation 2 is considered to be an appropriate estimate of sample size when the population is large. However, when the population size is small, the *finite population correction* (FPC) term should be considered.

$$[3] \quad \text{FPC} = \frac{(N-n)}{(N-1)}$$

The FPC adjusts for population size and provides a more precise estimate of sample size that reflects the finite nature of the population (Kalton, 1983). Equation 2 is thus transformed to the following:

$$[4] \quad n = \frac{1.96^2 pq \cdot N}{.05^2(N-1) + 1.96^2 pq}$$

Given that the estimated population size  $N$  for women diagnosed with breast cancer between July 1, 1997 and December 31, 1998 would be approximately 3,900 (NCIC, 1998), then  $n = 350^{20}$ .

The degree of non-response anticipated in a survey must also be considered when determining the required sample size. For example, if a response rate of 70% were predicted, then a selected sample size needed to generate the achieved sample of 350 would be 500. An

<sup>20</sup> Sample size estimates were calculated prior to the commencement of the study and made use of predicted population estimates.

additional consideration in the calculation of sample size for survey research is the design of the survey. For simple random sampling designs, such as used in this study, the design effect is equal to 1.0.

Turning towards this study, the estimate of primary interest was the proportion of women with breast cancer who were using ACTs. Given a margin of error of  $\pm 4.5\%$ , a confidence interval of 95%, and a conservative population estimate of 50%, a sample of 475 women was required. Because the population of women from which the sample was selected was relatively small (i.e.,  $N = 3,900$  according to National Cancer Institute of Canada, 1998) the FPC term reduced the sample size to 423 women. With previous survey research in this population resulting in response rates of approximately 65%, it was projected that a total sample of 650 women should be selected from the BC Cancer Registry.

Although the previous discussion provides a preliminary suggestion of the sample size required to estimate the proportion of women with breast cancer who used ACTs, it fails to consider the complexity posed by the three structural equation models under question. Not only did these models involve the estimation of numerous parameters, but the goodness of fit of each model was also tested. To date, no statistical technique has been developed that has achieved consensus as being an appropriate estimator of required sample size for SEM research.

Intuitively, the larger the sample, the more confident one can be that a model accurately represents the population. As a model increases in complexity with regards to the number of observed variables and covariances among variables, the sample size must also increase for confidence in the data to be maintained. The statistical theory that underlies SEM, however, is asymptotic in nature. That is, the sample from which confident conclusions can be drawn is assumed to approach infinity (Tanaka, 1987). SEM is thus considered to be a large sample technique. Problems arise, however, when one considers the interplay between large samples and statistical power in testing SEM (Hayduk, 1987). Simply put, if a sample is too large, trivial deviations between observed and estimated values will result in the rejection of a model that in fact "fits" the data. Too small a sample will mask errors and lead to the inappropriate acceptance of a model.

Simulation research on the effect of sample size on structural equation models has revealed the importance of other model characteristics in determining the required sample size for SEM research. In a Monte Carlo study of maximum likelihood confirmatory factor analysis, Anderson and Gerbing (1984) found significant effects on the variance of goodness-of-fit measures related to the number of indicators per latent construct, the number of factors, and

increasing non-normality. Hu and Bentler (1995) also suggested that estimation methods and violations of multivariate normality assumptions might further influence the power of SEM analyses. Tanaka's (1987) Monte Carlo examinations of the effect of sample size on normal and non-normal estimation methods supported the importance of the ratio of subjects to the number of estimated parameters in determining sufficient sample size.

Despite the extensive research that has been conducted on sample size determination in structural equation modelling, there exists no definitive answer to the question posed by Tanaka (1987) "How big is big enough?" Rules of thumbs, such as having five subjects per number of free parameters when using normal estimation methods and ten subjects per number of free parameters when using arbitrary estimation methods (Bentler & Chou, 1987) or a minimum sample size of 200 when using maximum likelihood estimation (Boomsma, 1983) provide researchers with approximations of required sample size. Given this uncertainty and taking into consideration the nature of the models to be tested in this study, the decision was made to use the sample size estimate provided by the population survey method. With over 2,500 new cases of breast cancer diagnosed each year in British Columbia, the recruitment of 423 women with breast cancer was feasible and appropriate.

### **Recruitment of Participants**

Of the total population who met the study criteria ( $N = 1,997$ ), a simple random sample of women with breast cancer was selected from the British Columbia Cancer Registry on November 17, 1999. Cases were randomly selected from the population dataset using SPSS select case command (random sample). Previous survey research within the breast cancer population in British Columbia has produced response rates between 60% and 70%.<sup>21</sup> Given this predicted response rate and the possible loss of participants as a consequence of the mailed survey protocol, language difficulties, and advanced disease or death, 650 women were randomly selected from the provincial cancer registry.

Following selection from the cancer registry, the status of the potential respondents and the appropriateness of their inclusion in the study were confirmed through their family physicians (see Appendix 1). Women were deemed ineligible for study participation by family physicians for a variety of reasons, including being unable to participate in survey research because of poor physical or mental health ( $n = 15$ ) or language ability ( $n = 1$ ), being uninterested in the study ( $n = 3$ ), or having moved out of the province ( $n = 1$ ). Other reasons included the women being involved in other research studies ( $n = 1$ ) or the physician disapproving of the study recruitment strategy ( $n = 1$ ). Women who were deemed ineligible by

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<sup>21</sup> T. Greg Hislop (personal communication, June, 23, 1999).

their family physician were removed from the study database. A letter of invitation and a consent form was then mailed to all remaining eligible women (see Appendices 2 and 3).

The representativeness of the sample with regards to selected demographic characteristics (i.e., age, marital status, education, ethnicity, and income) was to be determined by comparing the study sample with data from the British Columbia Cancer Registry. This comparison was not possible, however, because of the limited demographic information collected from women treated for breast cancer by the British Columbia Cancer Agency. A general comparison of demographic and disease characteristics of non-respondents and respondents was conducted and provided insight into the generalizability of the study findings.

### Survey Completion Rates

Table 3 illustrates the completion rates for the study sample. A total of 334 completed surveys were returned. The gross completion rate, comparing the 334 completed surveys to the 650 women randomly selected from the BC Cancer Registry was 51.4%. However, of the original sample of women, 73 women (9.8%) were ineligible because of refusal by their family physician, being unable to read English, having moved outside of British Columbia, or having died. Further, nine letters of invitation were returned without forwarding addresses. Exact statistics for ineligibility are provided on Table 4.

**Table 3. Survey Completion Rates**

Type of Rate	Comparison	Numerator/ Denominator	Rate (%)
Gross Completion Rate	All completions / All women in the sample	334/650	51.4%
Most reasonable completion rate (conservative)	All completions/ All possible eligibles <sup>a</sup>	334/577	57.9%
Most reasonable completion rate (liberal)	All completions / All eligibles <sup>b</sup>	334/464	72.0%

<sup>a</sup>Includes 113 no contacts in which eligibility was not determined

<sup>b</sup>Excludes 113 no contacts in which eligibility was not determined

**Table 4. Reasons for Ineligibility**

Reasons	Frequency (%)
Physician declined	24 (7.2)
Language issues	24 (7.6)
Died	9 (2.7)
Letter of invitation returned	9 (2.7)
Moved out of the province	7 (2.1)

Note. N = 73



Accordingly, a more reasonable but conservative estimate of the completion rate would be 57.9% (334 completed surveys / 577 all possible eligibles). Table 5 provides a complete list of all inclusion and exclusion selection criteria for the study.

**Table 5. Inclusion and Exclusion Selection Criteria**

• Breast primary site of cancer	• No participation in SCRN study and Bottorff et al. (2002) studies
• >17 years of age at diagnosis	• No refusal by family physician
• Women currently alive	• English language ability (reading)
• BC resident at time of diagnosis and survey completion	• Locatable through postal service
• Stage I/II breast cancer	• Informed consent provided
• No reported breast cancer recurrence	• Diagnosed between July 1, 1997 and December 31, 1998
• Received cancer care through BCCA	

Of the remaining 577 eligible women, 97 women declined to participate in the study for a variety of reasons (see Table 6 for exact statistics), including being not interested, too ill, too busy, and on holidays ( $n = 4$ ). Seven women believed that their participation was not appropriate because they "no longer had breast cancer" or "had no other treatment" than conventional medical care for their breast cancer. Fifteen women declined to participate without providing specific reasons. Consent to participate was received from 33 women who did not return their completed questionnaire despite multiple follow-up attempts by telephone.<sup>22</sup>

Despite multiple attempts by telephone<sup>23</sup> and one follow-up letter, 113 women provided no response to the letter of invitation to participate in the study. If it was assumed that these women were also ineligible for study participation, a more liberal completion rate of 72.0% is achieved. Thus, the actual completion rate of the questionnaire is between 51.4% and 72.0%, with at least one of every two eligible participants being successfully surveyed. A flow diagram of the recruitment process and response rates is provided in Figure 5.

**Table 6. Reasons for Non-Participation of Eligible Women**

Reasons	Frequency (%)
<b>Declined consent</b>	
Not interested	33 (10.4)
Too ill	24 (7.6)
Too busy	14 (4.2)
Not appropriate	7 (2.1)
Out of town	4 (1.3)
No reason given	15 (4.5)
<b>Consent given</b>	
Survey not returned	33 (10.4)
<b>No Response</b>	113 (33.8)

Note.  $N = 243$

<sup>22</sup> A minimum of three and a maximum of six attempts were made by telephone at a range of times throughout the day and evening.

<sup>23</sup> See above footnote.

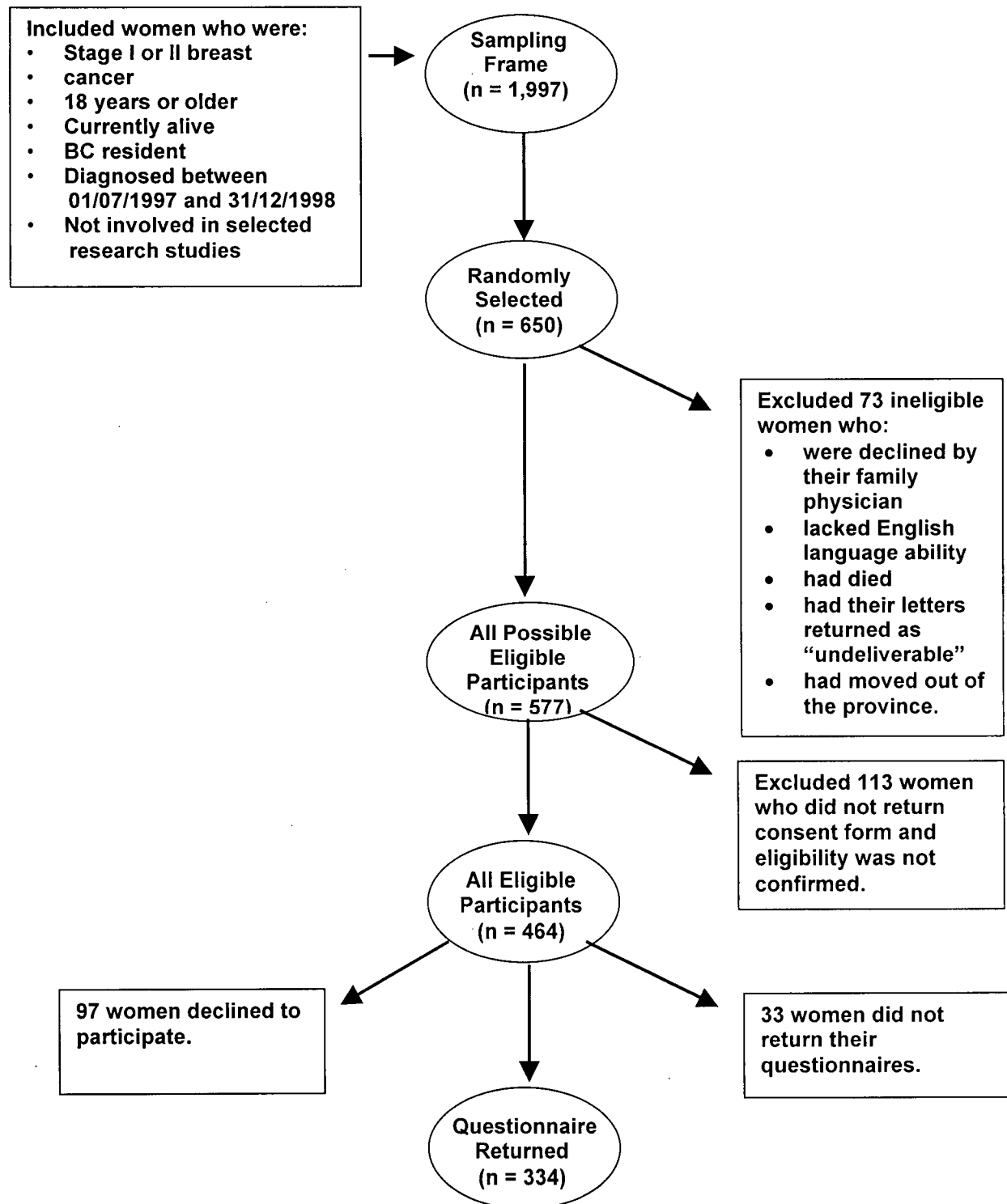


Figure 5. Flow diagram of the recruitment process

## Data Collection

The data were collected through mailed self-administered questionnaires. The following section describes the implementation of the mailed survey based on a modified version of Dillman's (1978) Total Design Method. A brief description of the pilot test of the study questionnaire is provided in addition to a full discussion of the operationalization of the study constructs.

### Modified Total Design Method

The Total Design Method (TDM) (Dillman, 1978) was developed to increase response rates to mail surveys and to address the reasons why people do and do not respond to questionnaires. Past survey research using the TDM has reported an average response rate of 74%. Drawing from the theoretical perspective of social exchange theory, the TDM proposes that participants in survey research are motivated by whether they expect the rewards of responding to a survey to exceed the costs of participation (Dillman, 1978). The TDM attempts to reward potential respondents by giving verbal appreciation, showing positive regard, and making the questionnaire interesting. Making the task appear manageable, preventing embarrassment, and eliminating any direct monetary expenses reduce the costs of participating in a survey. The development of trust is also important to the success of the TDM. Trust between the participant and the researcher is achieved partly through the development of legitimacy by identifying with a known organization and by providing a token of appreciation in advance.

Addressing these issues, however, is not sufficient to guarantee high response rates. The administration of a survey must be carefully organized and detailed to ensure that questionnaires and follow-ups are received in a timely and accurate manner. Dillman (1978) recommended the following four step-process, which is discussed within the context of the completed study.

Following receipt of each woman's signed consent form (described in the above section on patient recruitment), the first mail-out occurred, consisting of a cover letter (see Appendix 4), a study questionnaire (see Appendix 5), a token of appreciation (i.e., non-medicinal herbal tea bag), and a stamped return envelope. In the personalized cover letter, the women were thanked for agreeing to participate and provided another brief explanation of the study. The women were encouraged to complete and return their questionnaires via the self-addressed, stamped envelope within the next few days. The inclusion of an herbal tea bag was used as a token of appreciation and as an incentive for women to take a moment to complete the questionnaire.

After the first mailing, Dillman (1978) recommended sending a follow-up letter to remind potential participants about the questionnaire and the importance of their participation in the survey. According to Dillman (1978), follow-up mailings hold the potential to increase the

response rate two-fold. To increase the personal nature of the reminder and to answer any questions women had regarding the questionnaire, a maximum of six attempts were made to contact by telephone all women who had not returned their survey within two weeks of the original mailing. Dillman (1978) had noted the effectiveness and appropriateness of telephone contact for follow-up. Women who did not want to participate in the study were thanked for their time and assured of no further contact.

Four weeks following the original mailing, all non-respondents (irrespective of whether telephone follow-up contact had been made) were sent a follow-up letter (see Appendix 6) restating the invitation to participate. The cover letter emphasized the importance of each participant to the success of the survey and the value of their response. A contact telephone number was provided for those individuals requiring a replacement questionnaire. While Dillman (1978) suggested including a second survey in the package to replace original questionnaires that had been lost or misplaced, this step was omitted because of financial and environmental concerns.

Dillman (1978) recommended that a third follow-up, in the form of a registered letter, be sent to all non-respondents seven weeks following the original mail-out. This final step was not carried out because of concerns by the British Columbia Cancer Agency Clinical Investigation Committee regarding the potential "harassing" nature of this contact.

A further modification to the TDM was the addition of follow-up phone calls to clarify missing data following the receipt of the completed questionnaires. The respondents were asked at the end of the questionnaire whether they would agree to being contacted by the principal investigator to clarify missing information on their survey. Five women refused any further contact. Initially, a total of 188 women returned questionnaires with missing data, six of which had such extensive missing data ( $> 20$  items), that the decision was made to not pursue follow-up. Successful follow-up of missing data was completed with 159 women (84.6% of surveys with missing data). Follow-up was unsuccessful with 27 women, of which 19 were unable to be contacted despite repeated attempts (mean number of attempts = 2.7 times), four were too sick or had died, and four had telephone numbers that were no longer in service.

### **Pilot Testing**

A pilot study was conducted to evaluate the appropriateness, feasibility, and acceptability of the study questionnaire and planned data collection protocols. Quantitative and descriptive data were collected to address the following research questions: (1) Recruitment: Was the modified TDM for mailed surveys appropriate and feasible for this sample of women? What response rate could be expected? (2) Data Collection: Was the questionnaire readable and understandable by the participants? How long did it take the women, on average, to complete the questionnaire?

Twenty-five women were selected to take part in the pilot study in numeric order (1 through 25) from the randomly selected sample of the provincial cancer registry. As in the full study, letters of explanation were sent to family physicians to determine the women's eligibility. Consent was also sought from all participants before the distribution of the pilot study questionnaire. Once consent was gained, the modified TDM for mailed surveys was implemented as previously discussed. A one-page survey assessment form (see Appendix 7) was also included in the research package to allow participants to evaluate the questionnaire and study protocols.

A total of 13 women participated in the pilot study, resulting in a response rate of 52.0%. Of the 12 women who did not participate, 5 women (20.0%) were too ill or had died, 5 women (20.0%) did not respond following repeated attempts to contact them, one woman had moved out of the province, and one woman reported being "not interested". On average, it took participants 32.3 minutes (SD = 10.1) to complete the questionnaire. Several revisions were made to the questionnaire based on the women's comments and suggestions. These revisions are discussed in greater detail in the following sections: Encouragement to Use ACTs Scale (p. 85); Perceived Risk of Harm Scale (PRHS) (p. 87); and Perceived Efficacy of ACTs Scale (PEACTS) (pp. 89).

### **Operationalization of Study Constructs**

The study questionnaire was comprised of a number of self-report scales and items that, for the most part, were modified from scales used in previous social science research with cancer populations and that had sound psychometric properties. The majority of the scales used close-ended questions with Likert-type responses. The questionnaire was 25 pages long. A complete list of all scales and items used in the final questionnaire developed following the pilot study is found in Table 7.

In developing a study questionnaire that incorporated modified and investigator-developed scales and items, the question of validity and reliability arose. Validity is described as the "fit" between a construct of interest and the true score on a corresponding measure or instrument (Knapp, 1998). In contrast, reliability is the corresponding fit between the true score, which itself is a theoretical entity, and the observed score (Knapp, 1998). Most often, reliability is considered to be an estimate of the consistency or variability of a measurement. Several steps were taken to ensure the reliability of the survey and its corresponding scales. Foremost, wherever possible, multiple rather than single indicators were used to operationalize the study constructs. According to MacCallum (1995), multiple indicators are preferred in structural equation modelling as they better define the constructs and limit the biases in parameter estimates caused by measurement error. To determine the internal consistency of the scales with multiple indicators and the average inter-item correlations, reliability estimates (i.e.,

Cronbach's alpha) were calculated. Confirmatory factor analyses were also conducted prior to beginning the structural equation modelling to ensure the dimensionality of the study measures and the appropriate loading of the indicators on their corresponding constructs.

### Demographics

The sociodemographic and disease characteristics of the participants were assessed with 12 items, using a variety of open- and closed-ended formats (see Table 7). Demographic characteristics that were measured included age, marital status, ethnic/cultural background (open-ended), level of education, and total household income. The majority of demographic items were based on items from the National Population Health Survey, 1994-995 (Statistics Canada, 1995). Demographic variables used as measures in the three models of ACT use are described in greater detail below.

For the study construct *Age*, respondents were asked to report their date of birth. This value was subsequently subtracted from the date on which the questionnaire was received, providing an approximate measure of age in years at time of data collection. This continuous variable (AGE) was used as an indicator of the construct *Age*.

The latent construct, *Income*, was assessed by asking respondents, "What is your best estimate of the total income, before taxes and deductions, of your household, from all sources, in the past 12 months?" Responses ranged from 1 = "less than \$10,000" to 10 = "\$100,000 or more" (see Table 7). Responses for "*no response*" and "*refused to answer*" were coded as missing values. This categorical variable (TOTINC) was used as an indicator of the construct *Income*.

*Education* was measured by responses to the question, "*What is the highest level of education that you have received?*" The responses were coded from 1 = "*grade 8 or less*" to 12 = "*earned doctorate*", with no response being coded as a missing value. This variable (EDUCATE) was used as an indicator of the latent construct *Education*.

Disease characteristics measured included date of breast cancer diagnosis, date of recurrence (if applicable), other cancer diagnoses, and conventional breast cancer treatment history, including surgery type, chemotherapy, radiation, and hormone therapy (see Table 7). Women were also asked to report whether they had completed conventional cancer treatment at the time of survey completion.

### Encouragement to Use Alternative/Complementary Therapies

The construct, *Encouragement to Use ACTs*, was assessed with the modified Encouragement to Use Alternative Cancer Therapies Scale (Yates et al., 1993). This three-item scale was originally developed to assess the degree to which cancer patients were encouraged by others to use alternative cancer therapies. Conceptualized as representing the social pressure associated with using ACTs, respondents were asked whether their family, friends,

and people important to them had tried to convince them to use ACTs. Respondents were presented with a four-point Likert-type response format (1 = "Very true" to 4 = "Not true at all"). Inter-item correlations among scale items were high, with Kendall *Tau B* correlations<sup>24</sup> of at least 0.37 (Yates et al., 1993).

Revisions to the Encouragement to Use Alternative Cancer Therapies Scale were undertaken by Balneaves et al. (1999) to increase the comprehensiveness of the instrument. As a consequence of the redundancy between items assessing support received from family and friends and that received from "people important to them," the latter item was omitted from the scale. Two items were added to the scale to assess the potential encouragement received from the biomedical community. These items included, "*My doctor has encouraged me to use alternative/complementary therapies*" and "*Other health professionals have encouraged me to use alternative/complementary therapies*". The response format was also revised to a five-point scale (1 = "Strongly disagree" to 5 = "Strongly agree").

In this study, additional revisions were made to the Encouragement to Use Alternative Cancer Therapies Scale in response to comments received during the pilot study. Some women commented on the difficulty they experienced with the response scale (strongly disagree to strongly agree). Instead of measuring encouragement in terms of agreement, the women suggested that the response scale be modified so that the amount of encouragement that had been received could be assessed. Accordingly, the response scale was revised to a 4-point Likert-type scale ranging from 1 = "Not at all" to 4 = "Very much" (see Table 7). Items on this scale (ENCOUR1-4) were used as multiple indicators<sup>25</sup> of the *Encouragement to Use ACTs* construct, with higher scores indicating greater encouragement from others to use ACTs.

#### Perceived Likelihood of Recurrence

The construct, *Perceived Likelihood of Recurrence*, was assessed by a six-item modified version of Champion's Health Belief Model - Susceptibility Scale (Champion, 1984, 1999). The original instrument, comprised of five scales measuring perceived susceptibility, seriousness, benefits, barriers, and health motivations, was developed to apply the components of the HBM to breast screening behaviour. Within this framework, perceived susceptibility was defined as "the subjective risks of contracting a specific condition within a specified time period" (Champion, 1984). The original scale included such items as, "*My chances of getting breast cancer are great*" and "*Within the next year I will get breast cancer.*" All items on the scale were measured on a Likert-type response scale, ranging from "1" (*strongly disagree*) to "5" (*strongly agree*).

<sup>24</sup> Kendall Tau B is a nonparametric measure of association for ordinal or ranked variables. The sign of the coefficient indicates the direction of the relationship, and its absolute value indicates the strength, with larger absolute values indicating stronger relationships. Possible values range from -1 to 1.

<sup>25</sup> As previously mentioned, multiple indicators are preferred in structural equation modelling as they better define the constructs and limit the biases in parameter estimates caused by measurement error.

agree). Total scale scores were calculated by summing item responses, with higher scores indicating greater perceived likelihood of breast cancer.

Content and construct validity of the original version of the Health Belief Model - Susceptibility Scale has been determined through extensive developmental work and pilot testing of the instrument. In Champion's (1984, 1999) work on the Susceptibility Scale, content validity was determined by an expert panel of judges familiar with the HBM who were asked to rate the relevance of the items to the concept. Factor analysis results reported by Champion (1984, 1999) further validated the Susceptibility Scale as an independent and unidimensional factor. Despite some concerns related to the causal interpretation of correlations between perceived susceptibility and health behaviour (Sheeran & Abraham, 1995), the Susceptibility Scale has been shown to be predictive of breast health behaviour (Champion & Miller, 1996). Reliability coefficients for the scale have shown promise, ranging from .78 to .93 (Champion, 1984; Champion, 1991; Champion, 1999; Champion & Miller, 1996; Sortet & Banks, 1997).

For the purposes of the study, slight modifications to the Susceptibility Scale (renamed the Perceived Likelihood of Recurrence Scale or PLRS) were necessary to make the items (PLRS1-6) appropriate to women diagnosed with breast cancer (see Table 7). For example, the original item, "*My chances of getting breast cancer are great*" was revised to read, "*My chances of having breast cancer come back are great.*" These changes reflected women's perceived susceptibility to a recurrence of breast cancer. The six items were used as multiple indicators of the latent variable *Perceived Likelihood of Recurrence* in the Preventive Model.

#### Perceived Symptom Distress

In the Ameliorative Model, the study construct *Perceived Symptom Distress* was assessed with McCorkle and Young's (1978) Symptom Distress Scale (SDS). The SDS is a 13-item scale that measures the subjective distress experienced by cancer patients as a consequence of their disease or conventional cancer treatments. The SDS assesses the level of distress associated with such symptoms as nausea, pain, fatigue, and sleep disturbances. The instrument measures the frequency of symptoms and the intensity of the distress on five-point Likert-type response scales. Response scales range from "1" (least distress) to "5" (most distress).

The researchers first assessed symptoms experienced by individuals with cancer through qualitative interviews with 26 patients undergoing chemotherapy and radiation (McCorkle & Young, 1978). Follow-up interviews with 60 men and women undergoing conventional cancer treatment further confirmed the content validity of the scale. Extensive cancer research with the SDS has revealed reliability coefficients ranging from .78 to .89 (Ehlke, 1988; Mast et al., 1998; McCorkle & Young, 1978). While a total score is typically obtained for the SDS by summing item responses, with higher scores indicating greater distress, the



decision was made to use the 13 items as multiple indicators of the latent construct *Perceived Symptom Distress*.

#### Perceived Risk of Harm

The Perceived Risk of Harm Scale (PRHS) was developed by the investigator to measure perceptions of susceptibility to harm, a concept specified within the Restorative Model of ACT Use. In this model, perceptions of likelihood (or risk) were specific to the harm caused by the breast cancer experience to a woman's well being. No measures currently exist that operationalize these perceptions within the context of well being. Previous research that has examined the dimensionality of general health (Ratner, Johnson, & Jeffery, 1998) and the HBM construct of susceptibility (Champion, 1984, 1999) was instrumental in the development of this scale.

Research by Ratner et al. (1998) illustrated that physical, emotional, social, and spiritual health are unique dimensions of well being that cannot be adequately measured with a single question about perceived health status. To capture the multidimensionality of health, multiple indicators are needed that consider each element of well being. Items were thus developed for the PRHS that measured not only the anticipated impact of cancer and conventional cancer treatment on physical well being, but also on emotional and mental health, social relationships, and spiritual well being.

The original PRHS items (PRHS1-8) were developed based on the format of two items from Champion's (1984, 1999) Health Belief Model - Susceptibility Scale (i.e., "*There is a good possibility that I will get breast cancer*" and "*The chances of getting breast cancer are great*"). These items were revised to reflect perceptions of potential harm specific to women's physical, mental, social, and spiritual well being (e.g., "*There is a good possibility that my emotional well being has been harmed by my breast cancer experience*" and "*The chances that my emotional well being has been harmed by my breast cancer experience are great*"). Participants responded to each item on a five-point Likert-type scale, ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The pilot study participants, however, noted a redundancy between items PRHS1-4 and PRHS5-8, resulting in PRHS5-8 being omitted from the final questionnaire. The four remaining items (PRHS1-4) were modelled as multiple indicators of the latent construct *Perceived Risk of Harm* in the Restorative Model, with higher scores on each item indicating greater perceived risk of harm (see Table 7).

#### Perceived Severity of Harm

Drawing from previous research that examined perceptions of threat (Becker & Maiman, 1975; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986), the four-item Perceived Severity of Harm Scale (PSHS) was developed by the investigator to measure the construct *Perceived Severity of Harm* specified in the Restorative Model of ACT Use. According to Becker

and Mainman (1975), beliefs about one's personal susceptibility to harm are not sufficient to motivate health behaviour. An individual must also perceive the threat to be serious and to have significant consequences before action is taken. Using flu vaccination as an example, while individuals may perceive the likelihood of contracting the flu to be great, if they do not perceive the consequences of the illness (e.g., missing work/school, feeling sick) to be great, they are unlikely to make a doctor's appointment to request immunization.

Perceptions of severity have been measured in several ways, with the majority being disease-specific (e.g., breast cancer) (Champion, 1984, 1999; Champion & Miller, 1996; Fulton et al., 1991). To measure the more ambiguous concept of harm to well being, generic questions about the perceived seriousness of harm were needed. Women were asked to rate on a four-point Likert-type response scale (1 = "not at all" to 4 = "very much") how much their physical, emotional and spiritual well being and their relationships with others were harmed by their breast cancer experience (see Table 7). Items on the PSVHS (PSVHS1-4) were used as multiple indicators of the latent construct *Perceived Severity of Harm* in the Restorative Model of ACT Use, with higher scores on each item indicating greater perceived severity of harm to well being following breast cancer diagnosis and conventional treatment.

#### Perceived Efficacy of Alternative/Complementary Therapies

The seven-item Perceived Efficacy of Alternative/Complementary Therapies Scale (PEACTS) was developed by the investigator to measure the construct *Perceived Efficacy of ACTs*, which was included in the Preventive, Ameliorative, and Restorative Models of ACT Use. The items were derived from both the Belief in the Efficacy of Alternative Cancer Treatments Scale (Yates, 1991; Yates et al., 1993) and from qualitative research on the treatment practices of women living with breast cancer (Boon et al., 1999; Truant, 1998). The Belief in the Efficacy of Alternative Cancer Treatments Scale (Yates, 1991; Yates et al., 1993) was originally a 12-item instrument that measured cancer patients' beliefs about the efficacy, adverse effects, and relative importance of alternative cancer treatments. Factor analysis resulted in a six-item scale that included such items as "*they will cure my cancer*" and "*they will assist other treatments to work*". This scale, however, was developed with an advanced cancer population in mind and focussed on the curative aspects of ACT use. Qualitative studies of women with less advanced breast cancer have revealed a different set of beliefs about the efficacy of ACTs (Boon et al., 1999; Truant, 1998). These beliefs include using ACTs to manage the side effects of conventional cancer treatments, to promote feelings of well being, and to prevent recurrence. Items in the PEACTS attempted to capture these beliefs about the potential benefits of ACTs.

The first item (PEACTS1), "*Alternative/complementary therapies will prevent a recurrence of my breast cancer*", measured women's beliefs in the preventive role of ACTs. This item was used as a single indicator of the Perceived Efficacy of ACTs construct in the

Preventive Model. The second and third items (PEACTS2-3), "*Alternative/complementary therapies will relieve my symptoms*" and "*Alternative/complementary therapies will relieve the side effects of medical treatment*", measured perceived efficacy of ACTs within the context of ameliorative behaviour. Slight modifications were made to the wording of PEACT2-3 as a result of pilot testing, with the items altered to read "*ACTs will relieve some of my symptoms/the side effects....*". This revision was made in response to one woman's observation that the ACTs she had used had relieved "some symptoms but not all". These two items served as multiple indicators of perceived efficacy of ACTs in the Ameliorative Model of ACT Use. The final four items on the PEACTS (PEACTS4-7) examined women's beliefs about the effectiveness of ACTs in restoring women's physical, mental, social, and spiritual well being following the diagnosis and treatment of breast cancer (e.g., *Alternative/complementary therapies will improve my physical well being*). These items were used as multiple indicators of the *Perceived Efficacy of ACTs* construct within the Restorative Model of ACT Use. Response formats for all items on the PEACTS ranged from 1 to 5 (*strongly disagree* to *strongly agree*), with a higher value indicating a higher degree of confidence in the efficacy of ACTs (see Table 7).

#### Perceived Barriers to Alternative/Complementary Therapy Use

The construct, *Perceived Barriers to ACT Use* was measured with a revised version of Champion's (1984; 1999) Health Belief Model - Barriers Scale. The original eight-item scale was developed to measure the negative components of breast screening behaviour that could dissuade individuals from undertaking either breast self-examination or mammography screening. Negative aspects of health behaviour assessed by the scale included monetary consequences, pain, changing habits, inconvenience, embarrassment, side effects, and the need for new patterns of behaviour (Champion, 1984). All items were measured on a Likert-type response scale, ranging from 1 to 5 (*strongly disagree* to *strongly agree*). Total scale scores were calculated by summing item responses so that higher scores indicated greater perceived barriers associated with the health behaviour in question.

The original version of the Health Belief Model - Barriers Scale has been subjected to extensive reliability and validity testing in Champion's program of research on breast health behaviour (Champion, 1984; Champion, 1991; Champion, 1994; Champion, 1999; Champion & Miller, 1996). Reliability estimates have ranged from Cronbach's alphas of .76 to .85. Despite concerns about the ability of the Health Belief Model - Barriers Scale to assess the multidimensional nature of perceived barriers (i.e., practical and psychological barriers), factor analysis has supported the construct validity of the scale (Champion, 1984). Concurrent validity of the scale has been supported by research that has illustrated beliefs about barriers to be significantly related to previous breast health behaviour (Champion, 1991; Champion, 1999; Champion & Miller, 1996).

For the purposes of this study, seven items judged to be the most relevant barriers to using ACTs were selected from the original Health Belief Model - Barriers Scale (see Table 7). The item, "*It is embarrassing for me to do monthly breast exams*" was omitted from the revised scale. Minor revisions were also necessary to make the remaining seven items applicable to barriers associated with ACT use. For example, the item, "*Self breast exams are time consuming*" was revised to read "*Using alternative/complementary therapies would be time consuming*." The item, "*Self breast exams can be painful*" was altered to read "*Using alternative/complementary therapies would be uncomfortable*" to reflect the less invasive nature of ACTs espoused within the popular literature (Lerner, 1994). In addition, the self-efficacy item, "*I am afraid I would not be able to do self breast exam*" was changed to read "*I am afraid that I would not be able to use alternative/complementary therapies the way they should be used*." This item reflects individuals' confidence in following what are often complex regimens using multiple forms of ACTs. Although the Health Belief Model - Barriers Scale was originally developed to measure negative impediments to preventive breast health practices, Champion (1984) also suggested that the instrument could be applied across a range of health behaviours, including sick role and illness behaviour. Accordingly, items on the scale were used as multiple indicators of the *Perceived Barriers to ACT Use* construct across the three models of ACT use without modification.

#### Perceived Control

The items on the Perceived Control Over Health Scale (CONTRL) were developed by the investigator and were used as indicators of the *Perceived Control* construct modelled in the Preventive, Ameliorative, and Restorative Models of ACT Use. The items for this scale were derived from the Internal Scale of the Multidimensional Health Locus of Control (MHLC) instrument (Wallston et al., 1978). The MHLC was originally developed in response to criticisms of the unidimensional nature of the Health Locus of Control Scale (Wallston, Wallston, Kaplan, & Maides, 1976), which measured beliefs about control on a single internal-external scale. In contrast, the MHLC was comprised of three dimensions of locus of control: internality, powerful others, and chance externality. The original 12-item Internal Scale measures the extent to which individuals believe in their own ability to influence their health or illness (Zindler-Wernet & Weiss, 1987). In contrast, the Powerful Others Scale and the Chance Scale measure beliefs that one's health is either determined by other people or by fate, luck, or chance.

The internal consistency, as well as construct and criterion validity of the MHLC scales, were investigated with data collected from a convenience sample of 115 individuals from the general public (Wallston et al., 1978). Alpha reliabilities for the MHLC Internal scale ranged from .77 to .86. The Internal Scale was also found to be highly correlated with the internal scale from

Levenson's locus of control (1973) scales and with respondents' health status ( $r = 0.40$ ,  $p < .001$ ).

Given that the *Perceived Control* construct within the three models of ACT use is defined in terms of personal control and responsibility over health, the Internal Scale of the MHLC was chosen as the most appropriate template for the Perceived Control over Health Scale. Three items were selected from the MHLC Internal Scale that accurately represented women's perceptions of control within the context of the breast cancer experience. Modifications were needed to reflect perceptions of control specific to preventive, ameliorative, and restorative health behaviour. The following revisions were made to the original items to measure perceived control (see Figure 6):

<u>Original Items</u>	<u>Preventive Model<sup>26</sup></u>	<u>Ameliorative Model<sup>27</sup></u>
<i>I am in control of my health</i>	→ <i>I am in control of whether I have breast cancer again</i> [CONTRL1]	→ <i>I am in control of whether I experience side effects of medical cancer treatment</i> [CONTRL4]
<i>If I take care of myself, I can avoid illness</i>	→ <i>If I take care of myself, I can avoid having breast cancer again</i> [CONTRL2]	→ <i>If I take care of myself, I can avoid the side effects of medical cancer treatment</i> [CONTRL5]
<i>If I take the right actions, I can stay healthy</i>	→ <i>If I take the right actions, I can prevent having breast cancer</i> [CONTRL3]	→ <i>If I take the right actions, I can manage the side effects of medical cancer treatment</i> [CONTRL6]

**Figure 6. Transformation of *Perceived Control* Items**

In the Restorative Model of ACT Use, the original item "*I am in control of my health*" was used as a measure of *Perceived Control*. However, this item was expanded into four separate items that measured perceived control over the four dimensions of well being, including physical, emotional, social, and spiritual well being<sup>28</sup> (e.g., "*I am in control of my spiritual well*").

<sup>26</sup> The *Perceived Control* construct is labeled "*Perceived Control over Breast Cancer Recurrence*" in the Preventive Model.

<sup>27</sup> The *Perceived Control* construct in the Ameliorative Model is labeled "*Perceived Control over Adverse Effects*".

<sup>28</sup> The *Perceived Control* construct in the Restorative Model is labeled "*Perceived Control over Well Being*".

*being*") (see Table 7). Revisions also were made to the original six-point response format (*strongly agree* to *strongly disagree*) to increase consistency across the questionnaire. A five-point Likert-type response scale was used, ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The three items used in the Preventive (CONTRL1-3) and Ameliorative Models (CONTRL4-6) acted as multiple indicators of *Perceived Control*, with higher scores indicating greater perceived control. The four items pertaining to the restorative use of ACTs (CONTRL7-10) were used as multiple indicators of *Perceived Control* in the Restorative Model. In all models, higher item scores corresponded with greater levels of perceived control.

#### Commitment to Alternative/Complementary Therapies

The Alternative/Complementary Therapy Use Questionnaire (ACTUQ) was developed by the investigator to provide a comprehensive assessment of the use of ACTs by women with breast cancer. The first part of the questionnaire provided respondents with a comprehensive list of over 65 ACTs (see Appendix 5). This list was derived from the *Guide to Unconventional Cancer Therapies*, developed by the Ontario Breast Cancer Information Exchange Project (1994). This resource provided a detailed description of therapies that Canadian breast cancer survivors have identified as being of potential interest and value within their cancer care, including dietary therapies, herbal remedies, and traditional systems of healing. Respondents were asked to check each therapy used since they were diagnosed with breast cancer in addition to listing those therapies that were not included in the therapy list.

The second part of the ACTUQ consisted of items that assessed in greater detail respondents' commitment to ACT use. For each therapy used since diagnosis, respondents were asked about the date the therapy was initiated, whether the therapy was currently in use, the frequency with which each therapy was used and the amount of effort associated with the treatment (see Table 7). This information provided a descriptive history of women's ACT use since being diagnosed with breast cancer, as well as more precise information regarding women's commitment to ACT use. The total number of therapies currently being used by the respondents (NUMACT) was used as the first of three indicators of the *Commitment to ACT Use* construct. The decision was made to include only those therapies that were currently in use because some of the health belief items were framed in the present tense (e.g. "...check the circle beside the statement that *most closely* indicates how you have been feeling lately"). By including only those therapies currently in use, the problem of establishing a consistent time frame for beliefs and behaviour inherent in cross-sectional survey research (Weisberg, Krosnick, & Bowen, 1996) was partially addressed. The decision also was made to include only therapies included under the "more conservative" classification of ACTs (see Table 7) in the operationalization of the *Commitment to ACTs* construct (i.e., NUMACT, FQEFTOT, and COSTTOT). This decision acknowledged the fact that many therapies are now part of

mainstream health care and are no longer considered by many individuals and practitioners to be "alternative", or even "complementary", to conventional medical care. Further, the inclusion of only "more conservative" ACTs in the structural modelling process ensured there was variability in the indicators measuring the *Commitment to ACTs* construct.

The frequency item asked respondents to indicate on a six-point Likert-type response scale, ranging from "*less than once a month*" to "*daily*" (1 to 6), how frequently they used each therapy. A higher value corresponded to more frequent usage and a greater commitment of time. The women also were asked to rate, on a ten-point scale, the degree of effort involved in using each indicated therapy, with 1 being "*no effort*" and 10 being "*most effort*". This item attempted to assess the amount of physical and mental energy needed to comply with an ACT regimen or therapy. Research has shown that the range of effort expended in using ACTs may vary considerably, depending on the type of treatment chosen and the associated protocol of use (Lerner, 1994). To create a comprehensive measure of the commitment involved in using ACTs, the frequency with which an ACT was used was multiplied by the effort expended in using that therapy. For example, a woman who used Vitamin C on a daily basis (i.e., frequency = 6) but who considered this therapy to require minimal effort (i.e., effort = 1) would have a combined frequency-effort commitment score of six. In contrast, a woman who used coffee enemas once a week (i.e., frequency = 4) and who perceived this therapy to require maximal effort (i.e., effort = 10) because of the invasive nature of the treatment would have a combined commitment score of 40. This combined measure provided a means of weighting the amount of effort expended in using an ACT by the amount of time committed to using that therapy. A total frequency-effort commitment score (FQEFTOT) was calculated by summing the frequency-effort commitment scores across all currently used therapies, with higher values indicating greater commitment to ACTs. This score was used as the second indicator of the construct, *Commitment to ACT Use*.

The ACTUQ also assessed the monthly cost of ACTs that had been used by the women since being diagnosed with breast cancer. Previous research on the financial costs associated with ACTs has been limited because of the use of general rather than treatment-specific questions about expenditures (Eisenberg et al., 1998; Eisenberg et al., 1993; Millar, 1997). This portion of the ACTUQ provided details on how the costs of ACTs varied across treatments. An overall total cost of ACT use per month was calculated for all therapies currently in use. This total (COSTTOT) was used as the third indicator of the *Commitment to ACT Use* construct included in the three models of ACT use.

Several other items were included on the ACTUQ for the purpose of providing a more comprehensive description of the context in which women with breast cancer used ACTs (see Table 7). The respondents were asked, "*Did you use alternative and complementary therapies*

*before you were diagnosed with breast cancer?"* (0 = "No" and 1 = "Yes") and *"How often did you use alternative and complementary therapies before you were diagnosed with breast cancer?"* (1 = "less than once a month" to 6 = "daily"). The dichotomous item (PREVIOUS) was used as a single indicator of the construct *Previous Use of ACTs* specified in the Preventive, Ameliorative, and Restorative Models of ACT Use; scores of one indicated previous ACT use. For descriptive purposes, an open-ended question was used to identify the type of therapies women had used before diagnosis.

Two items from the *Use of Alternative/Complementary Health Services by Breast Cancer Survivors* survey (Boon et al., 1999) were included in the ACTUQ to provide greater description of the context in which women with breast cancer used ACTs. This descriptive survey, funded by the Canadian Breast Cancer Initiative, was developed to provide a snapshot of ACT use within the Ontario breast cancer community. One item taken from the survey asked participants about their information source for the first ACT they used. This item was modified to read: *"Where or from whom do you receive most of your information about ACTs that you have used or are currently using?"* Participants were asked to circle all categories that applied, which included such resources as physicians, family members, magazines/books, and the Internet (see Table 7). Slight modifications to the response categories were necessary to increase the readability of the item (see Table 7). The other item included in the ACTUQ asked participants about whether they had informed their physicians about their use of ACTs. This item provided insight into whether ACTs were covertly used by women with breast cancer.

At the end of the study questionnaire, participants were presented with an optional, open-ended item that allowed them to write any additional comments about their experiences with alternative/complementary therapies.



**Table 7. List of Scales/Items in Final Study Questionnaire**

<b>Study Constructs</b>	<b>Observed Indicator (Questionnaire Subscale and Items)</b>	<b>Variable Name(s)</b>
Age	Part M. Q1. What is your birth date (month/day/year)?	AGE
Marital Status	Part M. Q2. What is your marital status? (please check one) <ul style="list-style-type: none"> <li>- Married</li> <li>- Living with a partner/common-law</li> <li>- Single (never married)</li> <li>- Widowed</li> <li>- Separated</li> <li>- Divorced</li> </ul>	MARITAL
Ethnicity	Part M. Q3. How would you describe yourself in terms of ethnic or cultural group? (open-ended question)	ETHNIC
Education	Part M. Q4. What is the highest level of education that you have received? (please check one) <ul style="list-style-type: none"> <li>- Grade 8 or less</li> <li>- Some high school</li> <li>- High school diploma</li> <li>- Some trade, tech, vocational, or business school</li> <li>- Some community college or nursing school</li> <li>- Some university</li> <li>- Diploma from trade, tech, or vocational school</li> <li>- Diploma from community college or nursing school</li> <li>- Bachelor's degree, undergraduate degree or Teacher's college</li> <li>- Master's degree (e.g., MA, MSc, MEd)</li> <li>- Degree in medicine, dentistry, veterinary medicine, or Optometry</li> <li>- Earned doctorate</li> </ul>	EDUCATE
Income	Part M. Q5. What is your best estimate of the total income, before taxes and deductions, of your household, from all sources, in the past 12 months? (please check one) <ul style="list-style-type: none"> <li>- less than \$10,000</li> <li>- \$10,000 to less than \$20,000</li> <li>- \$20,000 to less than \$30,000</li> <li>- \$30,000 to less than \$40,000</li> <li>- \$40,000 to less than \$50,000</li> <li>- \$50,000 to less than \$60,000</li> <li>- \$60,000 to less than \$70,000</li> <li>- \$70,000 to less than \$80,000</li> <li>- \$80,000 to less than \$90,000</li> <li>- \$90,000 to less than \$100,000</li> <li>- \$100,000 or more</li> </ul>	TOTINC
Diagnosis Date	Part M. Q6. When were you first diagnosed with breast cancer? (month/year)	DXDATE
Recurrence	Part M. Q7a. Have you had a recurrence of breast cancer? (No/Yes)	RECUR
	Q7b. If YES, when was this? (month/year)	DATEREC

Table 7. List of Scales/Items in Final Study Questionnaire (cont.)

Study Constructs	Observed Indicator (Questionnaire Subscale and Items)	Variable Name(s)
Other Cancer Diagnosis	Part M. Q8. Have you ever been diagnosed with another type of cancer? (No/Yes)	DXOTH
	Q8b. If YES, please indicate what type of cancer. (open-ended)	TYPEOTH
Conventional Treatment	Part M. Q9. What types of medical treatment have you received for breast cancer? (please check all that apply)	
	<ul style="list-style-type: none"> <li>- Mastectomy</li> <li>- Lumpectomy</li> <li>- Radiotherapy</li> <li>- Chemotherapy</li> <li>- Hormone Therapy</li> <li>- Other (please specify, open-ended)</li> </ul>	TXMAST TXLUMP TXRADIO TXCHEMO TXHORM TXOTH
Completion of Conventional Treatment	Part M. Q10a. Have you finished your medical treatment for breast cancer? (No/Yes)	TXCOMPL
	Q10b. What was the date of your last medical treatment for breast cancer? (month/year)	TXDATE
Encouragement to use ACTs	Part L. This part of the survey asks about the encouragement you have received to use alternative and complementary therapies during your breast cancer experience. Please check the one response that best describes how much encouragement you received. (Not at all/a little/quite a bit/very much)	ENCOUR1 – 4
<i>Modified from (Yates et al., 1993)</i>	Q1. My family has encouraged me to use alternative and complementary therapies. Q2. My friends have encouraged me ... Q3. My doctor has encouraged me ... Q4. Other health professionals have encouraged me ...	
Perceived Likelihood of Recurrence	Part D. This section describes thoughts that some women may have after being diagnosed and treated for breast cancer. Please check the one response that best describes how much you agree or disagree with each statement. (Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree)	PLRS1 - 6
<i>modified from (Champion, 1984; Champion, 1999)</i>	Q1. My chances of having breast cancer come back are great. Q2. My physical health makes it more likely that the breast cancer will come back. Q3. I feel that my chances of having breast cancer come back in the future are high. Q4. There is a good possibility that I will have breast cancer come back. Q5. I worry a lot about having breast cancer come back. Q6. Within the next year I will have the breast cancer come back.	

Table 7. List of Scales/Items in Study Questionnaire (cont.)

Study Constructs	Observed Indicator (Questionnaire Subscale and Items)	Variable Name(s)
Perceived Symptom Distress  <i>Modified from (McCorkle &amp; Young, 1978)</i>	Part E. Each of the following items lists 5 different numbered statements about your health. Think about what each statement says then check the circle besides the statement that <i>most closely</i> indicates how you have been feeling lately. The statements are ranked from 1 to 5, where "1" indicates no problem and "5" indicates maximum amount of problems.  e.g., Nausea 1. I seldom feel any nausea at all. 2. I am nauseated once in a while. 3. I am often nauseated. 4. I am usually nauseated. 5. I suffer from nausea almost continually.	SDS1-13
Perceived Risk of Harm <sup>a</sup>	Part F. This part of the survey lists beliefs some women may hold about HOW LIKELY it is that their well being has been harmed by their breast cancer experience. Please check the one response that best describes how much you agree or disagree with each statement. (Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree)  There is a good possibility that my... Q1. ...physical well being has been harmed by my breast cancer experience. Q2. ...mental well being has been harmed by my breast cancer experience. Q3. ...relationships with others have been harmed by my breast cancer experience. Q4. ...spiritual well being has been harmed by my breast cancer experience.	PRHS1 – 4
Perceived Severity of Harm	Part H. This next section lists beliefs that some women may hold about HOW MUCH their well being has been harmed by their breast cancer experience. Please check the response that best describes how you feel about each statement. (Not at all, a little, quite a bit, very much)  How much do you think your... Q1. ...physical well being has been harmed by your breast cancer experience? Q2. ...mental well being has been harmed by your breast cancer experience? Q3. ...relationships with others have been harmed by your breast cancer experience? Q4. ...spiritual well being has been harmed by your breast cancer experience?	PSHS1 – 4

Table 7. List of Scales/Items in Study Questionnaire (cont.)

Study Constructs	Observed Indicator (Questionnaire Subscale and Items)	Variable Name(s)
<p>Perceived Efficacy of ACTs<sup>b</sup></p> <p><i>Modified from (Yates et al., 1993)</i></p>	<p>Part I. This part of the survey lists beliefs some women may hold about alternative and complementary therapies. Please check the one response that best describes how much you agree or disagree with each statement, even if you have not used alternative and complementary therapies. (Strongly disagree, disagree, neither agree/disagree, agree, strongly agree)</p> <p>Alternative and complementary therapies will:</p> <p>Q1. ...prevent a recurrence of my breast cancer.</p> <p>Q2. ...relieve some of my symptoms.</p> <p>Q3. ...relieve some of my side effects.</p> <p>Q4. ...improve my physical well being.</p> <p>Q5. ...improve my mental well being.</p> <p>Q6. ...improve my relationships with others.</p> <p>Q7. ...improve my spiritual well being.</p>	<p>PEACTS 1 – 7</p>
<p>Perceived Barriers to ACT Use</p> <p><i>Modified from (Champion, 1984; Champion, 1999)</i></p>	<p>Part J. This next section of the survey lists beliefs some people may have about using alternative and complementary therapies. Please check the one response that best describes how much you agree or disagree with each statement, even if you have not used alternative and complementary therapies. (Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree)</p> <p>Q1. In order to use ACTs, I would have to give up a lot.</p> <p>Q2. Using ACTs would be uncomfortable.</p> <p>Q3. Using ACTs would be time consuming.</p> <p>Q4. My family would make fun of me if I used ACTs.</p> <p>Q5. Using ACTs would interfere with my activities.</p> <p>Q6. Using ACTs would require me starting a new habit, which is difficult.</p> <p>Q7. I am afraid that I would not be able to use ACTs the way they should be used.</p>	<p>PBACT 1-7</p>
<p>Perceived Control</p> <p><i>modified from (Wallston et al., 1978)</i></p>	<p>Part K. This part of the questionnaire lists beliefs some women may have about the amount of control they have over their health and well being. Please read each item and check the one response that best describes how you feel. (Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree)</p> <p>Q1. I am in control of whether I have breast cancer again.</p> <p>Q2. If I take care of myself, I can avoid having breast cancer again.</p> <p>Q3. If I take the right actions, I can prevent having breast cancer again.</p> <p>Q4. I am in control of whether I experience side effects from medical cancer treatments.</p> <p>Q5. If I take care of myself, I can avoid the side effects of medical cancer treatments.</p> <p>Q6. If I take the right actions, I can manage the side effects of medical cancer treatment.</p> <p>Q7. I am in control of my physical well being.</p> <p>Q8. I am in control of my mental well being.</p> <p>Q9. I am in control of my relationships with others.</p> <p>Q10. I am in control of my spiritual well being.</p>	<p>CONTRL 1-10</p>

Table 7. List of Scales/Items in Study Questionnaire (cont.)

Study Constructs	Observed Indicator (Questionnaire Subscale and Items)	Variable Name(s)
Commitment to ACT Use	Part A. This first section of the survey lists many of the therapies that people living with cancer may use in addition to their conventional medical treatments (e.g., surgery, chemotherapy, radiation). These therapies are sometimes referred to as alternative and complementary therapies. Please read the following list and check each therapy that you have used since you were diagnosed with breast cancer.	NUMACT
	Part B. The next section of the survey asks you some specific questions about each therapy you have used since you were diagnosed with breast cancer. For each therapy that you have listed, please answer the following questions: Q1. The date you started using the therapy (open-ended) Q2. Whether you are still using the therapy (No/Yes) Q3. How often you use/used the therapy (less than once a month to daily) Q4. How much effort is involved in using the therapy (1 to 10) Q5. How much it costs to use the therapy each month	FQEFTOT
		COSTTOT
	Part C. Q1a. Did you use alternative and complementary therapies before you were diagnosed with breast cancer? Remember, these are therapies such as those listed in the previous section, Part A. (No/Yes)	PREVIOUS
	Q1b. If YES, please list below the therapies you used before you were diagnosed with breast cancer. (open-ended)	PRIOR1-10
Previous ACT Use	Q2. In general, how often did you use alternative/complementary therapies before you were diagnosed with breast cancer? (Less than once a month/Once a month/Once every 2 weeks/Once a week/Every other day/Daily)	FREQPRE
	Part C. Q3. Where did you learn about the alternative/complementary therapies that you have used? (please check all that apply) - Doctor - Nurse - Family member - Friend - Support group - Health food store - Magazines/books - Television/radio - Internet/web - Other (please specify)	LEARN
	Part C. Q4. Have you told your physician(s) about your use of alternative/complementary therapies? (Yes, all my physicians know/Yes, my family physician knows, but my specialists do not/Yes, my specialists know, but my family physician does not/No, none of my physicians know)	DISCLOSE

<sup>a</sup> The following items were eliminated from the PRHS after completion of the pilot study: "The chances that my physical well being has been harmed by my breast cancer experience are great"; "The chances that my mental well being has been harmed by my breast cancer experience are great"; "The chances that my relationships with others have been harmed by my breast cancer experience are great"; "The chances that my spiritual well being has been harmed by my breast cancer experience are great." These items were deemed by pilot study participants to be redundant of the items retained in the PRHS.

<sup>b</sup> Items PEACTS2 and PEACTS3 were changed from "Alternative/complementary therapies will relieve my symptoms/side effects" to "Alternative/complementary therapies will relieve *some of* my symptoms/side effects". This addition was made as a consequence of pilot study participants' comments.

Table 8 provides an overview of the study constructs used in the structural equation modelling component of the analysis, the associated instrument/items, and in which models the constructs were included. Where relevant, the scales from which the subscales and items were derived are listed.

**Table 8. Study Constructs and Associated Instruments in the Preventive, Ameliorative, and Restorative Models**

Study Construct	Instrument/Item	Model 1a <sup>a</sup>	Model 2a <sup>b</sup>	Model 3a <sup>c</sup>
Age	<i>Age</i>	x	x	x
Education	<i>Highest Level of Education</i>	x	x	x
Income	<i>Total Household Income</i>	x	x	x
Previous Use of ACTs	<i>Previous Use of ACTs</i>	x	x	x
Encouragement to Use ACTs	<i>Encouragement to Use ACTs Scale (modified from Yates et al, 1993)</i>	x	x	x
Perceived Likelihood of Recurrence	<i>Perceived Likelihood of Recurrence Scale (modified from Champion, 1984; 1999)</i>	x		
Symptom Distress	<i>Symptom Distress Scale (McCorkle &amp; Young, 1978)</i>		x	
Perceived Risk of Harm	<i>Perceived Risk of Harm Scale (modified from Champion, 1984)</i>			x
Perceived Severity of Harm	<i>Perceived Severity of Harm Scale</i>			x
Perceived Efficacy of ACTs	<i>Perceived Efficacy of ACTs Scale</i>			
a. Recurrence		x		
b. Symptom/Side Effects			x	
c. Well-being				x
Perceived Barriers to ACT Use	<i>Perceived Barriers to ACT Use (modified from Champion, 1984)</i>	x	x	x
Perceived Control	<i>Perceived Control Over Health Scale (modified from Wallston et al., 1978)</i>			
a. Recurrence		x		
b. Symptom/Side Effects			x	
c. Well being				x
Commitment to ACTs	<i>Alternative/Complementary Therapy Use Questionnaire</i>	x	x	x

<sup>a</sup>Preventive Model of ACT Use

<sup>b</sup>Ameliorative Model of ACT Use

<sup>c</sup>Restorative Model of ACT Use

## Data Analysis

Before any data analyses was undertaken the data collected in this study were screened for coding and data entry errors. Data analyses were conducted using SPSS 10.0 for Windows and LISREL 8.51 (Jöreskog & Sörbom, 2001). Univariate statistics were used to summarize sample demographics and study constructs. All scales were subjected to psychometric evaluation (i.e., Cronbach's alpha) to assess the internal consistency of the measures. Factor analyses on scales with multiple indicators were also conducted to support the hypothesized factor structure. Two-step structural equation modelling (SEM) was then undertaken to test the three models of ACT use. Level of significance was set at  $p = .05$  for all statistical procedures except where multiple comparisons required the use of the Bonferroni correction factor.

### Missing Data

Missing data can be handled in several ways depending on the assumptions about the cause of the missing data and the statistical method used. In this study, cases missing more than 15% of the items required in the structural equation models were deleted from the modelling process. Estimation of missing values was undertaken for the frequency, effort and cost items of the ACTUQ using the group mean replacement method. This moderately conservative approach to imputing missing values uses a group mean for the missing value. In this study, the group mean was calculated using a therapy-specific average for frequency of use, effort, and monthly cost. Although this method has been criticized for reducing the variance of a variable and thus its correlation with other measures (Tabachnick & Fidell, 1996), the limited variability in the frequency, effort and cost items across individual therapies supported the use of this estimation method. For all other missing data, list-wise deletion<sup>29</sup> was used to delete cases with missing data from the structural equation modelling process.

### Structural Equation Modelling

Structural equation modelling (SEM) is a comprehensive, multivariate statistical approach to developing and testing theoretical models and the associated hypothetical relationships among study variables. SEM has proven to be an attractive technique for assessing models for several reasons. Foremost, in SEM it is not assumed that all relevant variables have been included in the theory or that perfect measurement of variables has been achieved. Instead, with SEM, a realistic stance is taken, assuming that research occurs in a world in which influential predictors are not always apparent prior to developing theoretical

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<sup>29</sup> List-wise deletion is conducted when cases that have missing values for any of the variables included in the structural equation modelling process are omitted from the analysis. List-wise deletion prevents estimation problems from occurring in SEM because of ambiguous sample size and non-positive definite covariance matrices (Hayduk, 1987; Schumacker & Lomax, 1996).

models and that reality can only be imperfectly assessed through measurement (Hayduk, 1987; Hoyle, 1995). Secondly, in contrast to other multivariate methods, SEM allows reciprocal relationships, in some cases, to be tested within theoretical models, reflecting the complex nature of phenomena within health research (Boyd, Frey, & Aaronson, 1988). SEM has been also considered a useful statistical method because hypotheses can be tested without adherence to experimental manipulation or random assignment within a study (Hickey, 1993). Data from survey and quasi-experimental designs can be used within SEM (Ratner, Bottorff, & Johnson, 1998). However, any conclusions regarding causality within a SEM model are tentative and merely plausible interpretation of reality rather than definitive statements. An unspecified theory may exist beyond the hypothesized model that provides a more accurate explanation of the relationships among observed variables (Hayduk, 1987).

In this study, three structural equation models of ACT use were developed and tested using LISREL 8.51 (Jöreskog & Sörbom, 2001). A two-step process was undertaken, permitting the fit of the measurement models to be tested via confirmatory factor analyses prior to the testing of the structural models. This approach was selected in contrast to a one-step approach, where the measurement and structural models are tested simultaneously, for several reasons. Foremost, Mulaik and James (1995) suggested that testing the validity and reliability of the measurement model prior to the structural model is necessary to ensure that the assumptions within the measurement model are met. A two-step approach allows the researcher to determine where in the model modifications may be required. Kelloway (1998) further recommended using confirmatory factors analysis when there is a debate about the dimensionality or factor structure of a measure. Given the number of modified and investigator-developed scales and items in this study, a two-step approach was considered to be a prudent analysis strategy that would prevent possible misspecification of the models. Further description of the modelling process, including the fit and modification indices used in the study, is provided in Chapter 6 - Model Development.

## **Ethical Considerations**

Before conducting the study, ethical approval was secured from the British Columbia Cancer Agency Clinical Investigation Committee, the British Columbia Cancer Agency Breast Tumor Group, the British Columbia Cancer Registry and the Behavioural Ethics Review Board of the University of British Columbia.

The literature has revealed that a clinically significant number of individuals with cancer are hesitant to discuss their use of ACTs with conventional care providers (Balneaves et al., 1999; Cassileth et al., 1984; Eisenberg et al., 1998). Women with breast cancer who use ACTs, may fear reprisals from their conventional health professionals and may attempt to keep their



ACT use hidden. In developing models of ACT use by women, such covert treatment practices may be revealed. Consequently, only women who provided consent were sent a questionnaire. In addition, women participating in this study were assured that their participation was voluntary, that they had the right to refuse to participate (either by returning their consent form indicating that they did not wish to participate or by telephone during follow-up contact), and that their responses would remain anonymous and have no effect on the care they received from their health-care providers.

Ensuring that no identifying information was requested on the questionnaire, other than sociodemographic information, further protected the participants' confidentiality. The questionnaires were labeled with a participant or case number and the participants were advised not to place their names on the questionnaires. The participants also were asked to mail their completed questionnaires directly to the researcher, using the stamped, return envelope. Study questionnaires were stored in a locked filing cabinet in the principal investigator's home office, with the participant number list kept in a locked filing drawer separated from the data. A participant number list matching numbers to participants was necessary to facilitate follow-up of the research package and to determine the demographic characteristics of non-respondents. All data were treated as confidential and were accessible only to the co-investigators of the study and study personnel (i.e., research assistants). Only grouped data are reported.

The nature of the study presented minimal risks to the participants. Anecdotal comments from women with breast cancer who have participated in similar research have suggested that sharing their experiences about breast cancer and ACTs can be a positive and empowering experience (Balneaves, 1996). However, some items and scales pertaining to beliefs about efficacy of conventional treatment and perceived risk of recurrence may have caused emotional discomfort for some women, particularly those who experienced doubt about the conventional and alternative therapies they had undergone. The participants who had worries were encouraged within the letter of explanation/invitation to contact the study's investigators to discuss any concerns they had about the study. Women who raised concerns in follow-up telephone contact also were encouraged to consult with their conventional health-care provider(s) or to contact the Canadian Cancer Society's Information Line. The participants were also informed in the introduction to the questionnaire that items pertaining to cancer recurrence and treatment efficacy reflected the views expressed by some cancer patients and are not representative of a specific medical opinion. A contact number for the principal investigator was provided to the women who had further questions about their participation or the content of the questionnaire.

No known benefits were anticipated as a consequence of participating in the study. However, all potential participants received a non-medicinal herbal tea bag (e.g., peppermint), in their research package as a token of appreciation for taking the time and energy to complete the study questionnaire. An herbal tea bag was also thought to be in keeping with the study's focus on ACTs. Women who returned their questionnaire were also given the choice of receiving a lay report of the study results.

## Chapter 5

# Descriptive Findings

## The Sample

### Demographic, Disease, and Treatment Characteristics of Non-Respondents

The mean age of the 243 non-respondents at diagnosis was  $60.1 \pm 1.9$  years<sup>30</sup> ( $SD = 14.7$ ). The majority of the non-respondents ( $65.4 \pm 3.6\%$ ) were between 12 months to 24 months from diagnosis at the time of sampling, with  $72.9 \pm 6.0\%$  being diagnosed with stage I breast cancer (33 missing due to incomplete data in the British Columbia Cancer Registry). The majority of the non-respondents had undergone breast surgery ( $98.8 \pm 1.4\%$ ) and radiation therapy ( $71.4 \pm 5.7\%$ ). Twenty-four percent ( $\pm 5.4\%$ ) of the non-respondents had received chemotherapy and  $36.0 \pm 6.1\%$  had been prescribed hormone therapy. Only three non-respondents were noted in the British Columbia Cancer Registry as having refused some form of conventional cancer treatment. One of these individuals was listed as having received surgery, radiation and chemotherapy but not hormone treatment. Another woman received surgery but not radiation, chemotherapy or hormone therapy. The remaining woman was listed as not having received any conventional treatment, including surgery.

### Demographic Characteristics of the Respondents

The 334 respondents ranged in age from 34 to 89 years ( $M = 62.6 \pm 1.2$  years;  $SD = 11.2$ ), and the majority were legally married ( $68.0 \pm 5.0\%$ ) at the time of their participation in the study. The women's education ranged from Grade 8 or less to an earned doctorate, with  $82.0 \pm 4.1\%$  achieving at least a high school education. The women's total household income from all sources in the past 12 months ranged from less than \$10,000 to \$100,000 or more; the median annual income was between \$40,000 and \$50,000. Just over 16% of the sample did not

<sup>30</sup> 95% confidence intervals are calculated for all point estimates including means and percentages.

respond to, or refused to answer, the total household income survey item. The majority of the respondents listed their race/ethnicity as "Caucasian" ( $71.6 \pm 4.9\%$ ). Table 9 provides more detailed demographic information.

### **Disease Characteristics of the Respondents**

The mean age at breast cancer diagnosis for the 334 respondents was  $59.9 \pm 1.2$  years ( $SD = 11.1$ ). Just over 48% of the respondents had been diagnosed 12 months to 24 months before they were randomly selected for participation in the study ( $M = 22.9 \pm 0.5$  months;  $SD = 4.5$ ), with 48.8% being diagnosed more than 24 months before sampling. At the time of data collection, the majority of women (83.2%) were between 24 months to 36 months post-diagnosis ( $M = 27.9 \pm 0.5$  months;  $SD = 4.6$ ). The time elapsed between sampling and completed data collection averaged five months ( $SD = 0.8$ ) and was a consequence of the multi-step data collection process (i.e., modified Total Design Method) and delayed return of questionnaires by the respondents. The majority of the respondents ( $65.0 \pm 5.1\%$ ) (35 missing due to incomplete data in the British Columbia Cancer Registry) were diagnosed with stage I breast cancer.

Despite being part of the exclusion criteria for the study sample, 31 women ( $9.4 \pm 3.1\%$ ) reported experiencing a recurrence of breast cancer following their initial diagnosis. This was attributed, in part, to the fact that data entry for the British Columbia Cancer Registry was considered complete only up to December 31, 1998. Registry data for women diagnosed with breast cancer recurrences following this date might not have been current. In addition, several women indicated on their questionnaires or during follow-up telephone interviews that they had experienced a recurrence while they were participants in the study (i.e., following registry sampling). Ten percent ( $\pm 3.2\%$ ) of the respondents also reported having been diagnosed with other types of cancer, including skin cancer, gynecological cancers (cervix, uterus, and vulva), and lung cancer. For the purposes of the descriptive analysis of ACT use, women who had experienced a recurrence of breast cancer or an additional cancer diagnosis were included in the sample. For all other analyses (i.e., structural equation modelling), this group of women were to be excluded to prevent the introduction of bias or unmeasured sources of confounding effects.

### **Conventional Cancer Treatment History of the Respondents**

Almost all of the 334 women reported having had breast surgery ( $98.8 \pm 1.2\%$ ), with the majority of the respondents reporting having had a lumpectomy ( $58.1 \pm 5.3\%$ ). A small percentage of the women reported receiving both a mastectomy and a lumpectomy ( $9.9 \pm 3.2\%$ ). Only two women in the sample reported having had reconstructive surgery. With regard to adjuvant treatment,  $72.2 \pm 4.8\%$  of the women reported receiving radiation treatment,  $33.8 \pm 5.1\%$  reported receiving chemotherapy, and  $35.3 \pm 5.1\%$  reported receiving hormone therapy.

**Table 9. Demographic Characteristics of the Respondents**

Characteristics	Frequency (%)
<b>Age</b>	
Less than 40 years	7 (2.1)
40 years to less than 50 years	37 (11.1)
50 years to less than 60 years	94 (28.1)
60 years to less than 70 years	85 (25.4)
70 years to less than 80 years	98 (29.3)
80+ years	13 (3.9)
<b>Marital Status</b>	
Married or Common-law	242 (72.5)
Single	9 (2.7)
Widowed	50 (15.0)
Divorced/Separated	33 (9.9)
<b>Education<sup>a</sup></b>	
< Grade 8	15 (4.5)
Some High School	45 (13.5)
High School Diploma	58 (17.3)
Some Post-Secondary (trade or business school, community college, university)	90 (27.0)
Post-Secondary Diploma/Degree	113 (33.9)
Graduate Degree (Master's, Doctorate)	12 (3.6)
<b>Income per annum (Canadian Funds)<sup>b</sup></b>	
< \$20,000	49 (17.5)
\$20,000 < \$40,000	71 (25.4)
\$40,000 < \$60,000	73 (26.4)
\$60,000 < \$80,000	36 (12.8)
\$80,000 < \$100,000	26 (9.3)
\$100,000+	24 (8.6)
<b>Race/Ethnicity<sup>c</sup></b>	
Black/African-American	1 (0.3)
Caucasian/White	229 (71.6)
Chinese	6 (1.9)
South Asian/Pakistani/Indo-Canadian	5 (1.6)
Filipino	1 (0.3)
First Nations/Aboriginal/Native	6 (1.9)
Japanese	2 (0.6)
Jewish	4 (1.3)
Other	9 (2.8)
Just Canadian/Nothing in Particular	57 (17.8)

Note. N = 334

<sup>a</sup> Missing data = 1

<sup>b</sup> Missing data = 54

<sup>c</sup> Missing data = 14

Table 10 provides more detailed information regarding the respondents' conventional treatment history.

**Table 10. Conventional Cancer Treatment of the Respondents**

Adjuvant Treatment	Surgery Type				Totals (%)
	Mastectomy (%)	Lumpectomy (%)	Lumpectomy & Mastectomy (%)	No Surgery (%)	
No Adjuvant Treatment	29 (8.7)	7 (2.1)	7 (2.1)	-	43 (12.9)
Radiation Only	9 (2.7)	81 (24.2)	9 (2.7)	3 (1.0)	102 (30.5)
Chemotherapy Only	10 (3.0)	2 (0.6)	3 (1.0)	-	15 (4.5)
Hormone Therapy Only	20 (6.0)	7 (2.1)	3 (1.0)	-	30 (9.0)
Radiation & Chemotherapy	12 (3.6)	40 (12.0)	4 (1.2)	-	56 (16.8)
Radiation & Hormone Therapy	10 (3.0)	35 (10.5)	1 (0.3)	-	46 (13.8)
Chemotherapy & Hormone Therapy	2 (1.0)	1 (0.3)	2 (0.6)	-	5 (1.5)
Radiation, Chemotherapy & Hormone Therapy	11 (3.3)	21 (6.3)	4 (1.2)	1 (0.3)	37 (11.1)
<b>Totals</b>	103 (30.9)	194 (58.1)	33 (9.9)	4 (1.2)	334

Reports of additional conventional cancer treatment were limited in the sample. Two women reported receiving Clondronate, a drug often used to alleviate menopausal symptoms. One woman reported receiving Ocritide, a drug used for osteoporosis symptoms. Taxol (a form of chemotherapy) and Herceptin (a monoclonal antibody used in gene therapy) were received by one participant.

At the time of data collection, 265 of the respondents ( $79.8 \pm 4.3\%$ ;  $n = 332$ ) reported that they had completed conventional medical therapy for their breast cancer. The mean elapsed time since receiving conventional treatment for breast cancer to survey completion was  $18.4 \pm 0.9$  months ( $SD = 7.3$ ). The 67 women who indicated that they were still undergoing conventional treatment were involved in a long-term trial of Tamoxifen (i.e., hormone therapy). The British Columbia Cancer Registry provided additional information on the reasons why some women did not receive initial treatment for their breast cancer, including patient refusal. No

study participant was noted in the provincial database as having refused conventional cancer treatment.

Discrepancies in conventional cancer treatment history were noted between the participants' self-reports and the British Columbia Cancer Registry (see Table 11). These differences may reflect the incompleteness of the British Columbia Cancer Registry or changes in treatment plans that were not entered into the provincial database. Respondents may have also erred in their understanding of survey items measuring conventional treatment history. The decision was made to report the women's self-reported treatment history because it was believed to be the most accurate and up-to-date representation of the women's treatment experiences.<sup>31</sup> This decision was also applied to women who reported that their conventional cancer treatment was complete but indicated that they were still taking hormone therapy. These women were classified as having completed conventional cancer treatment.

**Table 11. Discrepancies between Respondents' Self-Reports and BC Cancer Registry Data on Conventional Treatment History**

Conventional Treatment	% of Respondents who Received Treatment (95% CI)	
	Self-Report	British Columbia Cancer Registry
Surgery	98.8 (97.6 – 100.0)	99.4 (98.6 – 100.2)
Radiation	72.2 (67.4 – 77.0)	72.5 (67.7 – 77.3)
Chemotherapy	33.8 (28.7 – 38.9)	30.7 (25.7 – 35.7)
Hormone Therapy	35.3 (30.2 – 40.4)	45.7 (40.3 – 51.1)

Note. N = 334

### Differences between the Respondents and Non-Respondents

The only significant differences found between the respondents and non-respondents were in relation to conventional cancer treatment history. Women who responded to the survey were more likely to have received hormone therapy,  $\chi^2_{(1, N = 596)} = 4.82, p = 0.03$  than the non-respondents (see Table 12).

<sup>31</sup> This decision was also made because of the number of women who reported during the telephone follow-up that they had decided independently to stop taking hormone therapy (Tamoxifen) because of the side effects they experienced.

**Table 12. Demographic and Disease Characteristics of Respondents and Non-Respondents**

Characteristics	Samples				p
	Respondents (n=334)		Non-Respondents (n=243)		
	n	%	n	%	
Age at Diagnosis					
< 50 years	63	18.9	58	24.2	0.15
50+ years	271	81.1	182	75.8	
Stage of Cancer					
Stage I	217	72.6	153	72.9	1.00
Stage II+	82	27.4	57	27.1	
Radiation					
Yes	242	72.5	172	71.4	0.41
No	92	27.5	69	28.6	
Chemotherapy					
Yes	103	30.9	57	23.9	0.08
No	230	69.1	181	76.1	
Hormone Therapy					
Yes	147	45.7	85	36.0	0.03
No	175	54.3	151	64.0	

### Use of Alternative/Complementary Therapies by Women with Breast Cancer

The following sections describe the use of ACTs by women living with breast cancer, including the prevalence of ACT use, the pattern of ACT use, and the effort and financial cost associated with the use of ACTs. The sources of information about ACTs used by the women, as well as their disclosure of ACT use to conventional health-care practitioners, also are examined. In keeping with the purposes of this study, all subsequent analyses were based on therapies reported by the women as being used following their breast cancer diagnosis, including those therapies that were initiated before diagnosis and continued.

#### Prevalence of Alternative/Complementary Therapy Use

Table 13 provides the prevalence rates of ACT use by the respondents following their breast cancer diagnosis. When the most liberal definition of ACTs was used, which encompassed the therapy classification systems recommended by the NIH NCCAM (Anonymous, 1997) and the Ontario Breast Cancer Information Exchange Project (1994), and included spiritual therapies,  $79.9 \pm 4.3\%$  of the respondents reported using at least one type of ACT. A full list of all therapies included in this liberal definition of ACTs can be found in Appendix 8. Inclusion of spiritual therapies as a type of ACT, however, is controversial both in the ACT literature (Cassileth, 1998) and to women participating in the study. As one woman wrote on her survey, "I don't believe prayer is an alternative therapy". Using a more limited



definition of ACTs that excludes spiritual therapies,  $76.6 \pm 4.5\%$  of the women reported using at least one type of ACT.

**Table 13. Prevalence of Alternative/Complementary Therapy Use**

Type of Prevalence of ACT Use	Numerator/ Denominator	Frequency (%)
Liberal Estimate of ACT Use (including all ACTs, see Appendix 8)	267 / 334	79.9
Conservative Estimate of ACT Use (all ACTs except spiritual therapies)	256 / 334	76.6
More Conservative Estimate of ACT Use (all ACTs except spiritual therapies, vitamin/mineral supplements, diet therapies, naturopathy, aromatherapy, chiropractic, massage therapy, therapeutic/healing touch, psychological therapies, art/music therapy)	160 / 334	48.2
Most Conservative Estimate of ACT Use (includes only Auyrvedic, homeopathy, First Nations healing, TCM, Essiac, Hoxsey therapy, shark cartilage, coffee enemas and colonic irrigation, Condriana, hydrogen peroxide, chelation, immuno-augmentative therapy)	65 / 334	19.5

In an attempt to provide a more realistic estimate of prevalence of ACT use that acknowledged the "mainstreaming" of certain ACTs through the use of these therapies in conventional cancer treatment centres (e.g., relaxation therapy, music therapy), partial reimbursement through the British Columbia Medical Services Plan at the time of survey completion (e.g., naturopathy, massage therapy), and the recognition of selected therapies as being lifestyle choices (e.g., vitamin/mineral supplements, dietary changes, yoga), a more conservative estimate of ACT use was calculated. This estimate excluded the following ACTs: spiritual therapies; vitamin/mineral supplements; diet changes (cleansing diets, juice therapy, mushrooms, soy); aromatherapy and naturopathy; tai chi, yoga, and qi gong; imagery, meditation, relaxation and therapeutic/healing touch; and art/music therapy. This conservative definition of ACTs resulted in  $48.2 \pm 5.4\%$  of the respondents reporting the use of at least one type of ACT following their breast cancer diagnosis.

A final, most conservative estimate of prevalence of ACT use, was calculated that included those therapies that have been considered by some North American conventional health-care providers to be the farthest along the continuum of "alternativeness". Therapies included in this definition were physically invasive (e.g., coffee enemas, chondriana) and have been claimed to cure cancer (e.g., Essiac, shark cartilage) (Kaegi, 1998a; Miller, Anderson, Stark, Granick, & Richardson, 1998). Natural health practices, including Auryvedic medicine, homeopathy, First Nations healing, and traditional Chinese medicine were also included in this definition because of the acknowledgement of these practices as alternative health-care systems that have developed independent of conventional medicine and have an explicit belief

paradigm (Anonymous, 1997). Only  $19.5 \pm 4.3\%$  of respondents reported using at least one of these types of ACTs.

The overall prevalence rate of ACT use in this sample ranged from a most liberal estimate of  $79.9\% \pm 4.3\%$  to a most conservative estimate of  $19.5\% \pm 4.3\%$ . When using the most conservative estimate of ACT use, at least one in five women surveyed reported using one type of ACT since her diagnosis of breast cancer. For all subsequent analyses, both the liberal and the more conservative inclusion criteria for ACT use are used.

#### **Prevalence of Alternative/Complementary Therapy Use by Therapy Type**

Table 14 illustrates the ten most frequently reported ACTs used by women following breast cancer diagnosis. With the exception of prayer, echinacea and massage therapy, vitamin and mineral supplements comprised the majority of these therapies. A more detailed enumeration of ACT use is found in Appendix 8.

**Table 14. Most Frequently Reported Alternative/Complementary Therapies**

<b>Alternative/Complementary Therapy</b>	<b>Frequency</b>	<b>% (95% CI)</b>
Vitamin E	166	49.7 (44.3 – 55.1)
Vitamin C	155	46.4 (41.0 – 51.8)
Calcium	147	44.0 (38.7 – 49.3)
Prayer	114	34.1 (29.0 – 39.2)
B Vitamins	94	28.1 (23.3 – 32.9)
Vitamin D	94	28.1 (23.3 – 32.9)
Echinacea	87	26.0 (21.3 – 30.7)
Selenium	81	24.3 (19.7 – 28.9)
Vitamin A	72	21.6 (17.2 – 26.0)
Massage Therapy	65	19.5 (15.2 – 23.7)

*Note.* N = 334. Percentages do not add to 100% because some of the respondents used more than one of the therapies listed.

The most frequently reported type of ACT used by the respondents following their breast cancer diagnosis was vitamin/mineral supplements. Sixty-eight percent ( $\pm 5.0\%$ ) of women reported using at least one type of vitamin or mineral supplement as part of their post-diagnosis health regimen. Herbal and plant therapies comprised the second most frequently reported type of ACT, with  $41.3 \pm 5.3\%$  of the women reporting the use of at least one type of herbal or plant remedy. Just over one third of the women used some combination of prayer, laying on of hands,

or other form of spiritual therapy. The least frequently reported ACTs were those classified under miscellaneous therapies (see Appendix 8) and included such invasive therapies as colonic irrigation, chondriana, hydrogen peroxide, chelation therapy, and immuno-augmentative therapy. Only 10 women reported using these types of therapies in the period following their breast cancer diagnosis. Further details of prevalence rates of ACT use by therapy type are provided in Table 15.

**Table 15. Prevalence of Alternative/Complementary Therapy Use by Therapy Type**

Type of Alternative/Complementary Therapy	Frequency	% (95% CI)
Vitamin/Mineral Supplements	227	68.0 (63.0 – 73.0)
Herbal/Plant Products	139	41.6 (36.3 – 46.9)
Spiritual Therapies	118	35.3 (30.2 – 40.4)
Physical/Movement Therapies	108	32.3 (27.3 – 37.3)
Psychological/Expressive Therapies	81	24.3 (19.7 – 28.9)
Alternative Medical Systems	56	16.8 (12.8 – 20.8)
Energy Therapies	52	15.6 (11.7 – 19.5)
Pharmacological/Biological Supplements	49	14.7 (10.9 – 18.5)
Diet Changes/Therapies	32	9.6 (6.4 – 12.8)
Miscellaneous Therapies	10	3.0 (1.2 – 4.8)

*Note.* N = 334. Percentages do not add to 100% because some respondents used more than one therapy.

### **Effect of Demographic Characteristics on Alternative/Complementary Therapy Use**

While the effect of selected demographic characteristics on the women's use of ACTs following their breast cancer diagnosis were tested within three comprehensive models of ACT use, the associations between age, marital status, education, income, ethnicity, and recurrence history and women's ACT use were examined. The results of the cross-tabulations are provided in Table 16. Marital status, educational attainment, and income were found to be significantly associated with the use of ACTs following breast cancer diagnosis. Women who were married, had attained greater than a high school education, and who reported an annual household income of \$40,000 or greater were more likely to report using ACTs than women who had not pursued education beyond high school and reported an annual household income under \$40,000. Age, ethnicity, and breast cancer recurrence were not found to be significantly associated with ACT use, however, sample size issues may have influenced the findings. In addition, the use of an open-ended question asking respondents to indicate what ethnic/cultural group best described them made determining respondents' country of origin and degree of acculturation difficult and may have reduced the usefulness of this variable. The low percentage

of respondents who reported to be of an ethnic/cultural group other than "Caucasian" or "nothing in particular" also reflects the fact that the questionnaire was not translated into languages other than English.

**Table 16. Association of Demographic Characteristics with Alternative/Complementary Therapy Use**

Demographic Variables	ACT Use	
	Yes	No
<u>Age<sup>a</sup></u>		
Under 50 years	37 (88.1)	5 (11.9)
50+ years	222 (77.4)	65 (22.6)
<u>Marital Status<sup>b</sup></u>		
Not Married	76 (71.0)	31 (29.0)
Married	188 (82.8)	39 (17.2)
<u>Educational Attainment<sup>c</sup></u>		
High school and less	84 (71.2)	34 (28.8)
Greater than high school	179 (83.3)	36 (16.7)
<u>Annual Household Income<sup>d</sup></u>		
Less than \$40,000	85 (70.8)	35 (29.2)
\$40,000+	133 (83.1)	27 (16.9)
<u>Ethnicity<sup>e</sup></u>		
Caucasian/"Nothing in Particular"	233 (81.2)	54 (18.8)
Other	27 (79.4)	7 (20.6)
<u>Recurrence<sup>f</sup></u>		
Yes	28 (90.3)	3 (9.7)
No	234 (78.5)	64 (21.5)

<sup>a</sup>  $\chi^2_{(1 \text{ df})} = 1.92$ ;  $p < .17$ , with continuity correction

<sup>b</sup>  $\chi^2_{(1 \text{ df})} = 5.41$ ;  $p < .02$ , with continuity correction

<sup>c</sup>  $\chi^2_{(1 \text{ df})} = 5.98$ ;  $p < .01$ , with continuity correction

<sup>d</sup>  $\chi^2_{(1 \text{ df})} = 5.32$ ;  $p < .02$ , with continuity correction

<sup>e</sup>  $\chi^2_{(1 \text{ df})} = 0.00$ ;  $p < .99$ , with continuity correction

<sup>f</sup>  $\chi^2_{(1 \text{ df})} = 1.74$ ;  $p < .19$ , with continuity correction

### Patterns of Alternative/Complementary Therapy Use

#### Number of Alternative/Complementary Therapies Used

The study participants reported using a total of 1,953 therapies following their breast cancer diagnosis. Using the liberal definition of ACT (all ACTs), the mean number of therapies used by the women following their breast cancer diagnosis was  $5.9 \pm 0.6$  ( $SD = 5.6$ ). The women who used vitamin and mineral supplements, however, were often found to use more than one of these therapies and, as such, may have elevated the mean number of therapies reported. When the use of multiple vitamin and mineral supplements was collapsed into one category of "any vitamin/mineral supplement", the mean number of therapies used was reduced

to  $3.5 \pm 0.4$  ( $SD = 3.6$ ). Using this categorization, only 5.1% of the respondents reported using more than ten ACTs following their breast cancer diagnosis (see Table 17).

When the more conservative estimate of ACT use was used (i.e., eliminating those therapies that are lifestyle choices or recognized within conventional care settings), the mean number of therapies used by women was  $1.2 \pm 0.2$  ( $SD = 1.8$ ). Only 4.0% of women reported using 5 or more of these ACTs following their breast cancer diagnosis.

**Table 17. Number of Alternative/Complementary Therapies Used**

Number of Therapies <sup>a</sup>	Frequency	% (95%CI)
None	67	20.1 (15.8 – 24.4)
1-2	98	29.3 (24.4 – 34.2)
3-5	92	27.5 (22.7 – 32.3)
6-10	60	18.0 (13.9 – 22.1)
>10	17	5.1 (2.7 – 7.5)

Note. N = 334

<sup>a</sup> All ACTs with vitamin/mineral supplements collapsed into one category.

#### Prior Experience with Alternative/Complementary Therapies

The majority of the 334 women who participated in the study ( $64.1 \pm 5.1\%$ ) reported having some experience with ACTs before their breast cancer diagnosis. The mean number of therapies the women had prior experience with was  $1.7 \pm 0.2$  ( $SD = 1.9$ ). Table 18 shows the results of a cross-tabulation conducted to determine the association between prior experience with ACTs and use of ACTs following breast cancer diagnosis. Women with prior experience with ACTs were 29.1 times more likely to have used ACTs after their breast cancer diagnosis than women without previous exposure to ACTs. The most common therapies reported by the 214 respondents who identified themselves as having prior experience with ACTs were vitamins (63.6%), prayer (41.1%), minerals (38.8%), echinacea (18.2%), chiropractics (13.1%), and massage therapy (12.1%). Only nine women reported prior use of therapies included within the most conservative definition of ACT use (i.e., homeopathy, Traditional Chinese Medicine [TCM], chelation, essiac, and shark cartilage).

#### Initiation of Alternative/Complementary Therapy Use

The respondents were asked about when they initiated their use of ACTs in relation to their breast cancer trajectories. This survey item allowed the women to report on those therapies that they had been using prior to their breast cancer diagnosis and continued to use afterwards, as well as those therapies that had been initiated following diagnosis. Of the

**Table 18. Association between Prior Alternative/Complementary Therapy Use and the Use of Alternative/Complementary Therapies Following Breast Cancer Diagnosis**

Prior Experience with ACTs	ACT Use Following Diagnosis	
	Yes	No
Yes	206 (96.3)	8 (3.7)
No	54 (47.0)	61 (53.0)

Note:  $\chi^2_{(1 \text{ df})} = 106.8, p < .001$  with continuity correction. N=329.

therapies for which complete information about initiation was provided ( $n = 1,298$ ), over one half of the therapies ( $55.2 \pm 2.7\%$ ) were initiated following diagnosis. Of the ACTs started prior to the diagnosis of breast cancer ( $n = 584$ ),  $34.8 \pm 3.9\%$  were considered by the women to be an important part of their breast cancer treatment and recovery.

Table 19 provides detailed information about the initiation of ACTs by therapy type. Only two categories of therapies, vitamin/mineral supplements and spiritual therapies were reported by the women to have been, in the majority of cases, initiated before diagnosis of breast cancer. Nearly 56% of vitamin/mineral supplements and 78.6% of spiritual therapies were initiated prior to the women's diagnosis ( $n = 1,298$ ). In contrast, over 80% of therapies within the pharmacological/biological supplements, dietary therapies, energy therapies and miscellaneous therapies categories were reported to have been initiated by the women following their breast cancer diagnosis.

**Table 19. Alternative/Complementary Therapy Initiation by Therapy Type**

Therapy Type	Frequency of Therapy Initiation	
	% Before Diagnosis (95% CI)	% After Diagnosis (95% CI)
Alternative Medical Systems	31.9 (30.8 – 33.0)	68.1 (67.0 – 69.2)
Vitamins and Mineral Supplements	55.9 (51.3 – 60.5)	44.1 (39.5 – 48.7)
Herbal/Plant Products	34.1 (27.9 – 40.3)	65.9 (59.7 – 72.1)
Pharmacological/Biological Supplements	17.7 (8.2 – 27.2)	82.3 (72.8 – 91.8)
Dietary Therapies	13.3 (1.1 – 25.5)	86.7 (74.2 – 99.2)
Physical/Movement Therapies	41.5 (33.5 – 49.5)	58.5 (50.5 – 66.5)
Energy Therapies	16.1 (6.9 – 25.3)	83.9 (74.7 – 93.1)
Psychological/Expressive Therapies	37.9 (29.4 – 46.4)	62.1 (53.6 – 70.6)
Spiritual Therapies	78.6 (71.4 – 85.8)	21.4 (14.2 – 28.6)
Miscellaneous Therapies	10.0 (0 – 28.6)	90.0 (71.4 – 100.0)

Note. Complete information regarding therapy initiation was available for 1,298 therapies (66.5% of therapies reported).

When vitamin/mineral supplements and spiritual therapies were collapsed into one category and compared with all other therapy types, the association between therapy type and therapy initiation (before vs. after diagnosis) was significant. Vitamin/mineral supplements and spiritual therapies comprised 60.9% of therapies that were started before the women's breast cancer diagnosis, whereas all other therapy types comprised only 31.9% of therapies started following diagnosis (see Table 20). Given the integration of vitamin/mineral supplements and spirituality into everyday life, it is not surprising that these therapies were more likely to have been initiated by women with breast cancer before diagnosis rather than afterwards.

**Table 20. Comparison of Therapy Initiation by Therapy Type**

Therapy Type	Therapy Initiation	
	Before Diagnosis	After Diagnosis
Vitamin/Mineral Supplements and Spiritual Therapies	60.9%	39.1%
All Other Therapy Types	31.9%	68.1%

Note.  $\chi^2_{(1 df)} = 108.7$ ;  $p < .001$  with continuity correction

#### Current Use of Alternative/Complementary Therapies

Of the 267 women who reported using ACTs following their breast cancer diagnosis,  $91.8 \pm 1.6\%$  were still using at least one type of ACT (using the liberal definition of ACT use) at the time they participated in the research study. The mean number of ACTs currently used by the respondents was  $3.8 \pm 0.4$  ( $SD = 2.8$ ). If the more conservative estimate of ACT use was used to examine the current use of ACTs,  $35.5 \pm 0.1\%$  were still using at least one type of ACT at time they completed the study questionnaire. The mean number of "more conservative" therapies currently used was  $0.72 \pm 0.1$  ( $SD = 1.2$ ).

The respondents listed a total of 330 therapies that they had stopped using at some time following their breast cancer diagnosis. Herbal/plant products ( $23.6 \pm 4.6\%$ ), physical therapies ( $17.6 \pm 4.1\%$ ), vitamin/mineral supplements ( $15.2 \pm 3.9\%$ ), and energy therapies ( $12.4 \pm 3.6\%$ ) were the four most frequently reported therapies that were discontinued. Of those ACTs that were included in the most conservative definition of ACT use (see Table 13), the respondents had discontinued  $48.5 \pm 10.0\%$  of these therapies. Excluding those respondents with a recurrence or second diagnosis of breast cancer, the mean elapsed time from initial breast cancer diagnosis to the discontinuation of an ACT was  $11.0 \pm 0.9$  months ( $SD = 7.5$ ).

Time of therapy initiation was associated with the women's current use of ACTs (see Table 21). Therapies that had been initiated before the women's breast cancer diagnosis were

6.4 times more likely to be in use at the time of data collection than those therapies initiated after the breast cancer diagnosis.

**Table 21. Association between Time of Therapy Initiation and Current Use of ACTs at Time of Survey Completion**

Time of Therapy Initiation	Current Use of ACTs	
	Yes (%)	No (%)
Before Breast Cancer Diagnosis	523 (91.0)	52 (9.0)
After Breast Cancer Diagnosis	430 (61.2)	273 (38.8)

Note:  $\chi^2_{(1 df)} = 146.0$ ,  $p < .001$  with continuity correction. N=1,278.

#### Frequency of Alternative/Complementary Therapy Use

The majority of the 1,331 therapies with complete frequency data (61.9%; see Table 22) were used on a daily basis, with vitamin/mineral supplements, herbal/plant therapies, and spiritual therapies comprising  $46.8 \pm 3.4\%$ ,  $17.8 \pm 2.6\%$  and  $11.2 \pm 2.2\%$  of these therapies, respectively. Therapies that were most often used less than once a week included physical/movement therapies ( $32.0 \pm 5.9\%$ ), herbal/plant therapies ( $17.4 \pm 4.8\%$ ), and energy therapies ( $16.2 \pm 4.7\%$ ).

**Table 22. Frequency of Alternative/Complementary Therapy Use**

Frequency of ACT Use	Frequency	% (95% CI)
Less than once a month	105	7.9 (6.4 – 9.4)
Once a month	75	5.6 (4.4 – 6.8)
Once every two weeks	61	4.6 (3.5 – 5.7)
Once a week	142	10.7 (9.0 – 12.4)
Every other day	124	9.3 (7.7 – 10.9)
Daily	824	61.9 (59.3 – 64.5)

Note: Complete information regarding the frequency of therapy use was available for 1,331 therapies.

#### **Effort Involved in Using Alternative/Complementary Therapies**

Using a ten-point scale (1 being “no effort” and 10 being “most effort”) the women were asked to rate the degree of effort involved in using each ACT. Respondents rated the majority of therapies ( $78.7 \pm 2.2\%$ ;  $n = 1,317$ ) as requiring an effort of 3 or less, with the average level of effort expended on an ACT being  $2.4 \pm 0.1$  ( $SD = 2.2$ ). When the degree of effort involved in using ACTs is considered by therapy type, the respondents rated miscellaneous therapies, energy therapies, and physical/movement therapies as requiring the greatest mean effort (see Table 23). When degree of effort was dichotomized into minimal effort (less than 4) and greater



effort (4 or greater), respondents rated pharmacological/biological supplements, vitamins/mineral supplements, and herbal/plant products as requiring minimal effort.

**Table 23. Effort Involved in Using Alternative/Complementary Therapies by Therapy Type**

Therapy Type	Mean	95% CI	SD	% Therapies	
				Min. Effort (0 to 3)	Greater Effort (4 to 10)
Miscellaneous Therapies	4.0	1.9-6.1	2.7	55.6	44.4
Energy Therapies	3.9	3.2-4.6	2.8	50.8	49.2
Physical/Movement Therapies	3.4	3.0-3.8	2.5	61.1	38.9
Psychological/Expressive Therapies	3.0	2.6-3.4	2.2	66.9	33.1
Alternative Medical Systems	2.8	2.3-3.4	2.3	73.1	26.9
Dietary Therapies	2.5	1.5-3.4	2.5	78.6	21.4
Spiritual Therapies	2.4	2.0-2.8	2.3	80.2	19.8
Herbal/Plant Products	2.0	1.7-2.2	1.7	86.8	13.2
Vitamins and Mineral Supplements	1.8	1.6-1.9	1.5	90.3	9.7
Pharmacological/Biological Supplements	1.6	1.3-2.0	1.3	91.2	8.8

*Note.* Complete information regarding effort involved in therapy use was available for 1,263 therapies.

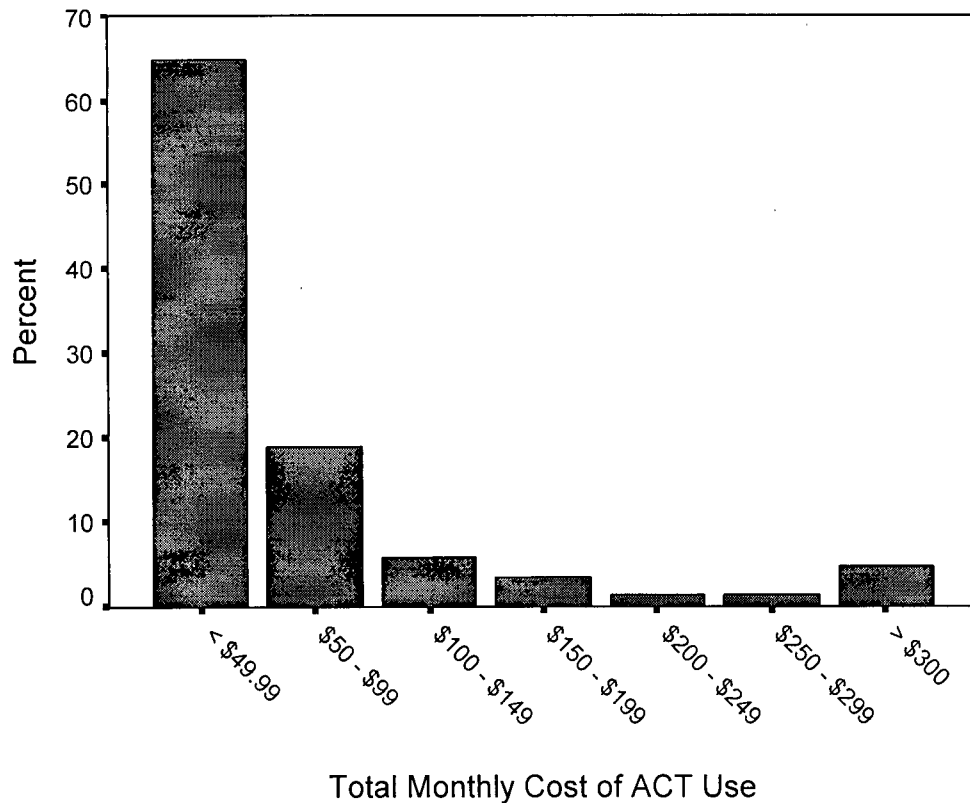
### Cost of Alternative/Complementary Therapy Use

The average monthly cost per specific ACT was  $\$20.61 \pm \$2.67$  ( $SD = \$47.48$ ;  $n = 1,217$ ), with the most expensive therapy (dietary changes and addition of soy products) reported by one woman to cost \$700.00 per month. Because some respondents had discontinued selected ACTs at the time of data collection, the women's monthly expenditures on ACTs were calculated for those therapies currently in use. The mean monthly expenditure for the women currently using ACTs (liberal definition of ACT use and  $n = 229$  women currently using ACTs with complete cost information) was  $\$70.05 \pm \$18.10$  per month ( $SD = 139.4$ ), with the majority of the women ( $64.6 \pm 6.2\%$ ) spending less than \$50 a month (see Figure 7). The mean monthly cost of current ACT use, however, was inflated by a small percentage of women ( $7.8 \pm 3.5\%$ ) who reported spending over \$200 a month on current ACT use. The median monthly cost of \$25.00 represents a more appropriate estimation of respondents' current expenditures.

Using the more conservative definition of ACT use (see Table 13), women spent an average of  $\$14.11 \pm \$4.95$  per month ( $SD = 44.14$ ) on ACTs, with most women ( $94.2 \pm 0.1\%$ ) spending under \$50 per month on these therapies. The median monthly expenditures on therapies classified as "more conservative" was \$25.00.

Some women in the study shared additional insights into the financial costs associated with their use of ACTs. Several women found their choice of ACTs to be restricted because of the "exorbitant expense" of selected therapies. Other women struggled with the financial burden

imposed by their ACT use. For example, one woman wrote, "...After one month of being on naturopathic remedies, I started to recover, but it cost me a fortune and I had to borrow money to pay for it all." Other respondents wrote about their disappointment in the lack of provincial medical insurance coverage for many therapies that they used, including vitamin/mineral supplements, herbal/plant products, and diet therapies.



**Figure 7. Total Monthly Cost of Current Alternative/Complementary Therapy Use (Liberal Definition)**

#### **Sources of Information about Alternative/Complementary Therapies**

The 267 respondents who reported using ACTs following their breast cancer diagnosis sought or received information about ACTs from a variety of sources. The most frequently cited sources of ACT information included family members or friends ( $56.7 \pm 5.9\%$ ), print material ( $37.6 \pm 5.8\%$ ), health food stores ( $22.4 \pm 5.0\%$ ), and conventional medical doctors ( $21.7 \pm 4.9\%$ ). One woman, who was personally contacted by the researcher for follow-up, spoke of having "everyone coming out of the wood-work to tell me about a therapy [ACT] that they had read about." Only  $5.3 \pm 2.7\%$  of respondents reported seeking or receiving information about ACTs from a nurse. Additional sources of information about ACTs used by respondents are listed in Table 24.

### Disclosure of Alternative/Complementary Therapy Use

In response to the query about whether they had disclosed their therapy use to their conventional health-care providers,  $42.1 \pm 6.9\%$  of the women reported that all of their physicians were aware of their use of these therapies ( $n = 195$ ). An additional  $28.2 \pm 6.3\%$  of ACT users reported that they had informed their family physician about their therapy use, but not their specialists (e.g., surgeon, oncologist, or radiologist). Only 3.4% of respondents had disclosed their ACT use to their specialists but not to their family physician.

**Table 24. Reported Sources of Information about Alternative/Complementary Therapies**

Sources of Information about ACTs	Frequency	% (95% CI)
Family and friends	149	56.7 (50.8 – 62.6)
Books/magazines/newspaper	99	37.6 (31.8 – 43.4)
Health food store	59	22.4 (17.4 – 27.4)
Medical doctor	57	21.7 (16.8 – 26.6)
Television/radio	32	12.2 (8.3 – 16.1)
Support group	23	8.7 (5.3 – 12.1)
Internet	15	5.7 (2.9 – 8.5)
Nurse	14	5.3 (2.6 – 8.0)
Church/religious training	13	4.9 (2.3 – 7.5)
Other conventional health professionals (e.g., dentist, pharmacist)	5	1.9 (0.3 – 3.5)
Educational courses	3	1.1 (0 – 2.4)
ACT practitioner	3	1.1 (0 – 2.4)

*Note:* N = 267. Percentages do not add up to 100% because some respondents reported more than one source of ACT information.

Several women wrote additional comments on their surveys regarding their experiences of disclosing ACT use within conventional health-care settings. For some women, they perceived their physicians to be “too old to change” or “too busy discrediting natural therapies” to feel comfortable in disclosing their use of ACTs. Other women praised the support and encouragement they received from their physicians regarding their use of selected ACTs to help them cope with the side effects of conventional cancer therapies or to restore their sense of well being. The following quotation illustrates both the positive and negative aspects of disclosure that women using ACTs encountered: “I was very fortunate to have a [doctor] that truly listened to my concerns and shared some literature regarding alternative therapies. This was not my experience with all [the doctors] I saw, which made the process difficult”.

## Chapter 6

### Model Preparation

This chapter describes the process followed prior to testing the three hypothesized structural equation models of alternative/complementary therapy (ACT) use. Model preparation included the management of missing data, examination of the univariate and bivariate properties of the models' indicators, confirmation of the indicators of the latent variables, and assessment of the measurement model using confirmatory factor analysis. This process is described for each of the three models of ACT use.<sup>32</sup>

### Preventive Model of Alternative/Complementary Therapy Use

#### Examination of Missing Data

The examination and handling of missing data in the Preventive Model (Model 1a) dataset occurred in a step-wise fashion: deletion of cases with substantial missing data, deletion of items with substantial missing data, imputation of values for selected variables with missing data, and list-wise deletion of remaining cases with persistent missing values (i.e., for which no imputation could be made). In the first step, eight cases that had missing data on more than 15% of the original set of indicators for the Preventive Model (Model 1a) were deleted from the sample to reduce the likelihood of systematic error or bias (Knapp, 1998). No significant difference on selected demographic variables (i.e., age, marital status, educational level achieved, recurrence of breast cancer) were noted between those cases deleted from the dataset because of missing data and those cases retained. The indicators were then examined to determine the incidence and pattern of remaining missing data (see Table 25). Variables of

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<sup>32</sup> A numbering system was established to distinguish between the three models and their respective modifications. The initial Preventive, Ameliorative, and Restorative models were numbered Models 1a, 2a, 3a, respectively. As revisions were sequentially added to the measurement or structural models, the model numbers were changed accordingly (e.g., 1a, 1b, 1c, 1d, 1e, and 1f). Each modification to a model was limited to one measurement or structural change (i.e., the addition of one and only one effect or covariance).

concern included household income (TOTINC), the combined frequency and effort measure (FQEFTOT), and total monthly cost of ACT use (COSTTOT). Just over 16% of the sample did not respond to the item on annual income. Several women commented that they did not understand the relevance of the income item on a survey about ACT use. The 52 cases with missing income data were examined with regards to age, marital status, level of education, and recurrence of breast cancer to determine if non-respondents differed from those who responded. Individuals who did not answer the income item were more likely to be older (i.e., 50 years or greater;  $\chi^2_{(1 \text{ df})} = 5.7, p < 0.01$ ) and to have less education (i.e., high school or less;  $\chi^2_{(1 \text{ df})} = 4.2, p < 0.05$ ) than individuals who answered the income item. Because this finding suggested that missing data on income occurred non-randomly, deletion of cases with missing values on income was not an appropriate procedure. While imputation of missing data may be preferred over the strategy of deleting indicators from a study, household income is a difficult measure to predict or estimate from known sociodemographic characteristics (Jeffery, 1998). Consequently, total household income was omitted from the Preventive Model (Model 1a) and education was used as an indicator of socioeconomic status. The interdependency of income and education has been noted by other researchers (Deonandam, Campbell, Ostbye, Tummon, & Robertson, 2000).

With regards to the *Commitment to ACTs* indicators, 3.1%, 6.4%, and 13.8% of the sample, respectively, had incomplete data on the NUMACT, FQEFTOT, and COSTTOT summative scores for those therapies currently in use and classified under the more conservative definition of ACT use. Because of the limited number of cases ( $n = 10$ ) that failed to provide information regarding whether a therapy was presently being used, the assumption was made that those therapies with missing data on the timing of their usage were currently in use, resulting in no missing data for the NUMACT variable. Cases with missing data on the FQEFTOT and COSTTOT variables were examined on selected sociodemographic characteristics to determine if the non-respondents differed from the respondents. No significant differences were found between individuals who responded to all items summarized by the FQEFTOT indicator and those who did not respond. Individuals who did not respond to all items measuring the monthly cost of ACTs were more likely to have post-secondary education (i.e., greater than high school;  $\chi^2_{(1 \text{ df})} = 11.1, p < 0.01$ ) and to be married ( $\chi^2_{(1 \text{ df})} = 4.8, p < 0.05$ ) than individuals who had no missing data on the COSTTOT indicator.

**Table 25. Summary of Missing Data in the Preventive Model of Alternative/ Complementary Therapy Use**

Variable	Frequency
Age (DATBIRTH)	0
Income (TOTINC)	52
Education (EDUCATE)	1
Previous Use of ACTs	
PREVIOUS	2
Encouragement to Use ACTs	
ENCOUR1	1
ENCOUR2	1
ENCOUR3	1
ENCOUR4	3
Perceived Likelihood of Breast Cancer Recurrence	
PLRS1	2
PLRS2	4
PLRS3	2
PLRS4	4
PLRS5	2
PLRS6	4
Perceived Efficacy of ACTs	
PEACTS1	0
Perceived Barriers to Using ACTs	
PBACT1	3
PBACT2	4
PBACT3	3
PBACT4	3
PBACT5	4
PBACT6	2
PBACT7	2
Perceived Control	
CONTRL1	0
CONTRL2	1
CONTRL3	0
Commitment to ACTs <sup>a</sup>	
NUMACTS <sup>b</sup>	10
FQEFTOT	21
COSTTOT	45

Note. N= 326

<sup>a</sup> Commitment to ACTs in the Preventive Model was limited to those therapies currently in use and classified under the "more conservative" definition of ACT use (see Table 13)

<sup>b</sup> Missing data for NUMACTS is a result of missing data related to whether the therapy(s) were currently in use.

Based on the non-random nature of the missing data on the COSTTOT indicator and the importance of the FQEFTOT and COSTTOT indicators in the structural equation models, a decision was made to impute values for cases with missing data using the therapy-specific means for the frequency, effort, and cost items. For example, if the monthly cost of echinacea was not provided by a respondent, the mean monthly cost of echinacea was substituted using the data from all respondents currently using echinacea. The summative COSTTOT score was then calculated as outlined in Chapter 4 (p. 93). Because the frequency and effort items were Likert-type scales, the mean value for these items was rounded to the nearest response

category (i.e.,  $2.6 = 3.0$ ). While the use of mean values for the imputation of missing data is controversial (Knapp, 1998), the method is considered to be conservative because the mean for the distribution of the variable is not altered (Tabachnick & Fidell, 1996). The variance of the variable, however, is reduced by this missing data technique and may attenuate the correlation the variable has with other variables. Table 26 provides an overview of which therapies and variables required imputation of missing data.

Following the imputation of values on the *Commitment to ACTs* variables and prior to structural equation modelling, the dataset was reviewed for any remaining missing data. Because a small number of cases had missing data on other variables, list-wise deletion was used, resulting in the further deletion of 14 cases. This method is preferred over pair-wise

**Table 26. Frequency of Imputed Missing Data for Commitment to Alternative/Complementary Therapy Variables by Therapy Type**

Therapy Type	Frequency of Imputed Values		
	Commitment to ACT Use Variables		
	Frequency	Effort	Cost
TCM	3	3	5
Aloe	2	2	2
Coffee enemas	1	1	1
Echinacea	9	9	24
Essiac	5	5	6
Ginseng	2	2	2
Hoxsey herbal treatment	-	-	1
Pau d'Arco	1	1	2
Grape seed	2	2	4
Evening primrose	4	4	8
Seaweed	3	3	3
Garlic	1	1	1
Ginkgo biloba	-	1	1
Milk thistle	-	-	1
Red clover	-	-	1
Co-enzyme Q10	1	1	2
Shark cartilage	2	2	3
Lecithin	1	1	3
Omega-3 oils	-	-	1
Glucosamine	-	-	1
Royal jelly	1	1	1
Reflexology	-	-	1
Reiki	1	1	1
Magnet therapy	1	1	1
Chondriana	1	1	1

Note. N = 326

deletion (all cases are included and covariances are calculated using only available pairs of observations), which can result in a non-positive definite covariance matrix and an ambiguous sample size (Schumacker & Lomax, 1996). Cases deleted as a result of list-wise deletion were examined on selected demographic characteristics (e.g., age, education, marital status, recurrence of breast cancer) to determine if missing data occurred randomly in the sample

population. Cases omitted through list-wise deletion were found to be more likely to have reported a recurrence of breast cancer than cases that were retained in the dataset. Given this, the results of the Preventive Model must be applied with caution to women with a recurrence of breast cancer, as the findings may not be generalizable to this sub-group of women.

### Tests of Normality

#### Univariate Normality

Following the examination and treatment of missing data, the univariate characteristics of all variables were examined. Summaries of the univariate characteristics of the exogenous and endogenous variables<sup>33</sup> in the Preventive Model (Model 1a) are provided in Tables 27 and 28, respectively. Of the exogenous variables, PREVIOUS, ENCOUR3, and ENCOUR4 were positively skewed and kurtotic.<sup>34</sup> Most of the respondents indicated that they had limited prior

**Table 27. Univariate Statistics for Exogenous Variables (Preventive Model – Model 1a)**

Variables	Min - Max	M	SD	Median	Skew <sup>a</sup>	Kurtosis <sup>b</sup>
Age (AGE)	34 – 89	62.6	11.2	63.4	-0.19	-0.72
Education (EDUCATE)	1 – 12	5.3	2.8	5.0	0.24	-1.23
Previous Use of ACTs (PREVIOUS)	0 – 12	1.7	1.9	1.0	1.25	1.76
Encouragement to use ACTs:						
Family Members (ENCOUR1)	1 – 4	1.9	1.1	1.0	0.90	-0.62
Friends (ENCOUR2)	1 – 4	1.9	1.0	2.0	0.82	-0.51
Doctor (ENCOUR3)	1 – 4	1.6	0.9	1.0	1.50	1.44
Other Health-Care Providers (ENCOUR4)	1 – 4	1.5	0.8	1.0	1.54	1.58

Note. N = 326

<sup>a</sup>The standard error for the skew of the exogenous variables was 0.14.

<sup>b</sup>The standard error for the kurtosis of the exogenous variables was 0.27.

<sup>33</sup> Exogenous variables are those items representing concepts that are not influenced by other concepts in the model. Endogenous variables are those items representing concepts that are influenced by other concepts in the model.

<sup>34</sup> In SPSS, the ratios of skewness and kurtosis to their standard errors are used as tests of normality, with ratios less than -2.00 and greater than +2.00 indicating substantial deviations from normality. Tabachnick and Fidell (1996) note, however, that the standard errors of skewness and kurtosis decrease with increasing sample size. As a consequence, even minor deviations from normality may result in the null hypothesis being rejected. Simulation research has further found that in samples of 200 or more, violations of normality have minimal effect (Waternaux, 1976). In large samples, Tabachnick and Fidell (1996) suggest using the shape of the distribution and the absolute skewness and kurtosis values rather than formal inference tests to determine violations of normality. Bootstrapping was conducted following SEM to address the possibility of biases in the parameter estimates because of non-normality (West, Finch, & Curran, 1995).



experience with ACTs and had received little or no encouragement to use ACTs from their physician(s) or other health professionals. As violations of normalcy in structural equation modelling can lead to model estimation difficulties (West et al., 1995), a logarithmic transformation was conducted on the exogenous variable PREVIOUS. The skew and kurtosis of this variable was reduced (skew = .12, kurtosis = -1.21). Given the potential ambiguity in ENCOUR4 with regards to "other health professionals" and the high correlation between ENCOUR3 and ENCOUR4 ( $r = 0.72$ ), ENCOUR4 was omitted from the Preventive Model (Model 1a) and ENCOUR3 was retained as an indicator of conventional health providers' support of women's use of ACTs. The decision to transform or re-code ENCOUR3 was deferred until the bivariate normality of the item was considered.

Of the endogenous variables (see Table 28), NUMACT, FQEFTOT, and COSTTOT had the most serious violations of univariate normality. Logarithmic transformations

**Table 28. Univariate Statistics for Endogenous Variables (Preventive Model- Model 1a)**

Items	Min- Max	<i>M</i>	<i>SD</i>	Median	Skew <sup>a</sup>	Kurtosis <sup>b</sup>
Perceived Likelihood of Recurrence:						
Chances are great (PLRS1)	1 to 5	2.8	1.1	3.0	0.11	-0.62
Physical health (PLRS2)	1 to 5	2.4	1.1	2.0	0.57	-0.43
Chances in future are high (PLRS3)	1 to 5	2.5	1.1	2.0	0.42	-0.62
Good possibility (PLRS4)	1 to 5	2.7	1.1	3.0	0.01	-0.89
Worry a lot (PLRS5)	1 to 5	2.5	1.2	2.0	0.47	-0.84
Within next year (PLRS6)	1 to 5	1.9	0.9	2.0	0.73	-0.02
Perceived Efficacy of ACTs						
PEACTS1	1 to 5	2.9	1.0	3.0	-0.05	0.16
Perceived Barriers to ACTs						
Give up a lot (PBACT1)	1 to 5	2.4	1.0	2.0	0.38	0.08
Uncomfortable (PBACT2)	1 to 5	2.3	0.8	2.0	-0.03	-0.46
Time consuming (PBACT3)	1 to 5	2.9	0.9	3.0	-0.21	-0.43
Make fun of me (PBACT4)	1 to 5	1.8	0.8	2.0	1.00	0.99
Interfere with activities (PBACT5)	1 to 5	2.4	0.9	2.0	0.23	-0.18
Starting new habit (PBACT6)	1 to 5	2.7	1.0	3.0	0.15	-0.63
Not able to use properly (PBACT7)	1 to 5	2.5	1.0	2.0	0.22	-0.41
Perceived Control						
I am in control (CONTRL1)	1 to 5	2.6	1.1	2.0	0.44	-0.57
Take care of myself (CONTRL2)	1 to 5	2.9	1.0	3.0	0.22	-0.42
Take the right actions (CONTRL3)	1 to 5	2.8	1.0	3.0	0.25	-0.39
Commitment to ACTs						
Number of ACTs (NUMACT)	0 to 8	0.8	1.4	0	2.11	4.69
Frequency x Effort (FQEFTOT)	0 to 225	8.2	20.2	0	5.46	45.02
Monthly Cost (COSTTOT)	0 to 407	16.7	45.8	0	5.30	34.42

N = 326

<sup>a</sup>The standard error for the skew of the endogenous variables was 0.14.

<sup>b</sup>The standard error for the kurtosis of the endogenous variables was 0.27.

were conducted on these variables, resulting in a substantial reduction in skew and kurtosis (NUMACT - skew = 1.11, kurtosis = 0.07; FQEFTOT - skew = 1.04; kurtosis = -0.34; and COSTTOT - skew = 1.00, kurtosis = -0.44). The final item on the Perceived Likelihood of Breast Cancer Recurrence Scale (PLRS6) and PBACT4 on the Perceived Barriers to ACT Use Scale were also examined because of the skew of these variables in relation to other items on their respective scales. Both PLRS6 and PBACT4 had slightly positive skewness, indicating that the majority of respondents disagreed or strongly disagreed with the idea that their breast cancer would recur within the next year and that their family would make fun of their ACT use. The decision was made to delete these indicators from the Preventive Model (Model 1a) dataset.

#### Bivariate Normality

Unlike continuous data, ordinal data are best analyzed in structural equation modelling using polychoric and polyserial correlations<sup>35</sup> (Jöreskog & Sörbom, 1996; Muthén, 1984). Given the nature of the data in the Preventive Model (Model 1a), it was initially decided to undertake structural equation modelling using polychoric and polyserial correlations for all covariate pairs with ordinal variables. Jöreskog (2001) recently provided a method of testing violations to bivariate normality in polychoric and polyserial correlations using a Root Mean Square Estimation of Approximation (RMSEA) measure of population discrepancy. In simulation studies, Jöreskog (2001) found no serious effects of non-normality with RMSEA < 0.100.

PRELIS (a preprocessor computer program for LISREL 8.51) was used to examine the bivariate normality of variables remaining in the Preventive Model (Model 1a) dataset following the elimination of the three variables that violated univariate normality assumptions. Table 29 provides a summary of the variable dyads with questionable bivariate normality, with RMSEA values equal to or greater than 0.100.

While ENCOUR3 performed well in relation to bivariate normality, ENCOUR1 was found to violate bivariate normality assumptions in several dyads. In an attempt to improve the distribution of the item and acknowledge the theoretical similarity between ENCOUR1 and ENCOUR2, the average of ENCOUR1 and ENCOUR2 was used as a combined family and friends' encouragement score. This new item had acceptable univariate characteristics (see Table 31) and was recoded as ENCOURCM.

The Perceived Likelihood of Breast Cancer Recurrence Scale item, PLRS3, was also found to have a non-normal relationship with PLRS2 (RMSEA = 0.108). Given the similarity in wording and meaning between PLRS3 and PLRS1, PLRS3 was omitted from the Preventive Model (Model 1a) dataset. A closer examination of the Perceived Likelihood of Breast Cancer Recurrence Scale items also led to the decision to remove PLRS5 (i.e., "I worry a lot about

<sup>35</sup> Likert-type variables may not have equidistant scale steps, resulting in the distortion of Pearson product moment correlations (or covariances) (Muthén, 1984).

having breast cancer come back”) from the Preventive Model (Model 1a) dataset. This decision was supported by the results of an exploratory factor analysis with principal component extraction that found PLRS5 to have the lowest loading (0.62) on the specified single factor.

**Table 29. Bivariate Normality Violations for Exogenous and Endogenous Variables in the Preventive Model (Model 1a) Following Transformations**

Variables			Correlation	Test of Close Fit	
				RMSEA	p-value
ENCOUR1	VS	ENCOUR2	.68	0.103	.404
ENCOUR1	VS	FQEFTOT	.38	0.162	.007
ENCOUR1	VS	COSTTOT	.38	0.138	.062
PLRS3	VS	PLRS2	.64	0.108	.291
PBACT1	VS	FQEFTOT	.15	0.125	.119
PBACT1	VS	COSTTOT	.15	0.122	.151
PBACT2	VS	FQEFTOT	.17	0.115	.249
PBACT2	VS	COSTTOT	.17	0.132	.083
PBACT3	VS	PBACT1	.45	0.149	.001
PBACT3	VS	PBACT2	.48	0.170	.000
PBACT5	VS	PBACT1	.57	0.121	.080
PBACT5	VS	PBACT2	.64	0.129	.029
PBACT5	VS	PBACT3	.62	0.147	.001
PBACT6	VS	PBACT1	.48	0.109	.267
PBACT6	VS	PBACT2	.48	0.124	.054
PBACT6	VS	PBACT3	.60	0.123	.063
PBACT6	VS	PBACT5	.61	0.148	.001
PBACT7	VS	PBACT2	.59	0.106	.320
PBACT7	VS	PBACT3	.38	0.108	.282
PBACT7	VS	PBACT5	.53	0.138	.006
PBACT7	VS	PBACT6	.65	0.144	.002
CONTR3	VS	CONTR2	.92	0.101	.452

Note. N = 312 (list-wise deletion)

The Perceived Barriers to ACT Use items performed poorly with regard to bivariate normality. An exploratory factor analysis with principal component extraction estimated a one-factor solution with factor loadings ranging from .75 to .81. Despite this result, a three-factor extraction using principal component with varimax rotation was attempted because of the three distinct types of barriers to ACT use represented in the scale items. Based on the item wording, barriers to ACT use could be partitioned into external barriers (i.e., PBACT3 - time consuming; PBACT5 - interfere with activities; PBACT1 - give up a lot), internal barriers (i.e., PBACT6 - starting a new habit; PBACT7 - being able to use therapies properly), and pain barriers (i.e., PBACT2 - uncomfortable). This hypothetical factor solution was supported by the factor analysis with the exception of PBACT1, which had a factor loading of .87 on the pain barrier subscale. The decision was made to omit PBACT1 from the Preventive Model (Model 1a) dataset and combine PBACT3 and PBACT5 into an external barrier item (recoded as PBACTE)

and PBACT6 and PBACT7 into an internal barrier item<sup>36</sup> (recoded as PBACTI). The univariate statistics for the revised items are shown in Table 30.

The bivariate normality for CONTRL3 and CONTRL2 was slightly over the RMSEA criterion of .100. Based on the sound univariate properties of these variables and the preference of having at least three indicators for each latent construct (Kelloway, 1995), both CONTRL2 and CONTRL3 were retained in the Preventive Model dataset. Retention of these variables is well within the expectation that the tests of a model's indicators to determine if an underlying bivariate normal distribution occurs will result in a 1% long-run rejection rate (Jöreskog & Sörborm, 1996).

**Table 30. Univariate Statistics for Revised and New Variables (Preventive Model – Model 1a)**

Items	Min-Max	<i>M</i>	<i>SD</i>	Median	Skew <sup>a</sup>	Kurtosis <sup>b</sup>
Prior Use of ACTs PREVIOUS	0 to 1.0	0.4	0.3	0.3	0.12	-1.21
Encouragement to Use ACTs ENCOURCM	1 to 4	1.9	0.9	1.5	0.85	-0.39
Perceived Barriers to ACT Use PBACTE	1 to 5	2.7	0.8	3.0	-0.01	0.16
PBACTI	1 to 5	2.6	0.9	2.5	0.10	-0.38
Commitment to ACT Use NUMACT	0 to 1.0	0.2	0.3	0	1.11	0.00
FQEFTOT	0 to 2.4	0.4	0.6	0	1.02	-0.39
COSTTOT	0 to 2.6	0.5	0.7	0	0.99	-0.46

Note. N = 326

<sup>a</sup> The standard error for the skew of the revised and new variables was 0.14.

<sup>b</sup> The standard error for the kurtosis of the revised and new variables was 0.27.

Following the revisions to the Preventive Model (Model 1a) dataset resulting from the initial exploration of univariate and bivariate statistics, the bivariate normality of the model items was re-examined. While some variable dyads remained non-normal (see Table 31), Jöreskog (2001) has advised that polychoric correlations have proven to be very robust to violations of underlying bivariate normality in simulation research. Accordingly, no further revisions were made to the Preventive Model (Model 1a) dataset.

<sup>36</sup> Scores for the newly formed combined internal barriers item were obtained by adding the values of the two internal items and taking the average. The same approach was used to obtain scores for the combined external barrier item.

**Table 31. Bivariate Normality Violations for Exogenous and Endogenous Variables in the Preventive Model (Model 1a) following Transformations**

Variables			Correlation	Test of Close Fit	
				RMSEA	p-value
ENCOURCM	VS	FQEFTOT	.37	0.102	.421
PBACT2	VS	FQEFTOT	.18	0.114	.254
PBACT2	VS	COSTTOT	.17	0.132	.086
NUMACT	VS	COSTTOT	.90	0.827	.000

Note. N = 312 (list-wise deletion)

### Confirmatory Factor Analysis of the Measurement Model

A controversy exists in the literature regarding whether a one-step or two-step approach should be taken in structural equation modelling (Hayduk, 1996). In a one-step approach, the structural and measurement models are tested simultaneously. In contrast, the two-step approach tests and establishes the validity of the measurement model prior to testing the structural equation model. According to Jöreskog and Sörbom (1996), "...Testing of the initially specified theory may be meaningless unless it is first established that the measurement model holds" (p. 113). This is particularly appropriate when the factor structure or dimensionality of a scale is in question (Kelloway, 1998). Given the revised nature of many of the items and scales included in the Preventive Model, it was considered prudent to conduct a confirmatory factor analysis of the measurement model prior to beginning structural equation modelling.

The confirmatory factor analysis was conducted on those concepts (factors) in the Preventive Model with multiple indicators, including the concepts, *Encouragement to Use ACTs*, *Perceived Risk of Breast Cancer Recurrence*, *Perceived Barriers to ACT Use*, *Perceived Control over Breast Cancer Recurrence*, and *Commitment to ACT Use*. All factors were allowed to covary by setting the Phi matrix to ST, which fixed the diagonal elements of the matrix to one and the off-diagonal elements as free elements.

Diagonally Weighted Least Squares (DWLS) was selected as the most appropriate estimation method to fit the confirmatory factor model and the associated correlation matrix.<sup>37</sup> Use of the DWLS estimator, however, resulted in a non-positive definite fitted covariance matrix. This may have reflected the limitations of weighted estimation methods with regards to model complexity and sample size (West et al., 1995). The decision was made, based on the univariate and bivariate characteristics of the data<sup>38</sup> (i.e., skew and kurtosis < 1.0;

<sup>37</sup> Previous simulation research has shown maximum likelihood estimation (MLE) to result in biased fit indices, parameter estimates, and standard errors when categorical and non-normal data are modelled (Babakus, Ferguson, & Jöreskog, 1987; Muthén & Kaplan, 1992). DWLS was developed as one of several alternative weighted estimation procedures that provided more accurate parameter and model estimates under conditions of non-normality and categorical data (Wothke, 1993)

<sup>38</sup> While Jöreskog's method for testing bivariate normality violations was developed specifically for polychoric and polyserial correlations, this procedure is applicable in the case of MLE because it assumes each ordinal variable has an underlying continuous metric (Jöreskog, 2001).

RMSEA < .100) and the proven robustness of the maximum likelihood estimator (MLE) (Jöreskog & Sörbom, 1996; West et al., 1995), to use MLE to fit the confirmatory factor model. As such, the items included in the confirmatory factor analysis were treated as continuous variables and a covariance matrix was used to fit the model.

The overall fit<sup>39</sup> of the measurement model (Model 1a) was good (see Table 32), with RMSEA under the criterion of .05 (Steiger, 1990), GFI and AGFI over the criterion of .90 (Kelloway, 1995), and CFI over the criterion of .95 (Hu & Bentler, 1999). The parameter estimates were all statistically significant ( $t \geq 1.96$ ) and all indicators loaded on their respective factors as hypothesized (see Table 33). Factor loadings (completely standardized lambda-x values) ranged from 0.57 to 0.98 and the squared multiple correlations ranged from 0.32 to 0.96 (see Table 33). Item PLRS2 (0.57) approached the factor-loading criterion of  $\geq 0.60$ , but had 68% of its variance attributed to error. Also of concern was item ENCOUR3, which had 61% of its variance assigned as error. Given the small modification indices for the lambda-x and theta-delta (error) matrices and the high internal consistency estimates (Cronbach's alpha) for each subscale, no modifications were deemed necessary to the measurement model of the Preventive Model (Model 1a).

**Table 32. Goodness-of-Fit Indices for the Measurement Model of the Preventive Model (Model 1a)**

	$\chi^2$ (df)	<i>p</i>	RMSEA	GFI	AGFI	CFI
Model 1a	104.25 (67)	.002	.041	0.96	0.93	0.99

### **Inclusion of Women with Breast Cancer Recurrence and Other Cancer Diagnosis**

As mentioned in Chapter Five, women who had experienced a recurrence of breast cancer were to be excluded from the modelling process to prevent the introduction of bias or unmeasured sources of confounding effects. It was hypothesized, based on previous research on ACT use in cancer populations (Truant, 1998; Yates et al., 1993), that women with a recurrence of breast cancer may use ACTs in a manner different than women diagnosed with early-stage disease. Removing the 31 women who reported a breast cancer recurrence,

<sup>39</sup> It is suggested that a variety of fit indices, in addition to the chi square statistic, be used to assess model fit (Hu & Bentler, 1995; Kelloway, 1995). In this study, both absolute and comparative fit indices are reported. Absolute fit indices include the Root Mean Squared Error of Approximation (RMSEA) (based on the analysis of residuals, see Steiger, 1990), the goodness-of-fit index (GFI) (the ratio of the sum of the square discrepancies to the observed variances), and the adjusted goodness-of-fit index (AGFI) (adjusts the GFI for degrees of freedom in the model). The comparative fit index (CFI) is based on the noncentral chi square distribution and compares the theoretical model to a baseline model.

**Table 33. - Factor Loadings and *t*-values for the Measurement Model of the Preventive Model (Model 1a)**

Latent Variable	$\alpha^a$	Item	Loading <sup>b</sup>	<i>t</i> -value	<i>R</i> <sup>2</sup>
Encouragement to use ACTs	.73	ENCOURCM	0.90	12.04	.81
		ENCOUR3	0.63	9.49	.39
Perceived Risk of Recurrence	.82	PLRS1	0.86	16.90	.73
		PLRS2	0.57	10.38	.32
		PLRS4	0.90	17.93	.80
Perceived Barriers to ACT Use	.80	PBACT2	0.71	12.93	.51
		PBACTI	0.75	13.65	.56
		PBACTE	0.79	14.58	.63
Perceived Control over Recurrence	.90	CONTRL1	0.74	15.05	.55
		CONTRL2	0.94	21.52	.89
		CONTRL3	0.93	21.08	.87
Commitment to ACT Use	.90	NUMACT	0.98	24.04	.96
		FQEFTOT	0.97	23.53	.94
		COSTTOT	0.95	22.84	.91

<sup>a</sup> Cronbach's alpha<sup>b</sup> Completely Standardized Lambda-x values

however, substantially reduced the sample size for the Preventive Model, and may have influenced the power of the modelling procedure. Accordingly, *t*-tests were performed on the variables in the Model 1a dataset to determine if women with and without breast cancer recurrence differed significantly on important model constructs. Table 34 provides a summary of this analysis. Using a level of significance of  $p < 0.0027$  (i.e., Bonferroni correction factor =  $0.05/18$ )<sup>40</sup>, no significant mean difference was found between women with a breast cancer recurrence and women without a breast cancer recurrence on the Preventive Model (Model 1a) variables. Women with a recurrence of breast cancer were thus retained in the dataset.

A comparison between women who had been diagnosed with another type of cancer and those who had not was also conducted on the key model constructs. Using a level of significance of  $p < 0.0027$  (i.e., Bonferroni correction factor =  $0.05/18$ ), no significant mean difference was found between these two group of women on the Preventive Model (Model 1a) variables (see Table 35). Women diagnosed with another type of cancer were thus retained in the dataset.

<sup>40</sup> To control for an inflated Type I error because of multiple comparisons, the Bonferroni correction factor is calculated by dividing the level of significance ( $\alpha = .05$ ) by the number of comparisons. In calculating the potential differences between women with and without recurrence in Model 1a, the number of comparisons was equal to the number of model indicators (i.e., 18).

**Table 34. Mean Difference between Women with and without Breast Cancer Recurrence on Preventive Model (Model 1a) Variables**

Variables	t-value	df	p (2-tailed)	Mean Difference
Age (AGE)	0.27	320	.79	0.57
Education (EDUCATE)	-0.10	319	.92	-0.05
Previous Use of ACTs (PREVIOUS)	1.12	318	.26	0.06
Encouragement to use ACTs:				
Family Members/Friends (ENCOURCM)	-1.39	319	.17	-0.25
Doctor (ENCOUR3)	0.57	319	.57	0.09
Perceived Likelihood of Recurrence:				
Chances are great (PLRS1)	-1.83	319	.07	-0.37
Physical health (PLRS2)	-0.58	317	.56	-0.12
Good possibility (PLRS4)	-0.71	318	.48	-0.15
Perceived Efficacy of ACTs PEACTS1	2.23	319	.03	0.41
Perceived Barriers to ACTs				
Uncomfortable (PBACT2)	2.15	317	.03	0.33
Internal (PBACTI)	3.02	319	.003	0.50
External (PBACTE)	1.79	317	.07	0.27
Perceived Control				
I am in control (CONTRL1)	1.86	320	.06	0.38
Take care of myself (CONTRL2)	0.77	319	.44	0.15
Take the right actions (CONTRL3)	2.16	320	.03	0.41
Commitment to ACTs				
Number of ACTs (NUMACT)	-1.34	320	.18	-0.06
Frequency x Effort (FQEFTOT)	-2.15	320	.03	-0.25
Monthly Cost (COSTTOT)	-2.02	320	.04	-0.28

**Measurement Scaling and Reliabilities**

Prior to testing the initial structural model, measurement scaling and reliabilities were incorporated into the Preventive Model of ACT Use (Model 1a). Measurement scales for the concepts were achieved by fixing one concept-indicator relationship ( $\lambda$ -x and  $\lambda$ -y) for each concept at 1.0. Fixed  $\lambda$  coefficients ensured that the exogenous and endogenous concepts were measured on the same measurement scale as the observed indicators and that a unit change in the indicators corresponded to a unit change in the concepts (Hayduk, 1987). While the indicator chosen to have its  $\lambda$  value fixed is often an arbitrary decision (Byrne, 1998), the indicators that had the highest factors loadings and the most variance explained (squared multiple correlations) in the confirmatory factor analysis were chosen to have their  $\lambda$  values fixed at 1.0 (i.e., ENCOURCM, PLRS4, PBACTE, CNTRL2, and NUMACT). Fixing the  $\lambda$  value for these "best" indicators established a "clear and unchanging"



**Table 35. Mean Difference between Women with and without Other Cancer Diagnosis on Preventive Model (Model 1a) Variables**

Variables	t-value	df	p (2-tailed)	Mean Difference
Age (AGE)	-1.21	307	.23	-2.50
Education (EDUCATE)	0.28	306	.78	0.14
Previous Use of ACTs (PREVIOUS)	0.86	305	.39	0.05
Encouragement to use ACTs:				
Family Members/Friends (ENCOURCM)	1.46	306	.15	0.25
Doctor (ENCOUR3)	0.42	306	.68	0.06
Perceived Likelihood of Recurrence:				
Chances are great (PLRS1)	-1.15	305	.25	-0.23
Physical health (PLRS2)	0.55	303	.58	0.11
Good possibility (PLRS4)	-1.71	303	.09	-0.34
Perceived Efficacy of ACTs PEACTS1	0.71	307	.48	0.13
Perceived Barriers to ACTs				
Uncomfortable (PBACT2)	1.89	304	.06	0.29
Internal (PBACTI)	0.80	306	.43	0.14
External (PBACTE)	0.71	304	.48	0.11
Perceived Control				
I am in control (CONTRL1)	0.07	307	.94	0.01
Take care of myself (CONTRL2)	0.64	306	.52	0.12
Take the right actions (CONTRL3)	1.13	307	.26	0.21
Commitment to ACTs				
Number of ACTs (NUMACT)	2.14	307	.03	0.10
Frequency x Effort (FQEFTOT)	2.37	307	.02	0.27
Monthly Cost (COSTTOT)	2.28	307	.02	0.30

meaning and indicated which of the multiple indicators were most representative of the unobservable concepts (Hayduk, 1996). The lambda values for single indicators (AGE, EDUCATE, PREVIOUS, and PEACTION1) were also fixed at 1.0 to set the metric for the concepts.

The decision was also made to fix some of the measurement reliabilities in the Preventive Model (Model 1a).<sup>41</sup> Several SEM authors have contended that a researcher's familiarity with the data collection procedures and the reliability of selected measures should be incorporated into the modelling procedure (Hayduk, 1987, 1996; Ratner et al., 1998). According to Hayduk (1987), this procedure "implies that entities other than the underlying concept can influence the indicator and, hence, acknowledges some unreliability in the measurement of the

<sup>41</sup> In the case of the single-indicator concepts, the error terms had to be fixed to ensure an over-identified model.

concept" (p. 118). Fixing the error variance for the scaling indicators further sharpens the conceptual meaning underlying the model concepts and ensures greater theoretical precision (Hayduk, 1996). The fixed error variances were calculated by multiplying the proportion of the variance in an indicator that was error variance (determined either theoretically or equal to the squared multiple correlation determined in the confirmatory factor analysis) by the observed variance in the indicator. The following reliability assessments were made:

i) *Reported age*: Information on age was collected in the demographic portion of the mailed questionnaire, with participants being asked to provide their date of birth. Because of the limited error associated with the collection of participants' age, one percent of the variance in the indicator was assigned as error. Sources of error included keypunching errors or lack of knowledge of exact birth date by participants.

ii) *Reported education*: Ten percent of the variance was assigned as error for this indicator to accommodate such inaccuracies as the over-reporting of educational achievement and the inability of the response categories to encompass all forms of educational activity.

iii) *Reported previous use of ACTs*: Participants were asked to indicate whether they had used any ACTs before they were diagnosed with breast cancer. It was apparent following telephone contact with selected participants that some women did not conceive all the therapies listed in the questionnaire as "alternative or complementary". As such, a moderate level of variance (15%) for the PREVIOUS item was assigned as error to account for different interpretations of ACTs.

iv) *Measures of encouragement to use ACTs*: The amount of variance in the ENCOURCM variable explained in the confirmatory factor analysis by the underlying concept was 81%, resulting in 19% of the variance in ENCOURCM being designated as error. Error may have occurred as a result of the participants having different interpretations of the item. The error term for the ENCOUR3 item was freely estimated.

v) *Measures of perceived risk of breast cancer recurrence*: In the confirmatory factor analysis, 80% of the variance in the PLRS4 item was explained by the underlying concept. As a consequence, 20% of the variance in PLRS4 was assigned as error. This error may have been due to different interpretations of the item. PLRS1 and PLRS2 did not have fixed error terms.

vi) *Measures of perceived efficacy of ACTs*: The single indicator, PEACTS1, was hypothesized to have 10% of its variance attributable to error. This error may have been due to participants having different interpretations of which therapies were included under the rubric of "ACTs" and what was meant by "recurrence".

vii) *Measures of perceived barriers to using ACTs*: In the confirmatory factor analysis, PBACTE had 63% of its variance explained by the underlying concept *Perceived Barriers to ACT Use*. As a consequence, PBACTE was hypothesized to have 37% of its variance

attributable to error. This error may have been the consequence of participants having different interpretations of this item, depending on the type of ACTs that they had used prior to and following their breast cancer diagnosis. Some women in the study also had difficulty with this scale because of the global reference to "ACTs" that did not allow individual or specific therapy assessment. Items PBACT2 and PBACTI were not assigned fixed error terms.

viii) *Measures of perceived control over breast cancer recurrence*: Following the confirmatory factor analysis, 11% of the variance in the CNTRL2 indicator was specified as error, with the remaining 89% being explained by the underlying concept *Perceived Control*. The error in this indicator may have been the result of differences among participants in their understanding of this item. The error terms for CNTRL1 and CNTRL3 were freely estimated.

ix) *Measures of commitment to ACTs*: The variance of the NUMACT item was partitioned, as a consequence of the confirmatory factor analysis, into 96% explained by the underlying concept and 4% attributable to error. The latter may have been a consequence of different interpretations by participants of what therapies are considered "alternative or complementary" or incorrect information regarding the current status of ACT use. No error variance was fixed for the remaining items on the Commitment to ACTs scale.

### **Summary of the Preparation of the Preventive Model of Alternative/Complementary Therapy Use**

Figure 8 illustrates the structural and measurement portions of the Preventive Model of ACT Use (Model 1a), including all fixed and freed coefficients. This model is referred to in the following chapters as Model 1a, representing the initial Preventive Model of ACT Use to be tested using structural equation modelling. Model 1a attempts to conceptualize, within the context of preventing a recurrence of breast cancer, the relationships among selected health beliefs and women's commitment to ACT use while controlling for specific demographic factors and antecedents of ACT use.

### **Ameliorative Model of Alternative/Complementary Therapy Use**

The exogenous concepts and associated indicators used in the Preventive Model of ACT Use (Model 1a) and also present in the Ameliorative Model (Model 2a) were retained without revision in the latter model. Indicators transferred to the Ameliorative Model (Model 2a) included AGE, EDUCATE, PREVIOUS, ENCOURCM, and ENCOUR3. The endogenous concepts, *Perceived Barriers to ACT Use* and *Commitment to ACTs*, and associated indicators (i.e., PBACT2, PBACTI, PBACTE, NUMACT, FQEFTOT, COSTTOT) were also shifted to the Ameliorative Model of ACT Use (Model 2a) without any further revision. In particular, the imputation of missing values for the *Commitment to ACT Use* indicators and the log transformation of these variables conducted in the development of Model 1a were maintained.

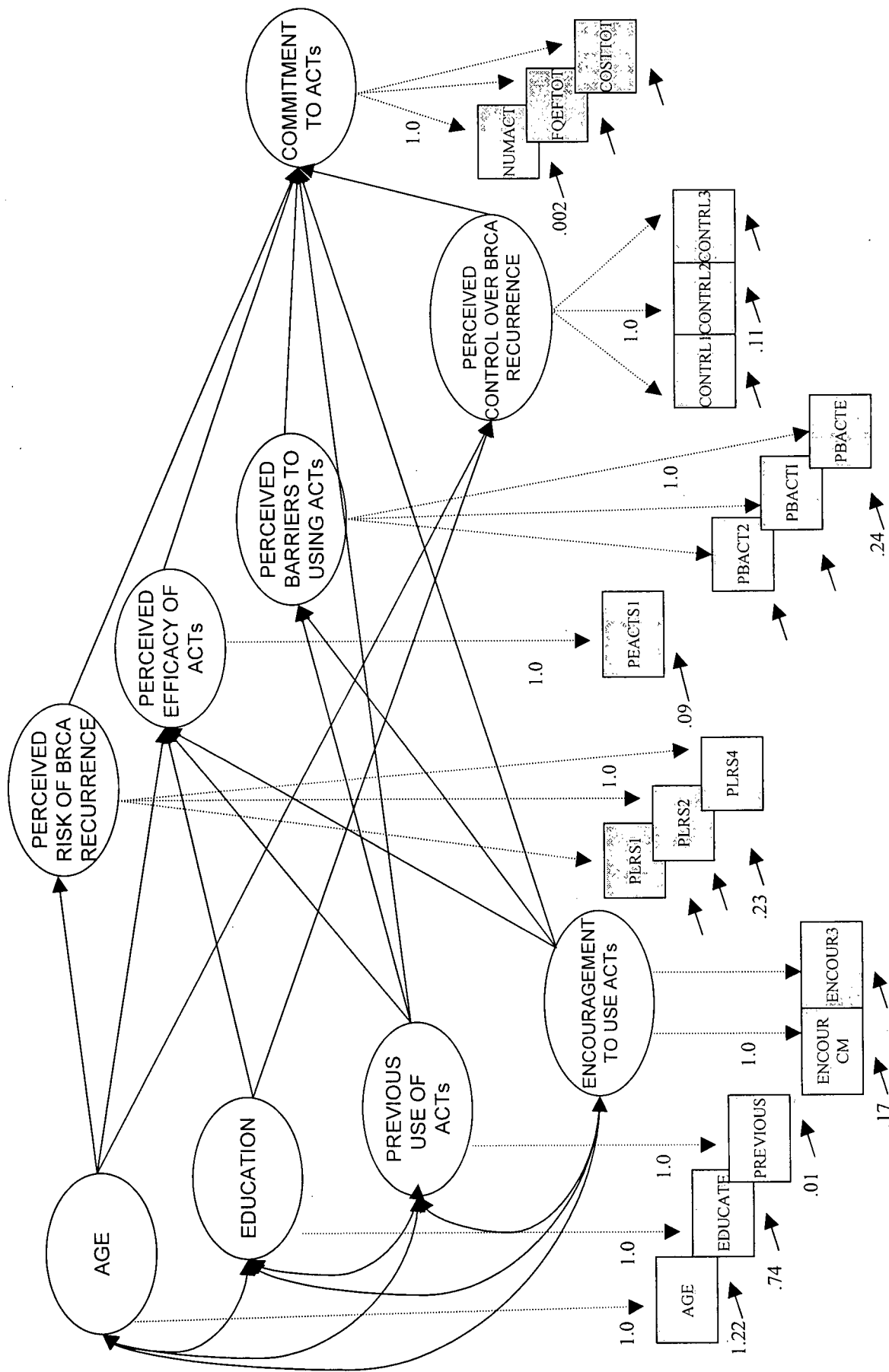


Figure 8. Model 1a - Preventive Model of Alternative/Complementary Therapy Use

Several new concepts and indicators were added to the Ameliorative Model (Model 2a) to capture women's use of ACTs within the context of coping with the adverse effects of breast cancer and conventional cancer treatment. These concepts included *Perceived Symptom Distress* (SDS1 – SDS13), *Perceived Efficacy of ACTs*<sup>42</sup> (PEACTS2 and PEACTION3), and *Perceived Control over Adverse Effects* (CONTRL4, CONTRL5, and CONTRL6).

The development of the Ameliorative Model of ACT Use (Model 2a) before testing with structural equation modelling followed the same process used in the Preventive Model. Missing data in the model were first examined, followed by careful scrutiny of the univariate and bivariate properties of the Ameliorative Model's indicators and confirmation of the indicators of the latent variables. Confirmatory factor analysis was also conducted to verify the measurement model and to establish the measurement scaling and reliabilities included in the model. Prior to conducting the confirmatory factor analysis, the decision was made to use the same estimation procedure (i.e., maximum likelihood estimation; MLE) used in developing and testing the Preventive Model. In using MLE, comparisons between the Preventive and Ameliorative Models of ACT Use were facilitated because both models were tested using the same type of matrix (i.e., covariance matrix).

### **Examination of Missing Data**

An initial review of the Ameliorative Model (Model 2a) dataset revealed that 11 cases were missing data on more than 15% of the total number of indicators. These individuals were deleted from the dataset, resulting in a sample size of 323. No significant difference on selected demographic variables (i.e., age, marital status, educational level achieved, recurrence of breast cancer) were noted between those cases deleted from the dataset because of missing data and those cases retained. Indicators were then examined to determine the incidence and pattern of missing data (see Table 36). No serious problems were noted, with PEACTION3 having the largest amount of missing data with less than 1% of respondents failing to provide an answer to the item. With no further revision indicated for the model indicators, list-wise deletion was used to delete those remaining cases with missing data ( $n = 8$ ). No significant difference was found between those cases deleted through list-wise deletion and those retained in the Ameliorative Model (Model 2a) dataset with regards to selected demographic and disease characteristics (i.e., age, education, marital status, or breast cancer recurrence).

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<sup>42</sup> The concept *Perceived Efficacy of ACTs* in the Ameliorative Model of ACT Use is similar to the concept used in the Preventive Model but measures efficacy of ACTs in the context of managing the side effects and symptoms of breast cancer and conventional cancer treatment rather than in preventing breast cancer recurrence.

**Table 36. Summary of Missing Data in the Ameliorative Model of Alternative/ Complementary Therapy Use (Model 2a)**

Variable	Frequency
Age (DATBIRTH)	0
Education (EDUCATE)	0
Previous Use of ACTs	
PREVIOUS	1
Encouragement to Use ACTs	
ENCOURCM	0
ENCOUR3	0
Perceived Symptom Distress	
SDS1	1
SDS2	1
SDS3	0
SDS4	0
SDS5	1
SDS6	1
SDS7	2
SDS8	0
SDS9	2
SDS10	0
SDS11	0
SDS12	1
SDS13	0
Perceived Efficacy of ACTs	
PEACTS2	1
PEACTS3	3
Perceived Barriers to Using ACTs	
PBACT2	2
PBACTI	0
PBACTE	2
Perceived Control over Adverse Effects	
CONTRL4	1
CONTRL5	1
CONTRL6	1
Commitment to ACTs <sup>a</sup>	
NUMACTS	0
FQEFTOT	0
COSTTOT	0

Note. N=323

<sup>a</sup> Commitment to ACTs in the Ameliorative Model was limited to those therapies currently in use and classified under the "more conservative" definition of ACT use.

## Tests of Normality

### Univariate Normality

The univariate characteristics of all the indicators in the Ameliorative Model (Model 2a) were examined following the analysis of the missing data. Tables 37 and 38 provide summaries of the univariate characteristics of the exogenous and endogenous variables in the model, respectively. As the exogenous variables and their corresponding univariate statistics were nearly identical to those reported in the final Preventive Model (Model 1a), no modifications were made to these variables in the Ameliorative Model (Model 2a).

**Table 37. Univariate Statistics for Exogenous Variables (Ameliorative Model – Model 2a)**

Variables	Min - Max	<i>M</i>	<i>SD</i>	Median	Skew <sup>a</sup>	Kurtosis <sup>b</sup>
Age (AGE)	34 – 89	62.3	11.1	62.9	-0.17	-0.69
Education (EDUCATE)	1 – 12	5.3	2.7	5.0	0.23	-1.29
Previous Use of ACTs (PREVIOUS)	0 – 1.04	0.4	0.3	0.3	0.11	-1.20
Encouragement to use ACTs:						
Encourage Combined (ENCOURCM)	1 – 4	1.9	0.9	1.5	0.84	-0.40
Doctor (ENCOUR3)	1 – 4	1.6	0.9	1.0	1.49	1.44

Note. N = 323

<sup>a</sup>The standard error for the skew of the exogenous variables was 0.14.

<sup>b</sup>The standard error for the kurtosis of the exogenous variables was 0.27.

Of the endogenous variables, several of the indicators on the Symptom Distress Scale (i.e., SDS1, SDS2, SDS3, SDS7, SDS8, SDS11, and SDS13) had serious violations of univariate normality.<sup>43</sup> The majority of respondents reported minimal symptom distress in relation to nausea, appetite, appearance, bowel function, breathing, and coughing. This result is not surprising given that the majority of women had completed their conventional cancer treatment and, as such, was not currently experiencing treatment side effects. In contrast, more variance ( $SD \approx 1.0$ ; Median = 2.0) was apparent in the women's responses to indicators measuring insomnia, presence of pain, fatigue, and outlook.

Exploratory factor analysis using principal component extraction with varimax rotation was used to further examine the factor structure of the Symptom Distress Scale (McCorkle & Young, 1978) and to determine which variables would function as the "best" indicators of women's symptom distress. A three-factor solution was suggested,<sup>44</sup> accounting for 50.0% of the variance.<sup>45</sup> The first factor was comprised of the following eight variables measuring a range of general physical and psychological symptoms (with factor loadings in brackets): SDS4 – Insomnia (0.67), SDS5 – Presence of Pain (0.65), SDS6 – Intensity of Pain (0.69), SDS7 – Appearance (0.57), SDS8 – Bowel Function (0.51), SDS9 – Concentration (0.64), SDS10 – Fatigue (0.67), and SDS12 – Outlook (0.54). The second factor encompassed indicators measuring gastrointestinal symptoms and included the following variables: SDS1 – Presence of Nausea (0.70), SDS2 – Intensity of Nausea (0.74), and SDS2 – Appetite (0.59). The final factor

<sup>43</sup> Violations of normality determined by examining the absolute skewness and kurtosis values and frequency distributions.

<sup>44</sup> Using eigenvalues > 1.00 as the criterion for determining the appropriate number of factors.

<sup>45</sup> Sarna and Brecht (1997) in their examination of the factor structure of the SDS in advanced lung cancer patients found a four-factor solution: emotional and physical suffering, gastrointestinal distress, respiratory distress, and malaise. While similar to the three-factor solution discussed above, discrepancies can be attributed to the advanced stage of disease of the patients participating in Sarna and Brecht's study.

**Table 38. Univariate Statistics for Endogenous Variables (Ameliorative Model – Model 2a)**

Items	Min-Max	<i>M</i>	<i>SD</i>	Median	Skew <sup>a</sup>	Kurtosis <sup>b</sup>
Symptom Distress						
Presence of Nausea (SDS1)	1 to 4	1.2	0.5	1.0	2.66	7.94
Intensity of Nausea (SDS2)	1 to 5	1.2	0.6	1.0	2.79	8.22
Appetite (SDS3)	1 to 4	1.2	0.6	1.0	2.93	8.58
Insomnia (SDS4)	1 to 5	2.1	1.1	2.0	0.84	-0.12
Presence of Pain (SDS5)	1 to 5	1.9	1.1	2.0	1.24	0.88
Intensity of Pain (SDS6)	1 to 4	1.5	0.7	1.0	1.35	1.43
Appearance (SDS7)	1 to 5	1.5	0.9	1.0	1.95	3.44
Bowel (SDS8)	1 to 5	1.5	0.9	1.0	2.21	5.46
Concentration (SDS9)	1 to 5	1.7	0.9	1.0	1.36	1.68
Fatigue (SDS10)	1 to 5	2.3	1.0	2.0	0.62	0.23
Breathing (SDS11)	1 to 5	1.3	0.6	1.0	2.76	9.45
Outlook (SDS12)	1 to 5	1.9	1.0	2.0	1.16	0.94
Cough (SDS13)	1 to 5	1.6	0.8	1.0	1.51	2.23
Perceived Efficacy of ACTs						
PEACT2	1 to 5	3.4	0.9	3.0	-0.50	0.49
PEACT3	1 to 5	3.4	0.9	3.0	-0.59	0.48
Perceived Barriers to ACTs						
Uncomfortable (PBACT2)	1 to 5	2.3	0.8	2.0	0.02	-0.46
Internal Barriers (PBACTI)	1 to 5	2.6	0.9	2.5	-0.10	-0.38
External Barriers (PBACTE)	1 to 5	2.7	0.8	3.0	0.01	0.16
Perceived Control over Adverse Effects						
I am in control (CONTRL4)	1 to 5	2.7	1.1	3.0	0.33	-0.64
Take care of myself (CONTRL5)	1 to 5	2.8	1.0	3.0	0.14	-0.66
Take the right actions (CONTRL6)	1 to 5	3.5	0.9	4.0	-0.74	0.25
Commitment to ACTs						
Number of ACTs (NUMACT)	0 to 0.9	0.2	0.2	0	1.03	-0.27
Frequency x Effort (FQEFTOT)	0 to 2.4	0.4	0.6	0	1.03	-0.37
Monthly Cost (COSTTOT)	0 to 2.6	0.5	0.7	0	1.01	-0.39

Note. N = 323

<sup>a</sup>The standard error for the skew of the exogenous variables was 0.14.

<sup>b</sup>The standard error for the kurtosis of the exogenous variables was 0.27.

was related to respiratory problems and included the indicators SDS11 – Breathing (0.79) and SDS13 – Cough (0.74). Following consideration of the results of the exploratory factor analysis and the univariate characteristics of the Symptom Distress Scale items (i.e., variability), the following four items were retained as indicators of general symptom distress: SDS4 – Insomnia, SDS5 – Presence of Pain, SDS10 – Fatigue, and SDS12 – Outlook. No other revisions to the endogenous variables included in the Ameliorative Model were suggested by the univariate statistics.

#### Bivariate Normality

PRELIS was used to examine the bivariate normality of variables in the Ameliorative Model (Model 2a) dataset. Table 39 provides a summary of the variable dyads with questionable bivariate normality, with RMSEA values equal to or greater than 0.100.



**Table 39. Bivariate Normality Violations for Exogenous and Endogenous Variables in the Ameliorative Model (Model 2a) Following Transformations**

Variables			Correlation	Test of Close Fit	
				RMSEA	p-value
PEACTS3	VS	PEACTS2	.87	.112	.193
CONTRL5	VS	CONTRL4	.79	.147	.001
CONTRL6	VS	CONTRL4	.42	.123	.063
CONTRL6	VS	CONTRL5	.57	.130	.024
ENCOURCM	VS	FQEFTOT	.37	.104	.386
PEACTS2	VS	FQEFTOT	.30	.104	.394
PEACTS3	VS	FQEFTOT	.36	.113	.252
PBACT2	VS	FQEFTOT	.18	.121	.177
PBACT2	VS	COSTTOT	.18	.141	.042

Note. N = 314 (list-wise deletion)

Serious violations in bivariate normality were apparent among the indicators measuring the *Perceived Control of Adverse Effects* concept. Given that the univariate characteristics of these variables were acceptable and the preference to have three indicators per latent concept (Kelloway, 1995), the decision was made to retain all three control variables without modification. A similar decision was made with regards to the *Perceived Efficacy of ACTs* indicators, with both PEACTS2 and PEACTS3 kept in the model without revision. According to Jöreskog and Sörbom (1996), retention of these variables is well within the expectation that the tests of a model's indicators to determine if an underlying bivariate normal distribution occurs will result in a 1% long-run rejection rate. In addition, given the robustness of the structural equation modelling process to violations of normality and the limited number of variable dyads with significant violations ( $p < .05$ ), no further revisions were made to the model's indicators.

#### **Confirmatory Factor Analysis of the Measurement Model**

In keeping with the model development procedure used in the Preventive Model of ACT use, a confirmatory factor analysis<sup>46</sup> was conducted on those factors in the Ameliorative Model (Model 2a) with multiple indicators. Included in the factor analysis were the following concepts: *Encouragement to Use ACTs*, *Perceived Symptom Distress*, *Perceived Efficacy of ACTs*, *Perceived Barriers to ACT Use*, *Perceived Control over Adverse Effects*, and *Commitment to ACT Use*. All factors were allowed to covary by setting the Phi matrix to equal ST, which fixed the diagonal elements of the matrix to one and the off-diagonal elements as free elements.

The overall fit of the measurement model (Model 2a) was moderate (see Table 40), with a RMSEA under the criterion of .05 (Steiger, 1990), the AGFI just over the criterion of .90

<sup>46</sup> Based on the near normal univariate and bivariate characteristics of the data (i.e., skew and kurtosis < 1.0; RMSEA < .100) and the robustness of the maximum likelihood estimator (MLE) (Jöreskog & Sörbom, 1996; West et al., 1995), MLE was used to fit the confirmatory factor model. Indicators included in the confirmatory factor analysis were treated as continuous variables and a covariance matrix was used to fit the model.

(Kelloway, 1995), and CFI greater than the criterion of .95 (Hu & Bentler, 1999). The parameter estimates all loaded on their respective factors as hypothesized and were all statistically significant ( $t \geq 1.96$ ). Several indicators, however, had factor loadings below the criterion value of 0.60 (see Table 41). These variables included SDS5 – Presence of Pain (0.56), SDS12 – Outlook (0.44), and CONTRL6 – “If I take the right actions, I can manage the side effects of medical cancer treatment” (0.51). The remaining factor loadings were all  $\geq 0.60$ .

**Table 40. Goodness-of-Fit Indices for the Measurement Model of the Ameliorative Model (Model 2a and Model 2b)**

	$\chi^2$ (df)	$p$	RMSEA	GFI	AGFI	CFI
Model 2a	157.20 (104)	.000	.042	0.94	0.92	0.98
Model 2b <sup>a</sup>	138.32 (89)	.000	.043	0.95	0.92	0.98

<sup>a</sup>Model 2b differs from Model 2a by the omission of the indicator, SDS12.

Because of the low loading of SDS12 – Outlook on the *Perceived Symptom Distress* factor, the decision was made to delete this item from the Ameliorative Model (Model 2a). While the item SDS5 – Presence of Pain was also below the factor loading criterion value of 0.60, it was retained in the model dataset because of the preference of having a minimum of three indicators for each concept. The reliability coefficient for the revised *Perceived Symptom Distress* scale was 0.66. The CONTRL6 item was also kept as an indicator of the *Perceived Control over Adverse Effects* concepts despite its low loading value because of the desire to have three versus two indicators per factor. A review of the modification indices and standardized residuals revealed no further revisions to the measurement portion of the Ameliorative Model beyond the deletion of item SDS12. Goodness-of-fit indices and factor loadings for the revised Ameliorative Model (Model 2b) are provided in Tables 40 and 41. A  $\chi^2$  difference test revealed a significant improvement in model fit of Model 2b over Model 2a ( $\chi^2$  difference value = 18.88 (1 df),  $p < .001$ ) following the omission of SDS12 from the model.

**Table 41. Factor Loadings and *t*-values for the Measurement Model of the Ameliorative Model (Model 2a)**

Latent Variable	$\alpha^a$	Item	Loading <sup>b</sup>	t-value	R <sup>2</sup>
<u>Model 2a</u>					
Encouragement to use ACTs	.73	ENCOURCM	0.90	14.20	0.80
		ENCOUR3	0.64	10.75	0.42
Perceived Symptom Distress	.67	SDS4	0.65	10.61	0.42
		SDS5	0.56	9.13	0.32
		SDS10	0.74	11.95	0.54
		SDS12	0.44	6.95	0.19
Perceived Efficacy of ACTs	.90	PEACTS2	0.90	16.84	0.80
		PEACTS3	0.92	17.24	0.84
Perceived Barriers to ACT Use	.80	PBACT2	0.70	12.69	0.49
		PBACTI	0.75	13.66	0.56
		PBACTE	0.79	14.44	0.62
Perceived Control over Adverse Effects	.78	CONTRL4	0.75	13.30	0.56
		CONTRL5	0.96	17.20	0.92
		CONTRL6	0.51	8.94	0.26
Commitment to ACT Use	.89	NUMACT	0.99	24.30	0.97
		FQEFTOT	0.96	23.22	0.93
		COSTTOT	0.93	21.79	0.86
<u>Model 2b</u>					
Encouragement to use ACTs	.73	ENCOURCM	0.87	14.09	0.76
		ENCOUR3	0.65	10.96	0.43
Perceived Symptom Distress	.66	SDS4	0.61	9.57	0.37
		SDS5	0.58	9.21	0.34
		SDS10	0.76	11.55	0.58
Perceived Efficacy of ACTs	.90	PEACTS2	0.90	16.89	0.81
		PEACTS3	0.92	17.27	0.84
Perceived Barriers to ACT Use	.80	PBACT2	0.71	12.84	0.50
		PBACTI	0.75	13.79	0.57
		PBACTE	0.79	14.60	0.63
Perceived Control over Adverse Effects	.78	CONTRL4	0.74	13.21	0.55
		CONTRL5	0.97	17.21	0.93
		CONTRL6	0.50	8.93	0.25
Commitment to ACT Use	.89	NUMACT	0.99	24.34	0.97
		FQEFTOT	0.96	23.27	0.93
		COSTTOT	0.93	21.87	0.87

<sup>a</sup>Cronbach's alpha<sup>b</sup>Completely Standardized Lambda-X values

### Inclusion of Women with Breast Cancer Recurrence and Other Cancer Diagnosis

Similar to the Preventive Model, *t*-tests were performed on the variables in the Ameliorative Model (Model 2b) dataset to determine if women with and without breast cancer recurrence differed significantly on important model constructs. Table 42 provides a summary of

**Table 42. Mean Differences between Women with and without Breast Cancer Recurrence on the Ameliorative Model (Model 2b) Variables**

Variables	<i>t</i> -value	df	<i>p</i>	Mean Difference
Age (AGE)	-0.27	318	.79	0.57
Education (EDUCATE)	-0.12	318	.91	-0.06
Previous Use of ACTs (PREVIOUS)	1.14	317	.25	0.06
Encouragement to use ACTs:				
Family Members/Friends (ENCOURCM)	-1.37	318	.17	-0.24
Doctor (ENCOUR3)	0.58	318	.56	0.09
Perceived Symptom Distress				
Insomnia (SDS4)	-1.12	318	.26	-0.24
Presence of Pain (SD5)	-3.65	318	.000	-0.71
Fatigue (SD10)	-2.52	318	.01	-0.45
Perceived Efficacy of ACTs				
PEACTS2	0.09	317	.93	0.02
PEACTS3	1.46	315	.15	0.26
Perceived Barriers to ACTs				
Uncomfortable (PBACT2)	2.16	316	.03	0.34
Internal (PBACTI)	3.03	318	.003	0.50
External (PBACTE)	1.80	316	.07	0.28
Perceived Control				
I am in control (CONTRL4)	0.36	317	.72	0.07
Take care of myself (CONTRL5)	1.56	317	.12	0.30
Take the right actions (CONTRL6)	0.19	317	.85	0.30
Commitment to ACTs				
Number of ACTs (NUMACT)	-1.38	318	.17	0.06
Frequency x Effort (FQEFTOT)	-2.00	318	.05	-0.23
Monthly Cost (COSTTOT)	-2.03	318	.04	-0.28

this analysis. Using a level of significance of  $p < .0026$  (i.e., Bonferroni correction factor =  $.05/19$ ),<sup>47</sup> women with a recurrence of breast cancer were found to be significantly different on only one variable, SDS5 – Presence of Pain. Women who had reported having a recurrence of

<sup>47</sup> In calculating the Bonferroni correction factor,  $\alpha$  (level of significance) was divided by the number of comparisons, which was equal to 19.

disease experienced pain more frequently than women had not been diagnosed with a recurrence. Because only one variable was found to have a positive *t*-test and the mean difference was less than one unit on the SDS5 scale, the decision was made to retain the women with breast cancer recurrence in the dataset.

A comparison between women who had been diagnosed with another type of cancer and those who had not was also conducted on the key model constructs. Using a level of significance of  $p < 0.0026$  (i.e., Bonferroni correction factor =  $0.05/19$ ), no significant mean

**Table 43. Mean Differences between Women with and without Other Cancer Diagnosis on the Ameliorative Model (Model 2b) Variables**

Variables	<i>t</i> -value	df	<i>p</i>	Mean Difference
Age (AGE)	-1.21	305	.23	-2.51
Education (EDUCATE)	0.26	305	.79	0.13
Previous Use of ACTs (PREVIOUS)	0.89	304	.38	0.05
Encouragement to use ACTs:				
Family Members/Friends (ENCOURCM)	1.47	305	.14	0.25
Doctor (ENCOUR3)	0.43	305	.67	0.06
Perceived Symptom Distress:				
Insomnia (SDS4)	-0.77	305	.44	-0.16
Presence of Pain (SD5)	-0.69	305	.49	-0.13
Fatigue (SD10)	-0.18	305	.86	-0.03
Perceived Efficacy of ACTs				
PEACTS2	1.24	305	.03	0.37
PEACTS3	1.51	303	.13	0.26
Perceived Barriers to ACTs				
Uncomfortable (PBACT2)	1.90	303	.06	0.29
Internal (PBACTI)	0.80	305	.42	0.13
External (PBACTE)	0.72	303	.47	0.11
Perceived Control				
I am in control (CONTRL4)	-0.40	304	.69	0.08
Take care of myself (CONTRL5)	1.06	304	.29	0.20
Take the right actions (CONTRL6)	-0.19	304	.85	0.03
Commitment to ACTs				
Number of ACTs (NUMACT)	2.23	305	.03	0.10
Frequency x Effort (FQEFTOT)	2.36	305	.02	0.27
Monthly Cost (COSTTOT)	2.31	305	.02	0.31

difference was found between these two group of women on Ameliorative Model (Model 2b) variables (see Table 43). Women diagnosed with another type of cancer were thus retained in the dataset.

## Measurement Scaling and Reliabilities

As done in the Preventive Model, measurement scaling and reliabilities were incorporated into the Ameliorative Model of ACT Use (Model 2b) prior to testing the structural portion of the model. Measurement scales for the concepts were achieved by fixing at 1.0 the concept-indicator relationships ( $\lambda_x$  and  $\lambda_y$ ) associated with the "best" indicator<sup>48</sup> for each exogenous and endogenous concept. Indicators fixed as the metric included AGE, EDUCATE, PREVIOUS, ENCOURCM, SDS10, PEAacts3, PBACTE, CONTRL5, and NUMACT.

The error variances for the scaling indicators in the Ameliorative Model (Model 2b) were also fixed to improve the conceptual clarity and theoretical meaning of the model. Error variances were calculated by multiplying the proportion of the variance in an indicator that was error variance (determined either theoretically or equal to subtracting the squared multiple correlation determined by the confirmatory factor analysis from 1.00) by the observed variance in the indicator. Table 44 provides a summary of the fixed error variances and theoretical sources of error.

### Summary of the Preparation of the Ameliorative Model of Alternative/Complementary Therapy Use

Figure 9 illustrates the structural and measurement portions of the Ameliorative Model of ACT Use (Model 2b), including all fixed and freed coefficients. This model, illustrating the Ameliorative Model of ACT Use to be tested using structural equation modelling, is referred to in the following chapters as Model 2b. This model is comprised of 10 underlying concepts and 21 indicators and attempts to conceptualize the relationships among selected health beliefs and the commitment expressed by women with breast cancer with regards to ACT use in the context of amelioration of symptoms and side effects of breast cancer and conventional cancer treatments.

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<sup>48</sup> For concepts with single indicators, the concept-indicator relationship was fixed at 1.0. For concepts with multiple indicators, the "best" indicator was determined through the confirmatory factor analysis and was the variable that had the highest factor loading and squared multiple correlation out of a set of indicators associated with a given concept.

**Table 44. Error Variances in the Ameliorative Model of Alternative/Complementary Therapy Use (Model 2b)**

Indicators	Proportion of Error (%) <sup>a</sup>	Error Variance	Source of Error Variance
AGE	1.0	1.24	Keypunching error, unknown birth date
EDUCATE	10.0	0.73	Over-reporting, educational activity not included in the response categories
PREVIOUS	15.0	0.01	Different interpretations of what therapies are classified as "ACTs"
ENCOURCM	24.0	0.22	Different interpretations of the item by respondents
SDS10	42.0	0.38	Different subjective interpretations of fatigue
PEACTS3	16.0	0.14	Different interpretations of what is a "side effect", uncertainty related to which therapies are "ACTs"
PBACTE	37.0	0.24	Different interpretations of item related to which therapy respondents had used
CONTRL5	7.0	0.07	Different interpretations of what is a "side effect" and how respondents could "take care" of themselves
NUMACT	3.0	0.002	Different interpretations of what therapies are "ACTs", incorrect information regarding the current status of ACT use

<sup>a</sup> The proportions of error variance for ENCOURCM, SDS6, SDS10, PEACTS3, PBACTE, CONTRL5, and NUMACT were calculated by subtracting from 100 the amount of variance explained by the underlying concept (squared multiple correlation).

**Figure 9. Model 2b - Ameliorative Model of Alternative/Complementary Therapy Use**



## Restorative Model of Alternative/Complementary Therapy Use

Similar to the Ameliorative Model of ACT Use, the exogenous concepts and associated indicators used in the Preventive Model of ACT Use (Model 1a) and also present in the Restorative Model (Model 3a) were retained without revision. These indicators included AGE, EDUCATE, PREVIOUS, ENCOURCM, and ENCOUR3. In addition, the endogenous concepts (i.e., *Perceived Barriers to ACT Use* and *Commitment to ACTs*) and their associated indicators (i.e., PBACT2, PBACTI, PBACTE, NUMACT, FQEFTOT, and COSTTOT) used in all three models were transferred to the Restorative Model of ACT Use (Model 3a) without any further revision. To capture women's use of ACTs within the context of restoring well being following the diagnosis and conventional treatment of breast cancer, several new concepts and indicators were included in the Restorative Model. These concepts included *Perceived Risk of Harm to Well Being* (PRHS1 – PRHS4), *Perceived Severity of Harm to Well Being* (PSHS1 – PSHS4), *Perceived Efficacy of ACTs*<sup>49</sup> (PEACTS4 – PEACTION7), and *Perceived Control over Well Being* (CONTRL7 – CONTRL10).

The process of developing the Restorative Model of ACT Use (Model 3a) prior to testing with structural equation modelling was similar to the method used in the Preventive and Ameliorative Models. Missing data were first examined, followed by a review of the univariate and bivariate characteristics of the Restorative Model's (Model 3a) indicators. Confirmatory factor analysis was also conducted to ensure the appropriateness of the measurement model and to establish the measurement scaling and reliabilities included in the model. Maximum likelihood estimation (MLE) was used in developing and testing the Restorative Model to facilitate comparisons among the three models of ACT use.

### Examination of Missing Data

A total of 13 cases were found to be missing more than 15% of the total number of indicators in the Restorative Model (Model 3a). These individuals were deleted from the dataset, resulting in a sample size of 321. No significant difference<sup>50</sup> on selected demographic variables (i.e., age, marital status, educational level achieved, recurrence of breast cancer) were noted between those cases deleted from the dataset because of missing data and those cases retained.

The indicators were then examined to determine the incidence and pattern of missing data (see Table 45). No serious problems were noted, with PEACTION7 having the largest

<sup>49</sup> The concept *Perceived Efficacy of ACTs* in the Restorative Model of ACT Use is similar to the concept used in the Preventive Model but measures efficacy of ACTs in the context of restoring well being following the diagnosis and conventional treatment of breast cancer.

<sup>50</sup> Bonferroni correction factor of .0125 (.05/4) was used in this analysis because of multiple comparisons between women included in the dataset and those individuals excluded.

**Table 45. Summary of Missing Data in the Restorative Model of Alternative/ Complementary Therapy Use (Model 3a)**

Variable	Frequency
Age (DATBIRTH)	0
Education (EDUCATE)	0
Previous Use of ACTs PREVIOUS	1
Encouragement to Use ACTs ENCOURCM ENCOUR3	0 0
Perceived Risk of Harm to Well Being PRHS1 PRHS2 PRHS3 PRHS4	1 2 2 1
Perceived Severity of Harm to Well Being PSHS1 PSHS2 PSHS3 PSHS4	0 0 0 0
Perceived Efficacy of ACTs PEACTS4 PEACTS5 PEACTS6 PEACTS7	12 0 0 0
Perceived Barriers to Using ACTs PBACT2 PBACT1 PBACTE	3 1 3
Perceived Control over Well Being CONTRL7 CONTRL8 CONTRL9 CONTRL10	0 2 1 0
Commitment to ACTs <sup>a</sup> NUMACTS FQEFTOT COSTTOT	0 0 0

Note. N = 321

<sup>a</sup> Commitment to ACTs in the Restorative Model was limited to those therapies currently in use and classified under the "more conservative" definition of ACT use.

amount of missing data with less than 4% of the respondents failing to provide an answer.

These missing data were a consequence of the item being inadvertently omitted from the pilot test of the questionnaire. To retain these respondents in the dataset, the decision was made to use the average of their scores on the other three items included on the Perceived Efficacy

Scale (PEACTS5, PEACTS6, and PEACTS7) as a replacement value for item PEACTS4.<sup>51</sup> This decision was made based on the consistency that was observed across scores on this scale. With no further revisions to the model indicators suggested with regards to missing data, list-wise deletion was used to delete those remaining cases with missing data ( $n = 9$ ). No significant differences were found between those cases deleted through list-wise deletion and those retained in the Restorative Model dataset with regards to selected demographic and disease characteristics (i.e., age, education, marital status, or breast cancer recurrence).

### Tests of Normality

#### Univariate Normality

Following the examination and treatment of missing data in the Restorative Model (Model 3a) dataset, the univariate characteristics of the model variables were considered. Tables 46 and 47 provide summaries of the univariate statistics of the exogenous and endogenous variables, respectively. Given that the exogenous variables in the Restorative Model (Model 3a) were identical to those indicators included in the final Preventive and Ameliorative Models of ACT Use and minimal variability was apparent in their univariate statistics across models, no further modifications were deemed necessary.

**Table 46. Univariate Statistics for Exogenous Variables (Restorative Model – Model 3a)**

Variables	Min - Max	<i>M</i>	<i>SD</i>	Median	Skew	Kurtosis
Age (AGE)	34 – 89	62.3	11.1	62.6	-0.16	-0.69
Education (EDUCATE)	1 – 12	5.4	2.7	5.0	0.22	-1.28
Previous Use of ACTs (PREVIOUS)	0 – 1.0	0.4	0.3	0.3	0.12	-1.22
Encouragement to use ACTs:						
Encourage Combined (ENCOURCM)	1 – 4	1.9	0.9	1.5	0.85	-0.38
Doctor (ENCOUR3)	1 – 4	1.6	0.8	1.0	1.50	1.49

Note.  $N = 321$

With regards to the endogenous variables included in the Restorative Model (Model 3a), several violations of univariate normality were apparent.<sup>52</sup> Representing the *Perceived Risk of Harm* concept, indicators PRHS3 and PRHS4 were slightly positively skewed, with the majority of respondents disagreeing or strongly disagreeing with the possibility that their relationships with others or their spiritual well being had been harmed by their breast cancer experience. Similarly, indicators PSHS3 and PSHS4 from the *Perceived Severity of Harm* concept were

<sup>51</sup> The average score was rounded to the nearest whole number representing a response option on the Likert-type scale.

<sup>52</sup> Violations to univariate normality were determined by examining the absolute skewness and kurtosis values and frequency distributions.

found to be both positively skewed and highly kurtotic, with most respondents indicating that they perceived little or no harm to their relationships with others or their spiritual well being as a consequence of their breast cancer experience. CONTRL8, CONTRL9, and CONTRL10 were endogenous variables that were also found to be leptokurtic,<sup>53</sup> with a substantial proportion of

**Table 47. Univariate Statistics for Endogenous Variables (Restorative Model – Model 3a)**

Items	Min-Max	M	SD	Median	Skew <sup>a</sup>	Kurtosis <sup>b</sup>
Perceived Risk of Harm						
Physical well being (PRHS1)	1 to 5	3.2	1.2	3.0	-0.08	-1.13
Mental well being (PRHS2)	1 to 5	3.6	1.2	4.0	-0.53	-0.84
Relationships (PRHS3)	1 to 5	4.1	1.0	4.0	-1.32	1.25
Spiritual well being (PRHS4)	1 to 5	4.2	1.0	4.0	-1.21	0.97
Perceived Severity of Harm						
Physical well being (PSHS1)	1 to 4	2.0	0.8	2.0	0.55	-0.30
Mental well being (PSHS2)	1 to 4	1.8	0.8	2.0	0.78	-0.07
Relationships (PSHS3)	1 to 4	1.3	0.7	1.0	2.33	5.45
Spiritual well being (PSHS4)	1 to 4	1.3	0.6	1.0	2.21	4.80
Perceived Efficacy of ACTs						
Physical well being (PEACT4)	1 to 5	3.5	0.9	4.0	-0.53	0.39
Mental well being (PEACT5)	1 to 5	3.4	1.0	4.0	-0.51	0.15
Relationships (PEACT6)	1 to 5	2.9	1.0	3.0	-0.04	-0.13
Spiritual well being (PEACT7)	1 to 5	3.1	1.1	3.0	-0.20	-0.42
Perceived Barriers to ACTs						
Uncomfortable (PBACT2)	1 to 5	2.3	0.8	2.0	0.03	-0.46
Internal Barriers (PBACTI)	1 to 5	2.6	0.9	2.5	-0.10	-0.40
External Barriers (PBACTE)	1 to 5	2.7	0.8	2.5	0.01	0.13
Perceived Control over Well Being						
Physical well being (CONTRL7)	1 to 5	2.4	1.0	2.0	0.80	0.25
Mental well being (CONTRL8)	1 to 5	2.0	0.8	2.0	1.20	2.45
Relationships (CONTRL9)	1 to 5	1.9	0.7	2.0	1.04	2.65
Spiritual well being (CONTRL10)	1 to 5	1.8	0.7	2.0	0.76	1.76
Commitment to ACTs						
Number of ACTs (NUMACT)	0 to 0.9	0.2	0.2	0	1.05	-0.27
Frequency x Effort (FQEFTOT)	0 to 2.4	0.4	0.6	0	1.04	-0.37
Monthly Cost (COSTTOT)	0 to 2.6	0.5	0.7	0	1.03	-0.34

Note. N = 321

<sup>a</sup>The standard error for the skew of the exogenous variables was 0.14.

<sup>b</sup>The standard error for the kurtosis of the exogenous variables was 0.27.

the respondents clustering around the median score on each indicator. These violations of normality in the *Perceived Risk of Harm*, *Perceived Severity of Harm*, and *Perceived Control over Well Being* indicators suggested that limited variability existed in women's responses with

<sup>53</sup> Leptokurtic is a term used to describe a distribution that is too peaked to approximate a normal curve.

regards to their perceptions about their relationships with others and their spiritual well being in the context of breast cancer. For the most part, women felt in control of their relationships and spirituality and perceived their experience of breast cancer to have had limited impact on these aspects of their overall well being. As such, the role of ACTs in restoring women's relationships and spiritual well being in the wake of breast cancer diagnosis and treatment may be, at best, minimal. The decision was thus made to delete those indicators from the Restorative Model (Model 3a) that were related to either women's relationships with others or their spiritual well being (i.e., PRHS3, PRHS4, PSHS3, PSHS4, PEACTION6, PEACTION7, CONTRL9, and CONTRL10). CONTRL8 remained problematic with regards to violations of normality; the decision to transform or re-code this indicator, however, was deferred until the bivariate normality of the item was considered.

The bivariate correlations between the *Perceived Risk of Harm* indicators and those representing the *Perceived Severity of Harm* were also examined to determine whether the respondents interpreted the two concepts as being conceptually distinct. High correlations were found between the following indicator dyads: PRHS1 and PSHS1 (-0.74) and PRHS2 and PSHS2 (-0.70). Given the ambiguity and difficulty respondents may have experienced in interpreting the difference between assessing the "likelihood" of harm to their well being versus the "amount" of harm to their well being, the decision was made to omit the *Perceived Severity of Harm* concept and associated items from the measurement model. The *Perceived Risk of Harm* items were retained because theoretically, the presence of harm was hypothesized to precede the assessment of severity of harm.

#### Bivariate Normality

Similar to the procedure followed in the Preventive and Ameliorative Models of ACT Use, PRELIS was used to examine the bivariate normality of indicators in the Restorative Model (Model 3a) dataset. A summary of the indicator dyads with questionable bivariate normality (i.e., RMSEA > 0.100) is provided in Table 48.

Violations in bivariate normality were apparent among the indicators measuring *Perceived Efficacy of ACTs* (PEACTS4 and PEACTION5), and *Perceived Control over Well Being* (CONTRL7 and CONTRL8) concepts, with both indicator dyads having RMSEA values significant at the  $p < .05$  level. The bivariate normality for indicators PRHS1 and PRHS2 was also slightly over the RMSEA criterion of .100 set by Jöreskog (2001). Given the sound univariate characteristics of these variables and the preference to use multiple indicators versus single indicators in structural equation modelling, the decision was made to retain the perceived efficacy, control and perceived risk indicators without modification.

**Table 48. Bivariate Normality Violations for Exogenous and Endogenous Variables in the Restorative Model (Model 3a) Following Transformations**

Variables			Correlation	Test of Close Fit	
				RMSEA	p-value
PRHS2	VS	PRHS1	.67	.103	.393
PEACTS5	VS	PEACTS4	.89	.125	.047
PBACT2	VS	PEACTS4	.37	.114	.168
CONTRL8	VS	CONTRL7	.64	.161	.000
ENCOURCM	VS	FQEFTOT	.37	.108	.300
PEACTS	VS	FQEFTOT	.44	.124	.126
PBACT2	VS	FQEFTOT	.17	.112	.278
PEACTS	VS	COSTTOT	.44	.121	.152
PBACT2	VS	COSTTOT	.18	.132	.086
NUMACT	VS	COSTTOT	.89	.824	.000

Note. N = 314 (list-wise deletion)

Problems with the bivariate normality that were found in previous models with regards to the *Commitment to ACT Use* indicators (NUMACT, FQEFTOT or COSTTOT) were also found in the Restorative Model (Model 3a). Again, the robustness of the structural equation modelling process to violations of normality and rejection rate expectation (Jöreskog & Sörbom, 1996) were used as a rationale to make no further revisions to the indicators included in the Restorative Model of ACT Use (Model 3a).

#### **Confirmatory Factor Analysis of the Measurement Model**

Similar to the model development procedures used in the Preventive and Ameliorative Models of ACT use, a confirmatory factor analysis<sup>54</sup> was conducted on those factors in the Restorative Model (Model 3a) with multiple indicators. Included in the factor analysis were the following concepts: *Encouragement to Use ACTs*, *Perceived Risk of Harm to Well Being*, *Perceived Efficacy of ACTs*, *Perceived Barriers to ACT Use*, *Perceived Control over Well Being* and *Commitment to ACT Use*. All factors were allowed to covary by setting the Phi matrix to equal ST, which fixed the diagonal elements of the matrix to one and the off-diagonal elements as free elements.

**Table 49. Goodness-of-Fit Indices for the Measurement Model of the Restorative Model (Model 3a)**

	$\chi^2$ (df)	p	RMSEA	GFI	AGFI	CFI
Model 3a	133.27	.000	.058	.95	0.91	0.97

<sup>54</sup> Based on the near normal univariate and bivariate characteristics of the data (i.e., skew and kurtosis < 1.0; RMSEA < .100) and the robustness of the maximum likelihood estimator (MLE) (Jöreskog & Sörbom, 1996; West et al., 1995), MLE was used to fit the confirmatory factor model. Indicators included in the confirmatory factor analysis were treated as continuous variables and a covariance matrix was used to fit the model.

The overall fit of the measurement model (Model 3a) was good (see Table 49), with a RMSEA just over the criterion of .05 (Steiger, 1990), the GFI and AGFI over the criterion of .90 (Kelloway, 1995), and CFI greater than the criterion of .95 (Hu & Bentler, 1999). As shown in Table 50, all parameter estimates loaded on their respective factors as hypothesized and were statistically significant ( $t \geq 1.96$ ). All factor loadings were  $\geq 0.60$ . A closer examination of the standardized residuals and modification indices revealed no theoretically meaningful modifications to Model 3a.

**Table 50. Factor Loadings and  $t$ -values for the Measurement Model of the Restorative Model (Model 3a)**

Latent Variable	$\alpha^a$	Item	Loading <sup>b</sup>	$t$ -value	$R^2$
<u>Model 3a</u>					
Encouragement to use ACTs	.72	ENCOURCM	0.89	14.17	0.80
		ENCOUR3	0.63	10.54	0.40
Perceived Risk of Harm	.75	PRHS1	0.76	11.66	0.57
		PRHS2	0.79	12.04	0.62
Perceived Efficacy of ACTs	.91	PEACTS4	0.96	20.04	0.92
		PEACTS5	0.88	17.72	0.77
Perceived Barriers to ACT Use	.80	PBACT2	0.74	13.54	0.54
		PBACTI	0.76	14.14	0.58
		PBACTE	0.78	14.46	0.61
Perceived Control over Well Being	.71	CONTRL7	0.69	10.00	0.47
		CONTRL8	0.79	10.89	0.62
Commitment to ACT Use	.89	NUMACT	0.99	24.33	0.98
		FQEFTOT	0.96	23.17	0.93
		COSTTOT	0.93	21.96	0.87

<sup>a</sup>Cronbach's alpha.

<sup>b</sup>Completely standardized Lambda-x values.

### Inclusion of Women with Breast Cancer Recurrence and Other Cancer Diagnosis

Similar to the Preventive and Ameliorative Models,  $t$ -tests were performed on the variables in the Restorative Model (Model 3a) dataset to determine if women with and without breast cancer recurrence differed significantly on important model constructs. Table 51 provides a summary of this analysis. Using a level of significance of  $p < .0029$  (i.e., Bonferroni correction factor =  $.05/17$ ),<sup>55</sup> women with a recurrence of breast cancer were found to be significantly different on only one variable, PBACTI – Internal Barriers to ACT Use. Women who had a

<sup>55</sup> In calculating the Bonferroni correction factor,  $\alpha$  (level of significance) was divided by the number of comparisons, which was equal to 17.

breast cancer recurrence perceived themselves to face more internal barriers to using ACTs than women who had not experienced a recurrence. However, given that a significant mean

**Table 51. Mean Differences between Women with and without Breast Cancer Recurrence on the Restorative Model (Model 3a) Variables**

Variables	t-value	df	p	Mean Difference
Age (AGE)	0.50	316	.62	1.08
Education (EDUCATE)	-0.37	316	.75	-0.17
Previous Use of ACTs (PREVIOUS)	1.09	315	.28	0.06
Encouragement to use ACTs:				
Family Members/Friends (ENCOURCM)	-1.41	316	.16	-0.25
Doctor (ENCOUR3)	0.64	316	.53	0.10
Perceived Risk of Harm to Well Being:				
Physical Well Being (PRHS1)	2.42	315	.02	0.56
Mental Well Being (PRHS2)	0.88	314	.38	0.21
Perceived Efficacy of ACTs				
PEACTS4	0.90	316	.37	0.16
PEACTS5	1.84	316	.07	0.34
Perceived Barriers to ACTs				
Uncomfortable (PBACT2)	2.09	313	.04	0.33
Internal (PBACTI)	3.08	315	.002	0.52
External (PBACTE)	1.87	313	.06	0.29
Perceived Control				
Physical Well Being (CONTRL7)	-0.86	316	.39	-0.16
Mental Well Being (CONTRL8)	0.74	314	.46	0.11
Commitment to ACTs				
Number of ACTs (NUMACT)	-1.59	316	.11	-0.07
Frequency x Effort (FQEFTOT)	-2.19	316	.03	-0.26
Monthly Cost (COSTTOT)	-2.26	316	.03	-0.31

difference was found on only one variable and the mean difference was less than one unit on the PBACTI scale, the decision was made to retain women who had experienced a recurrence of breast cancer in the Restorative Model (Model 3a) dataset.

A comparison between women who had been diagnosed with another type of cancer and those who had not was conducted on the key model constructs. Using a level of significance of  $p < 0.0029$  (i.e., Bonferroni correction factor =  $0.05/17$ ), no significant mean difference was found between these two group of women on Restorative Model (Model 3a) variables (see Table 52). Women diagnosed with another type of cancer were thus retained in the dataset.



**Table 52. Mean Differences between Women with and without Other Cancer Diagnosis on the Restorative Model (Model 3a) Variables**

Variables	t-value	df	p	Mean Difference
Age (AGE)	-1.22	304	.22	-2.53
Education (EDUCATE)	0.27	304	.79	0.14
Previous Use of ACTs (PREVIOUS)	0.85	303	.40	0.05
Encouragement to use ACTs:				
Family Members/Friends (ENCOURCM)	1.43	304	.15	0.25
Doctor (ENCOUR3)	0.38	304	.71	0.06
Perceived Risk of Harm to Well Being:				
Physical Well Being (PRHS1)	-0.33	303	.74	0.07
Mental Well Being (PRHS2)	0.18	302	.86	0.04
Perceived Efficacy of ACTs				
PEACTS4	1.63	304	.10	0.27
PEACTS5	1.91	304	.06	0.34
Perceived Barriers to ACTs				
Uncomfortable (PBACT2)	1.95	301	.05	0.29
Internal (PBACTI)	0.80	303	.43	0.13
External (PBACTE)	0.74	301	.46	0.11
Perceived Control				
Physical Well Being (CONTRL7)	1.05	304	.29	0.19
Mental Well Being (CONTRL8)	-0.08	303	.94	0.01
Commitment to ACTs				
Number of ACTs (NUMACT)	2.17	304	.03	0.10
Frequency x Effort (FQEFTOT)	2.31	304	.02	0.26
Monthly Cost (COSTTOT)	2.25	304	.03	0.30

### Measurement Scaling and Reliabilities

Measurement scaling and reliabilities were incorporated into the Restorative Model of ACT Use (Model 3a) prior to testing the structural portion of the model. Measurement scales for the concepts were achieved by fixing at 1.0 the concept-indicator relationships ( $\lambda$ -x and  $\lambda$ -y) associated with the "best" indicator<sup>56</sup> for each exogenous and endogenous concept. Indicators fixed as the metric included AGE, EDUCATE, PREVIOUS, ENCOURCM, PRHS2, PEACTS4, PBACTE, CONTRL8, and NUMACT.

The error variances for the scaling indicators in the Restorative Model (Model 3a) were also fixed to improve the conceptual clarity of the model. Error variances were calculated by

<sup>56</sup> For concepts with single indicators, the concept-indicator relationship was fixed at 1.0. For concepts with multiple indicators, the "best" indicator was determined through the confirmatory factor analysis and was the variable that had the highest factor loading and squared multiple correlation out of a set of indicators associated with a given concept.

multiplying the proportion of the variance in an indicator that was error variance (determined either theoretically or equal to subtracting the squared multiple correlation determined by the confirmatory factor analysis from 1.00) by the observed variance in the indicator. Table 53 provides a summary of the fixed error variances and theoretical sources of error.

### **Summary of the Preparation of the Restorative Model of Alternative/Complementary Therapy Use**

The measurement and structural portions of the Restorative Model of ACT Use (Model 3a), including all fixed and freed coefficients, are illustrated in Figure 10. This model (referred to in the following chapters as Model 3a) is comprised of eight concepts and 17 corresponding indicators and represents the Restorative Model of ACT Use to be tested with structural equation modelling. Model 3a attempts to conceptualize the relationships among selected health beliefs and the commitment expressed by women towards ACT use within the context of restoring physical and mental well being following the diagnosis and conventional treatment of breast cancer.

**Table 53. Error Variances in the Restorative Model of Alternative/Complementary Therapy Use (Model 3a)**

Indicators	Proportion of Error (%) <sup>a</sup>	Error Variance	Source of Error Variance
AGE	1.0	1.24	Keypunching error, unknown birth date
EDUCATE	10.0	0.74	Over-reporting, educational activity not included in the response categories
PREVIOUS	15.0	0.01	Different interpretations of what therapies are classified as ACTs
ENCOURCM	20.0	0.18	Different interpretations of the item by respondents
PRHS2	38.0	0.54	Under- or over- reporting of level of harm, different subjective interpretations of harm and/or well being
PEACT4	8.0	0.07	Different interpretations of what is meant by harm to well being, uncertainty related to which therapies are "ACTs"
PBACTE	39.0	0.26	Different interpretations of item related to which therapy respondents had used
CONTRL8	38.0	0.23	Different interpretations of what is meant by harm to well being and how respondents could "take care" of themselves
NUMACT	2.0	0.001	Different interpretations of what therapies are "ACTs", incorrect information regarding the current status of ACT use

<sup>a</sup> The proportion of error variance for ENCOURCM, PRHS2, PEACTS4, PBACTE, CONTRL8, and NUMACT was calculated by subtracting from 100 the amount of variance explained by the underlying concept (squared multiple correlation).

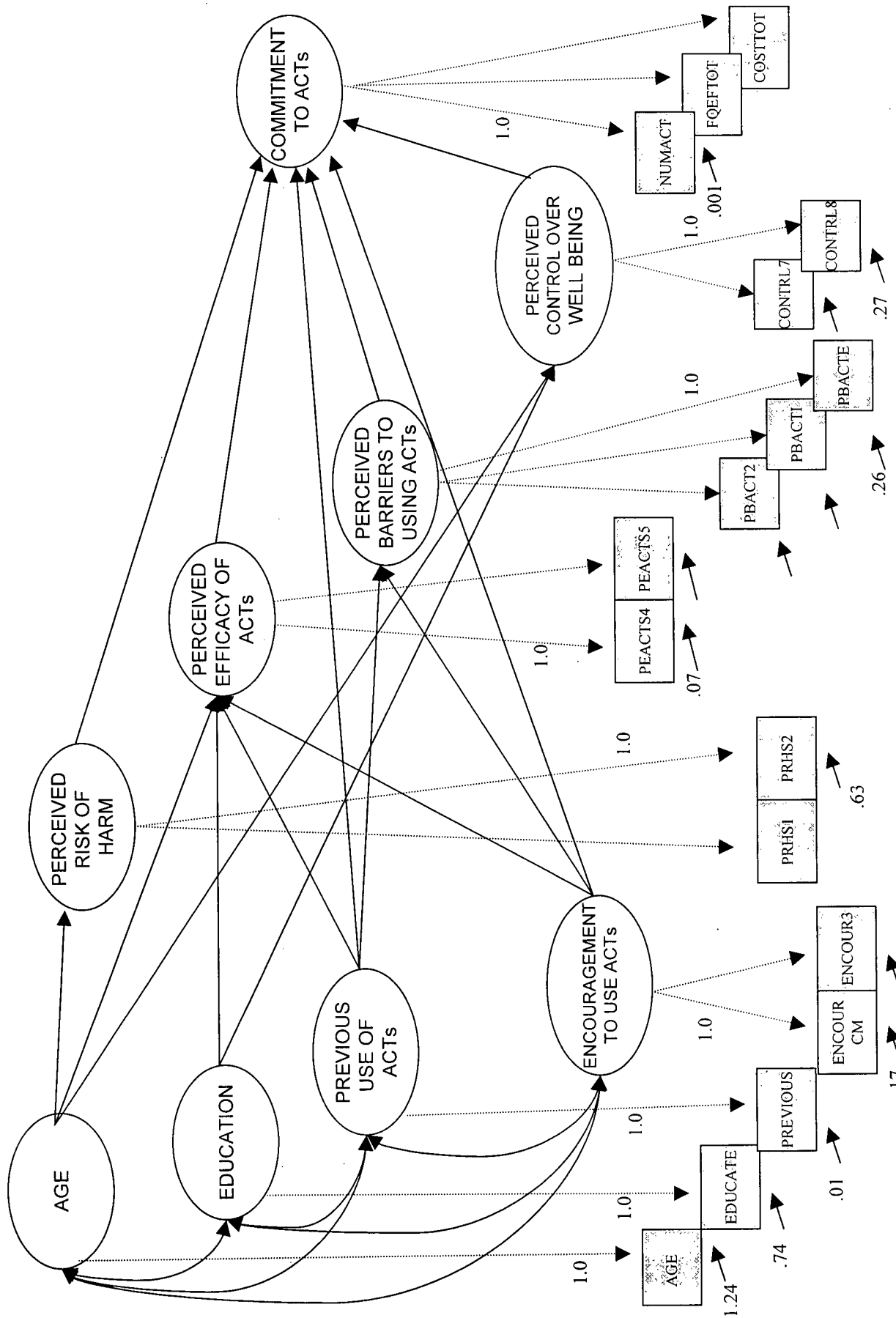


Figure 10 . Model 3a - Restorative Model of Alternative/Complementary Therapy Use

## Chapter 7

### Structural Equation Modelling Results

Following data preparation and the confirmation of the measurement models of the Preventive, Ameliorative, and Restorative Models of ACT Use, the full structural equation models were tested. This chapter describes the fit of the three initial models of ACT Use and the corresponding model modifications suggested by the diagnostic output. Model modifications were undertaken in the spirit of model generation in which the primary focus was to identify the sources of misfit in a theoretically-derived model and to re-estimate a model that better describes the sample data (Byrne, 1998). These modifications, however, were required to be theoretically justifiable prior to their inclusion in the revised models of ACT use.

#### Preventive Model of Alternative/Complementary Therapy Use

##### Structural Model 1a

Figure 11 illustrates the initial Preventive Model of ACT Use (Model 1a). The model hypothesized that women's commitment to ACT use was directly influenced by selected health beliefs, including perceived risk of breast cancer recurrence, perceived efficacy of ACTs in preventing recurrence, perceived barriers to using ACTs, and perceived control over breast cancer recurrence. Commitment to ACT use was also postulated to be directly affected by women's experience with ACTs prior to their breast cancer diagnosis and the encouragement they had received from significant others to use ACTs. The model further suggested that age, education, previous use of ACTs, and encouragement to use ACTs indirectly influenced women's commitment to ACTs through their effects on selected health beliefs.

The initial structural equation model (Model 1a) demonstrated poor overall fit with the data, with  $\chi^2 = 345.87$  ( $df = 123$ ),  $p = .00$  (see Table 54). Other fit indices were found to be marginally acceptable, with the RMSEA (0.08; 90% CI: 0.06 – 0.08) being just under the

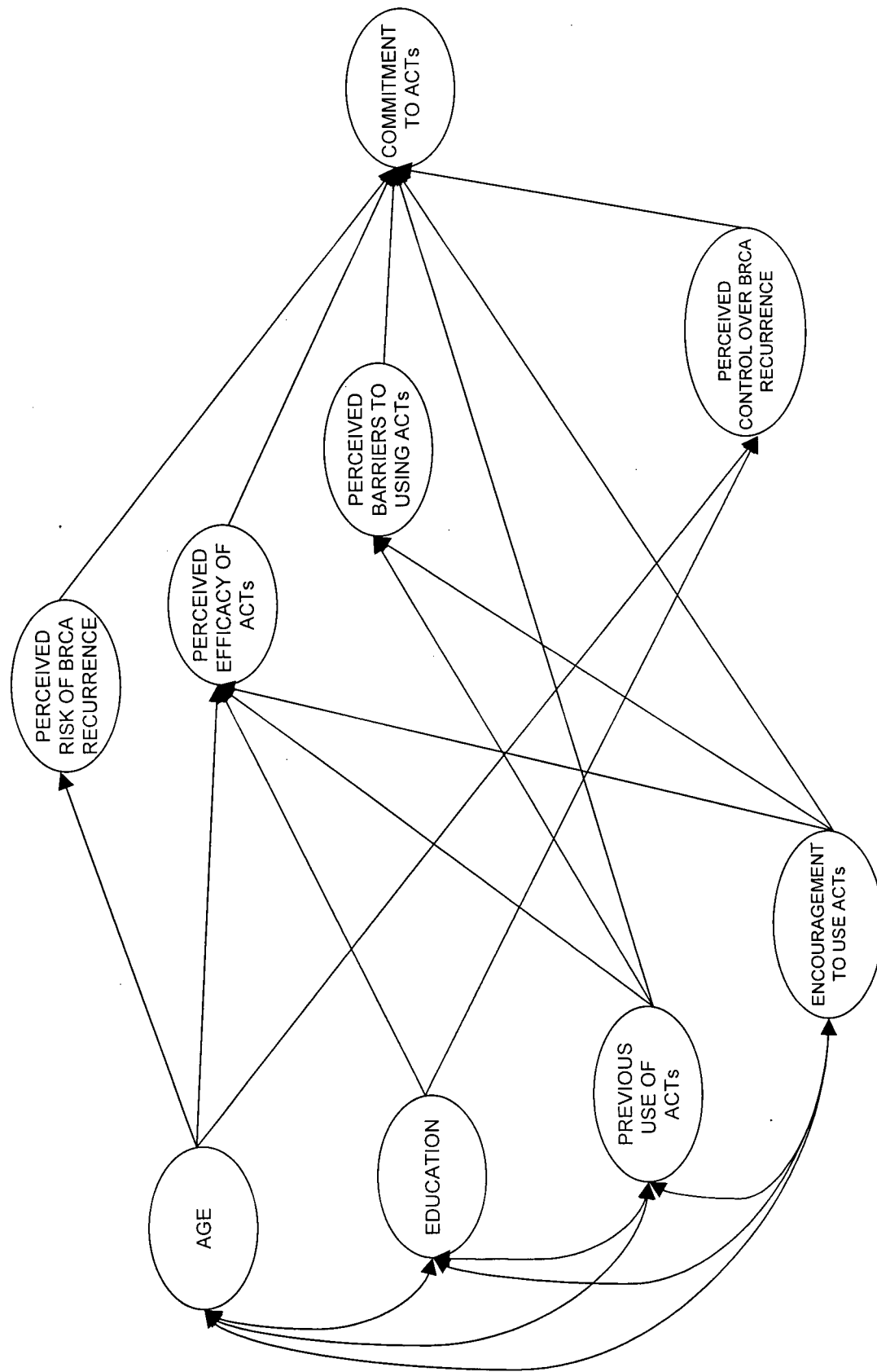


Figure 11. Structural Model 1a - Preventive Model of Alternative/Complementary Therapy Use

accepted criterion level of .08 for a reasonable fitting model (Browne & Cudeck, 1993), and the CFI (0.93) and the NFI (0.90) being under their accepted criterion levels of 0.95 (Hu & Bentler, 1995, 1999). The absolute indices of fit (GFI = 0.89; AGFI = 0.85) provided further evidence of a relatively poor fitting model. Of the 15 estimated parameters in the structural portion of the model (i.e., relationships among the latent constructs), only six were found to be statistically significant ( $t > 1.96$ ;  $p < .05$ ) and in the direction originally hypothesized. These pathways included the relationships between (1) *Age* and *Perceived Risk of Breast Cancer Recurrence*, (2) *Encouragement to Use ACTs* and *Perceived Efficacy of ACTs*, (3) *Encouragement to Use ACTs* and *Perceived Barriers to Using ACTs*, (4) *Previous Use of ACTs* and *Perceived Efficacy of ACTs*, (5) *Previous Use of ACTs* and *Commitment to ACTs*, and (6) *Encouragement to Use ACTs* and *Commitment to ACTs*.

#### Model Modifications to Model 1a

Given the poor fit of the initial Preventive Model of ACT Use, theoretically plausible model modifications were undertaken to identify possible areas of structural misspecification and to improve the fit of the model. Care was taken to avoid alterations to the model that merely improved the model fit but were not supported by theory or research (Hayduk, 1987). As recommended by Hayduk (1987), model respecification occurred in an incremental manner and was guided by the standardized residuals and modification indices provided by LISREL. Standardized residuals represent the discrepancies between the observed covariance matrix (S) and the model implied covariance matrix ( $\Sigma$ ), with values larger than  $\pm 2.00$  indicating substantial differences in variance or covariance (Schumacker & Lomax, 1996). The modification indices further illustrated the amount of reduction in the model  $\chi^2$  that would be obtained from estimating a parameter in the model that had been originally fixed at zero (Kelloway, 1998).

In Model 1a, only 62.0% of the standardized residuals fell within the expected range of  $\pm 2.00$ . The largest standardized residuals were found in the covariances between: PEACT1 and CNTRL3 (7.57), PEACT1 and CNTRL2 (7.17), PLRS4 and CNTRL2 (-6.20), and PLRS4 and CNTRL3 (-6.15). Closer examination of the modification indices (MI) revealed that the largest expected change in model fit (MI = 57.97) would occur if the structural coefficient between *Perceived Efficacy of ACTs* and *Perceived Control Over Breast Cancer Recurrence* were freed. This specific effect hypothesized that as a woman's perceived efficacy of ACTs in the prevention of breast cancer recurrence increases, her perceived control over breast cancer recurrence becomes correspondingly greater. Some research has provided preliminary evidence of the combined role of control and efficacy beliefs in predicting health behaviour (Kristiansen, 1987; Norman, 1991). Further, it is theoretically plausible that the influence of women's perceptions of treatment efficacy on their commitment to ACT use could be mediated

by the degree to which they believe “taking care of themselves” and “taking the right actions” would prevent them from experiencing breast cancer again. As such, both the direct and indirect relationships implied by this respecification appeared reasonable, were substantiated by research and were thus incorporated into the model (Model 1b).

### Structural Model 1b

Fit information for the revised model (Model 1b), with the added directed effect between *Perceived Efficacy of ACTs* and *Perceived Control over Recurrence* is reported in Table 54. The chi-square statistic decreased significantly, with a  $\chi^2$  difference test = 64.22 (1 df),  $p < .001$ , indicating improved model fit. Improvements were also noted in the fit indices.

### Model Modifications to Model 1b

In Model 1b, the standardized residuals for PLRS4 and CNTRL2 (-6.20), and PLRS4 and CNTRL3 (-6.15) remained high, with 68.4% of the residuals falling within the desired range of  $\pm 2.00$ . Examination of the modification indices following the first respecification of the model supported the addition of an effect between the concepts *Perceived Control of Breast Cancer Recurrence* and *Perceived Risk of Breast Cancer Recurrence* (MI = 43.67). This hypothesized relationship suggested that as a woman's perceived control over breast cancer recurrence increases her perceived risk of recurrence correspondingly decreases. There has been some

**Table 54. Goodness-of-Fit Indices for Sequential Modifications of the Preventive Model of Alternative/Complementary Therapy Use**

Models <sup>a</sup>	$\chi^2$ (df)	$p$	RMSEA (90% CI)	CFI	NFI	AGFI	GFI
Model 1a - initial model	345.87 (123)	.00	0.08 (0.06 – 0.08)	0.93	0.90	0.85	0.89
Model 1b - Efficacy → Control	281.65 (122)	.00	0.06 (0.05 – 0.07)	0.95	0.92	0.88	0.91
Model 1c - Control → Risk	234.57 (121)	.00	0.05 (0.04 – 0.06)	0.97	0.93	0.89	0.93
Model 1d - Encourage → Control	227.14 (120)	.00	0.05 (0.04 – 0.06)	0.97	0.93	0.90	0.93
Model 1e - Risk ↘ Barriers	218.53 (119)	.00	0.05 (0.04 – 0.06)	0.97	0.94	0.90	0.93
Model 1f - Previous use → Risk	208.73 (118)	.00	0.05 (0.04 – 0.06)	0.97	0.94	0.90	0.93

<sup>a</sup>The model modifications (i.e., effects or covariances) that were added to the Preventive Model in a sequential manner are listed. In total, five modifications were made to the Preventive Model of ACT Use. For example, the first modification was an added directed effect from Efficacy to Control.

evidence, both quantitative and qualitative, within the psychological literature that perceptions of control influence the level of perceived risk experienced, with increasing control associated with decreasing levels of perceived risk (Brockway & Heath, 1998; Friedland, 1990; Kolker & Burke, 1993). Conceptually, it seemed reasonable to expect that the effect of perceived control over recurrence on women's commitment to ACTs would be mediated by the level of risk perceived by the women - with increasing levels of risk, the effect of perceived control on health behaviour would be dampened.

### **Structural Model 1c**

The freeing of the parameter between *Perceived Control over Breast Cancer Recurrence* and *Perceived Risk of Breast Cancer Recurrence* in Model 1c resulted in a significant decrease in the chi-square statistic ( $\chi^2$  difference test = 47.08 (1 df),  $p < .001$ ). Slight improvements in the fit indices were also noted (see Table 54).

#### Modifications to Model 1c

A review of the standardized residuals and modification indices for Model 1c supported the desirability of further model respecifications. Just over 75% of the standardized residuals were under the criterion level of  $\pm 2.00$ , with the largest residual being between CNTRL2 and ENCOUR3 (3.58). Although the largest modification indices were between the concepts *Previous Use of ACTs* and *Perceived Risk of Breast Cancer Recurrence* (MI = 9.92) and *Perceived Risk of Breast Cancer Recurrence* and *Perceived Barriers to ACT Use* (MI = 9.86), potential model misspecification between *Encouragement to Use ACTs* and *Perceived Control over Breast Cancer Recurrence* was also suggested by the associated modification index (MI = 7.37). Given these statistics and the reasonable possibility that women who receive extensive encouragement to use ACTs (many of which can be categorized as "self-care") may, as a consequence, perceive themselves to have more control over their health than women who receive little support to use ACTs, a direct path between *Encouragement to Use ACTs* and *Perceived Control over Breast Cancer Recurrence* was added to the model (Model 1d).

### **Structural Model 1d**

With the addition of the directed effect between *Encouragement to Use ACTs* and *Perceived Control*, the chi-square statistic decreased significantly, with a  $\chi^2$  difference test = 7.43 (1 df),  $p < .01$ . Minimal improvements were also noted in the fit indices (see Table 54).

#### Modifications to Model 1d

Nearly 83.0% of the standardized residuals in Model 1d were under the criterion value of  $\pm 2.00$ . The largest standardized residuals were associated with the following indicator pairs: PLRS2 and PBACTI (3.66), FQEFTOT and NUMACT (-3.10), PLRS4 and PBACTI (3.00), and PBACT2 and PREVIOUS (-3.01). The modification indices further suggested that the largest improvement in model fit would occur by acknowledging a possible relationship between



*Perceived Likelihood of Breast Cancer Recurrence* and *Perceived Barriers to ACT Use* (MI = 9.52). Preliminary evidence for an association between these two concepts has been provided by research examining the intercorrelations among the Health Belief Model constructs (Amlung, 1996). There is insufficient evidence, however, regarding the direction of the association and whether perceptions of risk influence the perceived barriers to ACT use, or visa versa. As such, the decision was made to allow the two concepts to covary in order to test the association between *Perceived Risk of Recurrence* and *Perceived Barriers to ACT Use* without constraining the direction of the effect (Model 1e).

### **Structural Model 1e**

Following the addition of the covariance in the disturbance terms of *Perceived Risk of Breast Cancer Recurrence* and *Perceived Barriers to ACT Use*, the chi-square statistic was significantly reduced to 218.53 ( $\chi^2$  difference test = 8.61 (1 df),  $p < .005$ ). No changes were observed in the other fit indices (see Table 54).

### **Modifications to Model 1e**

With regards to standardized residuals, Model 1e performed slightly worse than Model 1d, with approximately 80.0% of the residuals being within the  $\pm 2.00$  criterion. The largest standardized residuals were between the following indicators: PBACT2 and PREVIOUS (-3.60), AGENEW and ENCOUR3 (2.93), FQEFTOT and PREVIOUS (-2.95), EDUCATE and PBACT1 (-2.91), and PREVIOUS and PSS4 (-2.78). Turning to the modification indices, the largest model misspecifications suggested were between *Previous Use of ACTs* and *Perceived Risk of Breast Cancer Recurrence* (MI = 9.73), *Education* and *Perceived Risk of Breast Cancer Recurrence* (MI = 5.41), and *Commitment to ACT Use* and *Perceived Risk of Breast Cancer Recurrence* (MI = 4.28). Of the model modifications implied by the standardized residuals and modification indices, only the direct effect between *Previous Use of ACTs* and *Perceived Risk* appeared to be of significance with regard to model fit and theoretical plausibility. Research based on the Health Belief Model has suggested that previous health behaviour can be predictive of perceived susceptibility, in addition to future health behaviour (Warshaw & Davis, 1985). Further, it is reasonable that women with past experience with ACTs may perceive their risk of breast cancer recurrence to be reduced because of their history of self-care and use of therapies purported to be health promoting (e.g., vitamins, herbal therapies). As such, a direct effect between *Previous Use of ACTs* and *Perceived Risk of Breast Cancer Recurrence* was added to the model (Model 1f).

### **Structural Model 1f**

A significant reduction in the chi-square statistic was observed following the addition of the effect between *Previous Use of ACT Use* and *Perceived Risk of Breast Cancer Recurrence*

( $\chi^2$  difference test = 9.80 (1 df),  $p < .005$ ). No changes in the other fit indices were observed (see Table 54).

#### Modifications to Model 1f

Just over 85.0% of the standardized residuals fell within the criterion level of  $\pm 2.00$ , with the largest residuals being observed between the following indicator dyads: PBACT2 and PREVIOUS (-3.04), PBACTE and EDUCATE (3.01), and AGE and ENCOUR3 (2.93). The differences between the observed and the model-implied correlations for these indicator dyads were minimal, ranging from -0.14 to 0.11. Within the context of the Health Belief Model and the preventive use of ACTs, the respecifications implied by the residuals were not theoretically justifiable. Further, the modification indices in Model 1f revealed no additional effects that would result in a significant improvement to the fit of the model.<sup>57</sup> As such, Model 1f was retained as the final model of the Preventive Model of ACT Use. The covariance matrix for the Preventive Model of ACT Use (Model 1f) is provided in Appendix 9.

#### Bootstrapping of Model 1f

The bootstrapping approach has become popular within SEM research as a useful diagnostic tool to determine the amount of bias present in a model's parameter estimates and fit indices (Kline, 1998; Schumacker & Lomax, 1996). A re-sampling procedure, bootstrapping treats the sample data as the population from which cases are randomly selected with replacement to create a series of datasets. The average of the model's parameter estimates is then calculated across the multiple datasets and compared to the original sample coefficient. Significant differences between the two estimates suggest instability in the estimates derived from the original dataset. Standard errors and  $t$ -values associated with the average parameter estimates are also provided. This procedure (referred to as "naïve bootstrapping", Bollen & Stine, 1992) has been found to approximate the distribution of parameter estimates and related statistics but generally fails when applied to test statistics and fit indices. Recent simulation research (Nevitt & Hancock, 2001) has further revealed that bootstrapping is most appropriate in sample sizes of  $n \geq 200$  and under conditions of normality. Recognizing these limitations of bootstrapping, the decision was made to use this procedure to evaluate the stability of the parameter estimates in the Preventive Model of ACT Use (Model 1f). A total of 100 replications<sup>58</sup> were conducted using a 100% sampling fraction that resulted in 100 samples of

<sup>57</sup> All modification indices for Model 1f were  $< 3.84$ , the  $\chi^2$  difference test value required for a significant result at the  $p < .05$  level (1 df).

<sup>58</sup> Efron and Tibshirani (1986) demonstrated through Monte Carlo bootstrapping that there is little improvement in the estimation of model parameters and their standard errors in bootstrap replications beyond 100.

size  $n = 321$ .<sup>59</sup>

Table 55 provides a comparison of the unstandardized and standardized parameter estimates for Model 1f prior to bootstrapping (i.e., with the original dataset) and the unstandardized model estimates following bootstrapping. Minimal bias was observed in Model 1f parameter estimates, with discrepancies between the unstandardized bootstrapped and

**Table 55. Parameter Estimates for Model 1f (Preventive Model)**

Parameters	Std. Parameter Estimates (before bootstrap)	Unstd. Parameter Estimates (before bootstrap)	Mean Unstd. Parameter Estimates (after bootstrap)	SE of Mean Unstd. Parameter Estimates (after bootstrap)
<b>GAMMAS<sup>a</sup></b>				
Age – Perceived Risk	-.15*	-.01*	-.01*	.01
Age – Perceived Efficacy	-.03	.00	-.00	.00
Age – Perceived Control	.13*	.01*	.01*	.00
Education – Perceived Efficacy	-.08	-.03	-.03	.02
Education – Perceived Control	-.09	-.03	-.03	.02
Previous Use – Perceived Risk	-.19*	-.69*	-.72*	.20
Previous Use – Perceived Efficacy	.16*	.55*	.58*	.29
Previous Use – Perceived Barriers	-.12	-.29	-.28	.16
Previous Use – Commitment to ACTs	.33*	.29*	.29*	.07
Encouragement – Perceived Efficacy	.30*	.33*	.33*	.08
Encouragement – Perceived Barriers	-.32*	-.24*	-.24*	.05
Encouragement – Perceived Control	.18*	.20*	.22*	.08
Encouragement – Commitment to ACTs	.21*	.06*	.06*	.02
<b>BETAS<sup>b</sup></b>				
Perceived Risk – Commitment to ACTs	.12	.03	.03	.01
Perceived Efficacy – Commitment to ACTs	.10	.03	.03	.02
Perceived Barriers – Commitment to ACTs	-.10	-.04	-.04	.03
Perceived Control – Commitment to ACTs	.04	.01	.01	.02
Perceived Efficacy – Perceived Control	.41*	.42*	.41*	.08
Perceived Control – Perceived Risk	-.37*	-.39*	-.38*	.06
<b>PSI<sup>c</sup></b>				
Perceived Risk – Perceived Barriers	.17*	.10*	.11*	.03

Note. Bootstrap  $N = 100$

<sup>a</sup>Gammas represent the relationships between exogenous and endogenous factors

<sup>b</sup>Betas represent the relationships between endogenous factors

<sup>c</sup>PSI are the covariances between the disturbance terms of the endogenous factors

\*  $p < .05$

unbootstrapped estimates ranging from .00 to .03. The greatest difference between the estimates (.03) and the largest standard error (.20 and .29) occurred between the concepts

<sup>59</sup> Sampling with replacement can result in the same case appearing more than once in a generated dataset and in the composition of cases varying across the datasets (Kline, 1998).

*Previous Use of ACTs* and *Perceived Barriers* and the concepts *Previous Use of ACTs* and *Perceived Risk*, suggesting slight instability in the estimation of these parameters. Eighty percent of the parameter estimates for Model 1f, however, were within  $\pm 0.01$  of the bootstrapped results. Given the limited bias in the estimates derived from the estimation of Model 1f, the decision was made to accept the unstandardized and standardized parameter estimates from Model 1f prior to bootstrapping as the coefficient values for the Preventive Model of ACT Use.<sup>60</sup> The final structural model is illustrated in Figure 12, including the unstandardized and standardized parameter estimates.

#### Direct and Indirect Effects in Structural Model 1f

Both the direct and indirect effects and the squared multiple correlations ( $R^2$ ) reported in Table 56 provide additional information regarding the theory modelled in the final Preventive Model of ACT use. Direct effects are those relationships between two latent concepts with a single directed arrow connecting them; indirect effects occur when one latent construct is influenced by a second latent construct through one or more other latent concepts (Schumacker & Lomax, 1996). Total effects are the sum of all direct and indirect effects that connect two latent concepts.

Twenty-eight percent of the variance in the primary outcome latent construct, *Commitment to ACT Use*, was explained by the two exogenous concepts alone (*Previous Use of ACTs* and *Encouragement to Use ACTs*). In keeping with the hypotheses posed in Chapter Three, encouragement from significant others to use ACTs and a prior history of ACT use were found to increase women's commitment to ACTs. No other significant relationships were observed between the study constructs and women's commitment to ACTs. While the data did not support the relevance of the health belief model constructs in the Preventive Model with regards to women's commitment to ACT use, several other significant relationships were apparent in the model. Over 21% of the variance in *Perceived Risk of Breast Cancer Recurrence* was explained by the model, with *Age*, *Previous Use of ACTs*, and *Perceived Control over Breast Cancer Recurrence* accounting for the largest direct and total effects. The relationships among these constructs and the perceived risk concept were found to be statistically significant and negatively related to women's perceived risk of breast cancer recurrence. With decreasing age and sense of control and without a prior history of ACT use, women reported increasing levels of perceived risk. *Perceived Efficacy of ACTs* was also found

<sup>60</sup> While it would have been preferable to use the more precise bootstrapped parameter estimates in Model 1f, technical problems arose in calculating the standardized version of the bootstrapped estimates and partitioning the total effects into direct and indirect effects. In addition, using the bootstrapped results would require one to make certain assumptions regarding the variance of the model concepts.

**Table 56. Direct and Indirect Effects from Structural Model 1f (Preventive Model)**

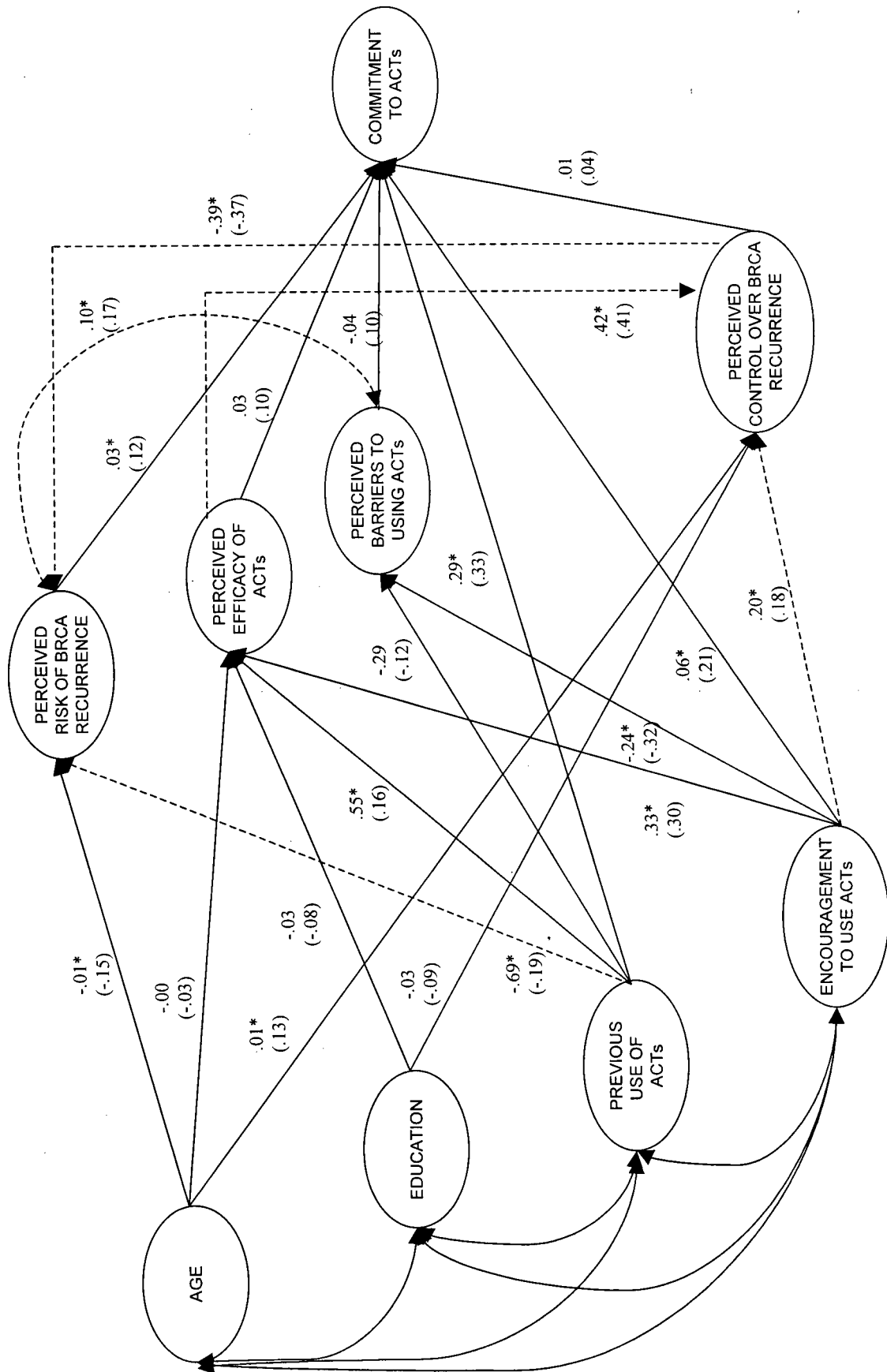
Effects	Std.Direct Effects (Gammas/ Betas)	Std. Indirect Effects	Std. Total Effects	R <sup>2</sup>
Effects on Perceived Risk of:				.21
Age	-.15*	-.05	-.20	
Education	--	.04	.04	
Previous use of ACTs	-.19*	-.02	-.22	
Encouragement to use ACTs	--	-.11	-.11	
Perceived Efficacy	--	-.15	-.15	
Perceived Control	-.37*	--	-.37	
Effects on Perceived Efficacy of:				.15
Age	-.03	--	-.03	
Education	-.08	--	-.08	
Previous use of ACTs	.16*	--	.16	
Encouragement to use ACTs	.30*	--	.30	
Effects on Perceived Barriers:				.15
Previous Use of ACTs	-.12	--	-.12	
Encouragement to use ACTs	-.32*	--	-.32	
Effects on Perceived Control of:				.24
Age	.13*	-.01	.12	
Education	-.09	-.03	-.12	
Previous Use of ACTs	--	.07	.07	
Encouragement to use ACTs	.18*	.12	.30	
Perceived Efficacy	.41*	--	.41	
Effects on Commitment to ACTs:				.28
Age	--	-.02	-.02	
Education	--	-.01	-.01	
Previous use of ACTs	.33*	.01	.34	
Encouragement to use ACTs	.21*	.06	.27	
Perceived Risk	.12	--	.12	
Perceived Efficacy	.10	.00	.10	
Perceived Barriers	-.10	--	-.10	
Perceived Control	.04	-.04	.00	

\*  $p \leq .05$  two-tailed

to be indirectly associated with women's perceived risk through the concept's effect on perceived control.

The model minimally explained *Perceived Efficacy of ACTs*, with only 15% of the variance explained. Women's prior history of ACT use and the amount of encouragement they received to use ACTs were both found to positively affect the degree to which the therapies were perceived to be efficacious. Social support, in particular, had the greatest influence on how useful ACTs were perceived to be in relation to preventing breast cancer recurrence.

The hypothesized effect of *Encouragement to Use ACTs* on *Perceived Barriers* was upheld in



**Figure 12. Structural Model 1f - Preventive Model of Alternative/Complementary Therapy Use**

NOTE: \* p < .05 two-tailed; Standardized parameters in brackets; Modifications shown with dashed lines

the model; it was negatively associated with the amount of barriers associated with ACT use. Those individuals who had received encouragement to use ACTs perceived fewer or, perhaps, less onerous barriers to using ACTs. A significant association was also observed between *Perceived Barriers to ACT Use* and *Perceive Risk of Recurrence*, with a positive standardized covariance of 0.17.<sup>61</sup> This relationship suggests that with increasing levels of perceived risk of breast cancer recurrence, a corresponding increase is observed in the perceived barriers to using ACTs. Only 15% of the variance in the concept *Perceived Barriers*, however, was explained by the Preventive Model.

With regards to *Perceived Control over Breast Cancer Recurrence*, *Perceived Efficacy of ACTs* had the largest direct effect on the amount of control women perceived over the possibility of their breast cancer returning. This relationship would suggest that women who used ACTs and perceived these therapies to be useful had a greater sense of control over their disease trajectory than women who perceived ACTs to be minimally efficacious. *Encouragement to Use ACTs* was also found to be significantly associated with women's perceived level of control over the possibility of a breast cancer recurrence. The women who received encouragement to use ACTs perceived themselves to have greater control regarding their chances of having breast cancer recur. The encouragement concept also indirectly influenced women's perceived control through its strong positive effect on the concept *Perceived Efficacy of ACTs*. In contrast to the hypothesized relationship between *Age* and *Perceived Control*, a woman's age was found to have a moderate, positive effect on the concept, with older women expressing a greater sense of control over breast cancer recurrence than younger women.

### **Summary of Model Testing of the Preventive Model of Alternative/Complementary Therapy Use**

The overall fit of the Preventive Model of ACT Use (Model 1f) was reasonable, with a substantial amount of variance in the main outcome concept, *Commitment to ACT Use*, explained by the structural model. The role of the three health beliefs in predicting women's use of ACTs was not supported by the data. However, women's prior history of ACT use and the encouragement they received from significant others to use ACTs were found to be significantly associated with the amount of commitment they expressed towards ACTs.

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<sup>61</sup> The unstandardized covariance for the *Perceived Barriers* and *Perceived Risk* effect was 0.10.

## Ameliorative Model of Alternative/Complementary Therapy Use

### Structural Model 2b

The Ameliorative Model of ACT Use (Model 2b)<sup>62</sup> tested using structural equation modelling is shown in Figure 13. In this model, it is hypothesized that selected health beliefs, including perceived symptom distress, perceived efficacy of ACTs in ameliorating the symptoms and side effects of breast cancer and conventional cancer treatment, perceived barriers to using ACTs, and perceived control over managing the adverse effects of breast cancer and its conventional treatment, influence women's commitment to ACT use. The above health beliefs, along with women's previous experience with ACTs and the social support they had received from significant others, were postulated to directly affect the manner in which ACTs were used by women with breast cancer. In addition, demographic factors such as age and education, and the women's prior use of ACTs and the encouragement they received with regards to ACT use, were theorized to indirectly influence their commitment to ACT use through their effects on selected health beliefs.

As shown in Table 57, the Ameliorative Model (Model 2b) had a moderate overall fit with the data, with a  $\chi^2 = 272.89$  (df = 139),  $p = .00$ . The RMSEA for Model 2b (0.05; 90% CI: 0.04 - 0.06) was under the criterion value of 0.08 for a reasonable fitting model (Browne & Cudeck, 1993), as were the CFI and GFI. The remaining fit indices were under the accepted criterion

**Table 57. Goodness-of-Fit Indices for Sequential Modifications of the Ameliorative Model of Alternative/Complementary Therapy Use**

Models <sup>a</sup>	$\chi^2$ (df)	$p$	RMSEA (90% CI)	CFI	NFI	AGFI	GFI
Model 2b - initial (following omission of SDS12)	272.89 (139)	.00	0.05 (0.04 – 0.06)	0.95	0.91	0.89	0.92
Model 2c - Encourage → Control	247.68 (138)	.00	0.05 (0.04 – 0.06)	0.96	0.92	0.89	0.92
Model 2d - Symptom Distress → Barriers	235.06 (137)	.00	0.05 (0.04 – 0.06)	0.97	0.93	0.90	0.93
Model 2e - Symptom Distress → Control	223.23 (136)	.00	0.05 (0.03 – 0.06)	0.97	0.93	0.90	0.93

<sup>a</sup>The model modifications (i.e., effects) that were added to the Ameliorative Model in a sequential manner are listed. In total, three modifications were made to the Ameliorative Model of ACT Use. For example, the first modification was an added directed effect between Encourage and Control.

<sup>62</sup> The original Ameliorative Model, Model 2a, was revised in the model development stage of the structural equation modelling process following confirmatory factor analysis (see p. 143-145), resulting in Model 2b.



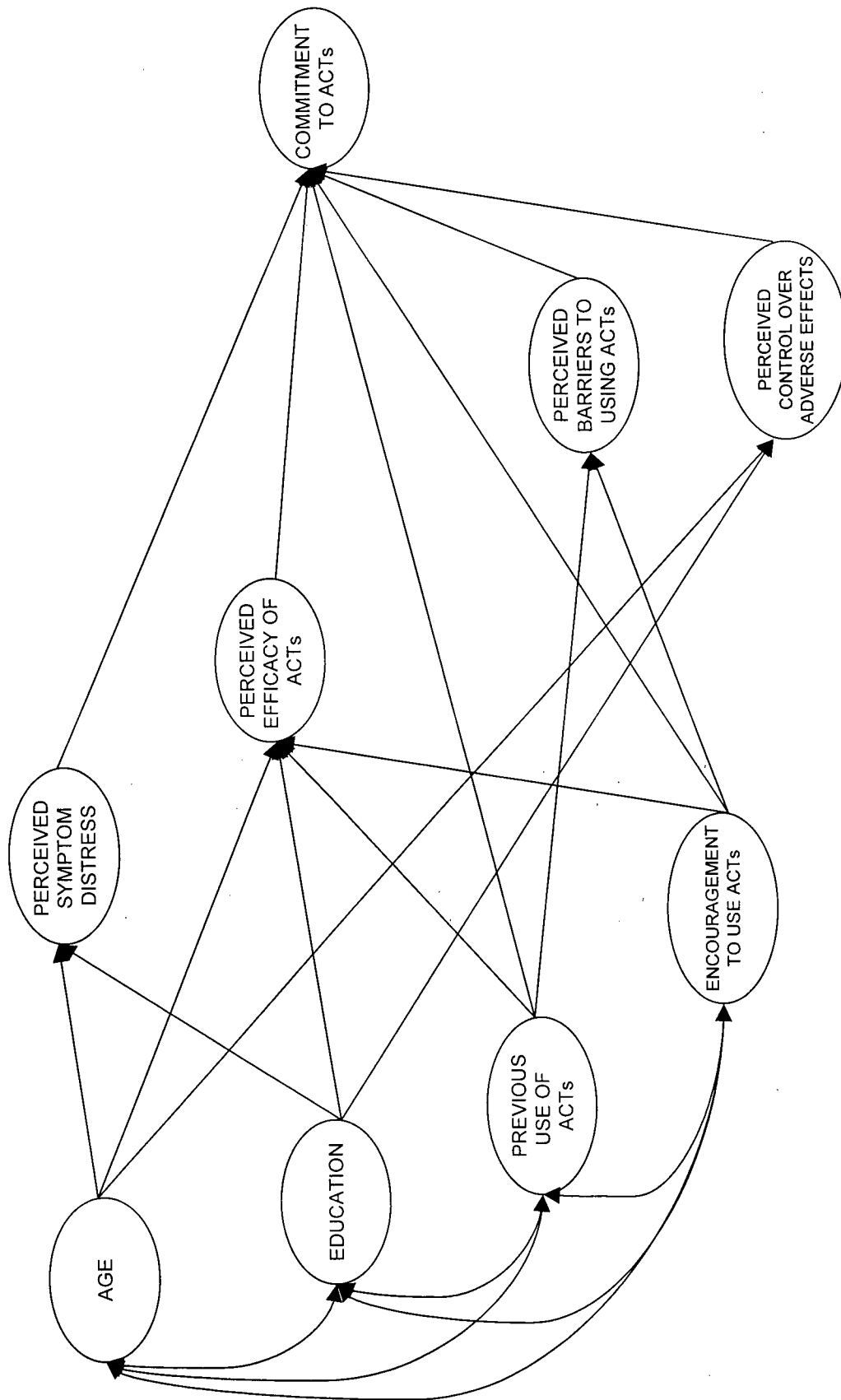


Figure 13. Structural Model 2b - Ameliorative Model of of Alternative/Complementary Therapy Use

values. Of the 16 structural parameters estimated in Model 2b, only 7 effects were statistically significant ( $t > 1.96$ ;  $p < .05$ ). These pathways included (1) *Age* and *Perceived Symptom Distress*, (2) *Age* and *Perceived Efficacy of ACTs*, (3) *Previous Use of ACTs* and *Perceived Efficacy of ACTs*, (4) *Previous Use of ACTs* and *Commitment to ACTs*, (5) *Encouragement to Use ACTs* and *Perceived Efficacy*, (6) *Encouragement to Use ACTs* and *Perceived Barriers to ACT Use*, and (7) *Encouragement to Use ACTs* and *Commitment to ACT Use*. All statistically significant parameters were in the direction originally hypothesized in the Ameliorative Model of ACT Use.

#### Model Modifications to Model 2b

Theoretically plausible model modifications were performed incrementally and directed by the standardized residuals and modification indices (MI)<sup>63</sup> to improve the fit of the Ameliorative Model of ACT Use and to address potential structural misspecifications. In Model 2b, approximately 29% of the standardized residuals were beyond the expected range of  $\pm 2.00$ . The largest standardized residuals were found in the covariances between the following indicators: CONTRL5 and FQEFTOT (4.78), CONTRL5 and NUMACT (4.52), CONTRL5 and ENCOURCM (4.18), CONTRL5 and ENCOUR3 (4.14), and in the variance for EDUCATE (-5.24). Examination of the modification indices further supported the freeing of the structural coefficient between the concepts *Encouragement to Use ACTs* and *Control over Adverse Effects* (MI = 24.17). Similar to the model respecification made in the Preventive Model of ACT Use (Model 1d), this hypothesized relationship implies that women who received encouragement to use ACTs experienced a greater sense of control over their ability to manage the symptoms and side effects of breast cancer and conventional cancer treatment. The addition of this pathway also suggests that the effect of social support on a woman's commitment to ACTs is mediated by their sense of control over adverse effects. Without a strong belief in one's ability to manage the physical and psychological consequences of breast cancer and treatment, encouragement to use ACTs may have little impact on women's actual ACT use. Given the theoretical plausibility of the association between *Encouragement to Use ACTs* and *Perceived Control over Adverse Effects*, this direct effect was added to the model (Model 2c).

#### **Structural Model 2c**

A significant difference in model fit was seen between Model 2b and Model 2c with the addition of the directed effect between *Encouragement to Use ACTs* and *Perceived Control* ( $\chi^2$  difference test = 25.21, 1 df;  $p < .001$ ). Slight improvements in the fit indices were also noted, as shown in Table 57.

<sup>63</sup> Standardized residuals greater than  $\pm 2.00$  and modification indices resulting in  $\chi^2$  difference tests significant at the  $p < .05$  level were used as criteria to guide model modifications.

### Model Modifications to Model 2c

In Model 2c, 84.7% of the standardized residuals fell within the desired range of  $\pm 2.00$ , with the largest residuals being found for the following indicator dyads: PBACT1 and SDS10 (3.47), ENCOUR3 and AGE (3.00), CONTRL5 and SDS4 (-2.97), AGE and CONTRL6 (-2.88), and PBACT2 and PEACTION3 (-2.81). An examination of the modification indices further supported the addition of an effect between *Perceived Symptom Distress* and *Perceived Barriers to ACT Use*, with a reported MI of 12.05. This hypothesized effect suggests that with increasing levels of symptom distress, expressed in the form of fatigue, sleep disturbances, and presence of pain, women perceived greater barriers to using ACTs. Research on the experience of fatigue in cancer populations has revealed this symptom to have a considerable impact on cancer survivors' activities of daily living (Curt et al., 2000), their self-care abilities (Rhodes, Watson, & Hanson, 1988), and their willingness to continue conventional cancer treatment (Winningham et al., 1994). This research and the diagnostic statistics from Model 2c provide sufficient support for the freeing of the structural coefficient between *Perceived Symptom Distress* and *Perceived Barriers to ACT Use* in the Ameliorative Model of ACT Use (Model 2d).

### **Structural Model 2d**

A significant improvement in model fit was seen between Model 2c and Model 2d ( $\chi^2$  difference test = 12.62, 1 df,  $p < .001$ ). As shown in Table 57, slight improvement in selected fit indices also occurred with the addition of the effect between *Perceived Physical Distress* and *Perceived Barriers to ACT Use*.

### Modifications to Model 2d

With the model respecification, Model 2d had only 15.8% of its standardized residuals beyond the accepted criterion range of  $\pm 2.00$ . Those indicator dyads with the highest standardized residuals included ENCOUR3 and AGE (3.05), CONTRL5 and SDS4 (-2.97), EDUCATE and PBACTE (2.97), AGE and PBACT2 (2.90), and AGE and CONTRL6 (-2.88). Examination of the modification indices provided additional evidence of possible misspecifications between the concepts *Perceived Symptom Distress* and *Perceived Control Over Adverse Effects and Symptoms* (MI = 11.42). This relationship is plausible in that fatigue, sleep disturbances, and pain are all symptoms that could affect a woman's sense of control over her ability to manage the side effects and symptoms of breast cancer and conventional cancer treatment. In a phenomenological study of the impact of fatigue on patients experiencing cancer or chronic obstructive airway disease, those individuals receiving treatment for cancer expressed frustration at their inability to control their fatigue or their lives in general (Ream & Richardson, 1997). It is not difficult to imagine that women reporting fatigue following conventional breast cancer treatment may feel a corresponding lack of control over the side effects and symptoms they are experiencing. Given this empirical evidence and based on the

modification indices, the decision was made to free the structural coefficient between the concepts *Perceived Symptom Distress* and *Perceived Control* (Model 2e).

### **Structural Model 2e**

A significant reduction in the chi-square statistic occurred as a result of the addition of the effect between *Perceived Symptom Distress* and *Perceived Control over Adverse Effects*. The  $\chi^2$  difference test was equal to 11.83 (1 df), which was significant at the  $p < .001$  level. No improvement on the other fit indices, however, was apparent (see Table 57).

### Modifications to Model 2e

A review of the standardized residuals revealed that just over 13% lay beyond the desired range of  $\pm 2.00$ . The largest residuals were found among the following indicator dyads: ENCOUR3 and AGE (-3.06), EDUCATE and PBACTE (2.98), AGE and PBACT2 (2.91), AGE and CONTRL6 (-2.88), and PBACT2 and SDS5 (-2.88). A closer examination of the discrepancies between the observed and model-implied correlations for these dyads revealed minimal difference, which ranged from -0.15 to 0.11. Theoretically, the respecifications suggested by the standardized residuals and modification indices were not justifiable within the context of the Health Belief Model and general health behaviour theory. In particular, it was implausible that reverse effects would occur between health beliefs and antecedent factors (i.e., ENCOUR3 and AGE), or that perceived barriers of ACT use would influence women's perceived symptom distress. Further, a review of the modification indices revealed no effects between the *Age* or *Education* concepts and either *Perceived Barriers* or *Control* that would significantly improve the fit of the Ameliorative Model.<sup>64</sup> Given these diagnostics, Model 2e was retained as the final model of the Ameliorative Model of ACT Use. The covariance matrix for the Ameliorative Model of ACT Use (Model 2e) is provided in Appendix 9.

### Bootstrapping of Model 2e

Similar to the procedure followed in testing the Preventive Model of ACT Use, bootstrapping was used to evaluate the stability of the parameter estimates in the Ameliorative Model of ACT Use (Model 2e). A total of 100 replications were conducted using a sampling fraction of 100%, resulting in 100 samples of size  $n = 315$ .

A comparison of the unstandardized and standardized parameter estimates prior to bootstrapping and the unstandardized structural coefficients following bootstrapping for Model 2e is provided in Table 58. Bias in the parameter estimates for Model 2e was minimal, with discrepancies between the unstandardized structural coefficients prior to and following bootstrapping ranging from .00 to .03. The largest difference between the estimates (.03) and the largest standard error (.20) occurred in the *Previous Use of ACTs* and *Perceived Efficacy of*

<sup>64</sup> All modification indices for Model 2e were  $< 3.84$ , the  $\chi^2$  difference test value required for a significant result at the  $p < .05$  level (1 df).

ACTs coefficient. This difference is suggestive of slight instability in the estimation of this structural coefficient. Just over 89% of the parameter estimates in Model 2e, however, were

**Table 58. Parameter Estimates for Model 2e (Ameliorative Model)**

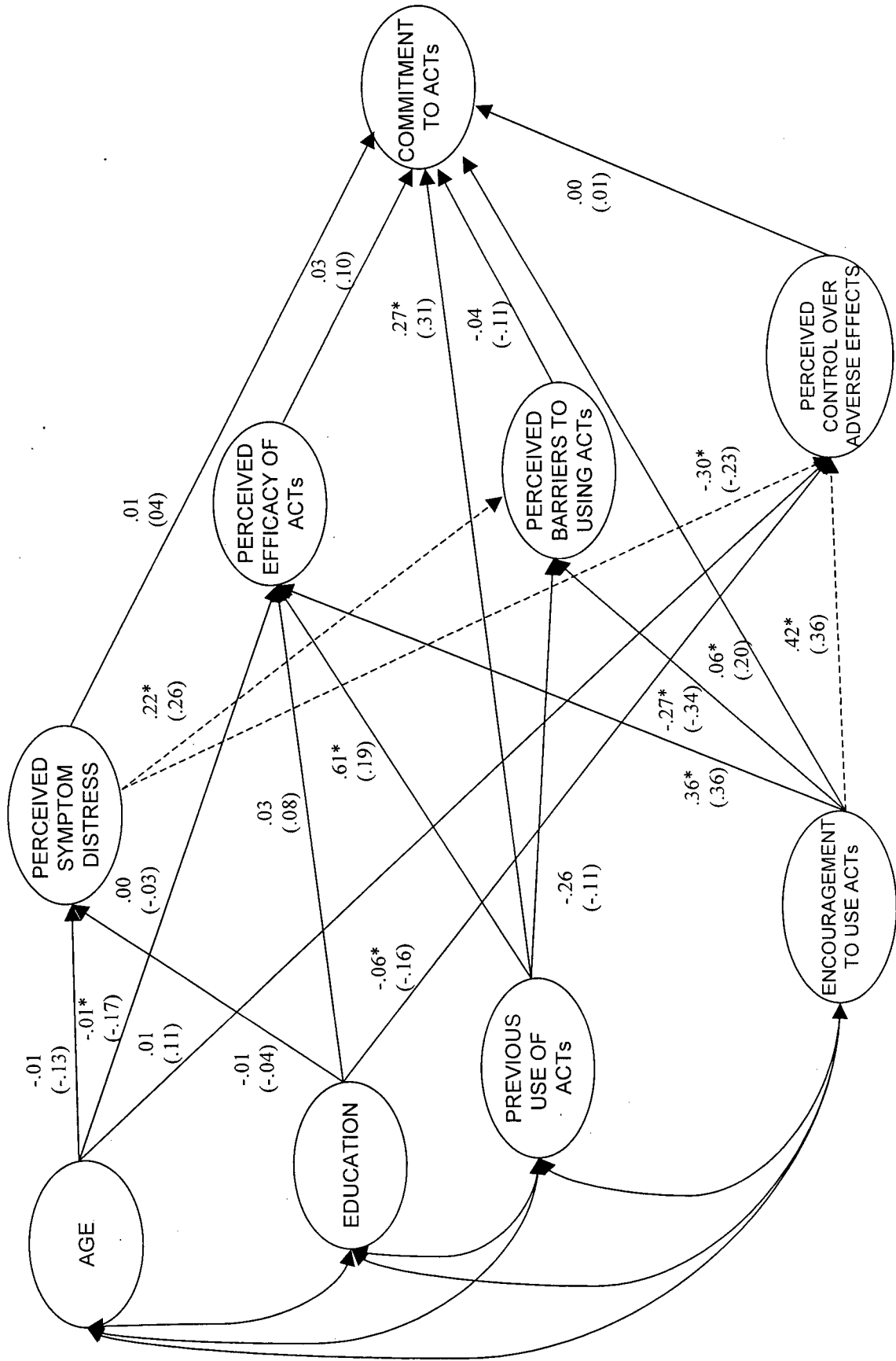
Parameters	Std. Parameter Estimates (before bootstrap)	Unstd. Parameter Estimates (before bootstrap)	Mean Unstd. Parameter Estimates (after bootstrap)	SE of Mean Unstd. Parameter Estimates (after bootstrap)
<b>GAMMAS<sup>a</sup></b>				
Age – Perceived Symptom Distress	-.13	-.01	-.01*	.00
Age – Perceived Efficacy	-.17*	-.01*	-.01*	.00
Age – Perceived Control	.11	.01	-.01*	.00
Education – Perceived Symptom Distress	-.04	-.01	-.01	.02
Education – Perceived Efficacy	.08	.03	.03	.02
Education – Perceived Control	-.16*	-.06*	-.06*	.02
Previous Use – Perceived Efficacy	.19*	.61*	.64*	.20
Previous Use – Perceived Barriers	-.11	-.26	-.28	.16
Previous Use – Commitment to ACTs	.31*	.27*	.27*	.05
Encouragement – Perceived Efficacy	.36*	.36*	.35*	.07
Encouragement – Perceived Barriers	-.34*	-.27*	-.27*	.06
Encouragement – Perceived Control	.36*	.42*	.42*	.08
Encouragement – Commitment to ACTs	.20*	.06*	.06*	.03
<b>BETAS<sup>b</sup></b>				
Perceived Symptom Distress – Commitment to ACTs	.04	.01	.01	.02
Perceived Efficacy – Commitment to ACTs	.10	.03	.02	.02
Perceived Barriers – Commitment to ACTs	-.11	-.04	-.04	.03
Perceived Control – Commitment to ACTs	.01	.00	.00	.01
Perceived Symptom Distress – Perceived Barriers	.26*	.22*	.22*	.07
Perceived Symptom Distress – Perceived Control	-.23*	-.30*	-.31*	.09

\*  $p < .05$ ; Bootstrap N = 100

<sup>a</sup>Gammas represent the relationships between exogenous and endogenous factors

<sup>b</sup>Betas represent the relationships between endogenous factors

within  $\pm 0.01$  of the bootstrapped results. Two parameter estimates *Age* and *Perceived Symptom Distress* and *Age* and *Perceived Control over Adverse Effects*, were noted to have changed with regards to their level of significance ( $t < 1.96$ ). These structural coefficients were not significant prior to bootstrapping, with their  $t$ -values equalling 1.85. As a consequence of the limited bias in the parameter estimates in Model 2e prior to bootstrapping, the decision was made to use the unstandardized and standardized parameter estimates from Model 2e as the reported structural coefficient values for the Ameliorative Model of ACT Use. Figure 14 illustrates the final structural model and includes both unstandardized and standardized parameter estimates.



**Figure 14. Model 2e - Ameliorative Model of Alternative/Complementary Therapy Use**

NOTE: \*  $p < .05$  two-tailed; Standardized parameters in brackets; Modifications shown with dashed lines

### Direct and Indirect Effects in Structural Model 2e

Table 59 provides more detailed information regarding the effects hypothesized in the Ameliorative Model of ACT Use, including both indirect and direct effects and the total variance explained by the model for each concept (squared multiple correlations).

Just under one half (47.4%) of the parameters estimated in the model were statistically significant ( $t > 1.96$ ;  $p < .05$ ). Twenty-nine percent of the variance in the primary outcome concept, *Commitment to ACT Use*, was explained by the two exogenous factors, *Previous Use of ACTs* and *Encouragement to Use ACTs*. No other significant effects were observed between the study construct and women's commitment to ACTs.

Only 2% of the variance in the *Perceived Symptom Distress* concept was defined by the model's parameters. No significant effects were observed between women's age or education and their reported symptom distress.

Despite the lack of significance of the Health Belief Model concepts in the Ameliorative Model of ACT Use, several other effects of substantive interest were noted in the model. One third of the variance in the *Perceived Efficacy of ACTs* concept was explained by the model, with *Age*, *Previous Use of ACTs*, and *Encouragement to Use ACTs* accounting for the largest total effects. Younger women, who had a prior history of ACT use and had received encouragement from significant others to use ACTs perceived higher therapy efficacy in relation to managing the adverse effects of breast cancer and conventional cancer treatment. Unlike the Preventive Model of ACT Use, a non-significant effect was observed between *Education* and *Perceived Efficacy*.

The concept *Perceived Barriers to ACT Use* had slightly more variance explained by the Ameliorative Model (22%) than the Preventive Model (18%), with both *Encouragement to Use ACTs* and *Perceived Symptom Distress* having significant effects on the barriers women perceived in relation to using ACTs in the context of ameliorating the side effects and symptoms of breast cancer. In the Ameliorative Model, women who received encouragement to use ACTs perceived less serious barriers to using ACTs than women who had little social support to use ACTs. With regards to symptom distress, those respondents who reported high levels of fatigue, sleep disturbances, and pain frequency were more likely to perceive serious barriers to using therapies that were alternative or complementary to their conventional medical care. The relationship between *Perceived Barriers* and *Perceived Symptom Distress* suggests that the symptoms experienced as a consequence of breast cancer and conventional cancer treatments may contribute to, or perhaps magnify, the perceived barriers that exist to using ACTs.

**Table 59. Direct and Indirect Effects from Structural Model 2e (Ameliorative Model)**

Effects	Std. Direct Effects  Gammas/ Betas	Std. Indirect Effects	Std. Total Effects	R <sup>2</sup>
Effects on Perceived Symptom Distress of:				.02
Age	-.13	--	-.13	
Education	-.04	--	-.04	
Effects on Perceived Efficacy of:				.32
Age	-.17*	--	-.17	
Education	.08	--	.08	
Previous use of ACTs	.19*	--	.19	
Encouragement to use ACTs	.36*	--	.36	
Effects on Perceived Barriers of:				.22
Age	--	.03	.03	
Education	--	.01	.01	
Previous Use of ACTs	-.11	--	-.11	
Encouragement to use ACTs	-.34*	--	-.34	
Perceived Symptom Distress	.26*	--	.26	
Effects on Perceived Control of:				.18
Age	.11	.03	.14	
Education	-.16*	.01	-.15	
Encouragement to use ACTs	.36*	--	.36	
Perceived Symptom Distress	-.23*	--	-.23	
Effects on Commitment to ACTs:				.29
Age	--	-.02	-.02	
Education	--	.01	.01	
Previous use of ACTs	.31*	.03	.34	
Encouragement to use ACTs	.20*	.08	.28	
Perceived Symptom Distress	.04	-.03	.01	
Perceived Efficacy	.10	--	.10	
Perceived Barriers	-.11	--	-.11	
Perceived Control	.01	--	.01	

\*  $p < .05$  two-tailed

Women's *Perceived Control over Adverse Effects* was moderately explained in the Ameliorative Model, with 18% of the variance in the concept being explained by the model's parameters. *Education*, *Encouragement to Use ACTs*, and *Perceived Symptom Distress* were all concepts found to be significantly associated with women's perceived control. The most significant effect was between *Encouragement* and *Perceived Control*, with those individuals receiving support to use ACTs expressing greater confidence in their ability to manage the side effects and symptoms related to breast cancer and its treatment than women who received limited encouragement to use ACTs. Not surprisingly, women who reported high levels of symptom distress expressed less conviction in their control over the negative health outcomes



of breast cancer and conventional cancer treatment. As in the Preventive Model, women's education was found to be negatively associated with the concept of control, which was contrary to the relationship initially hypothesized in the Ameliorative Model. Having less education was found to increase the level of perceived control women held in relation to managing their side effects and symptoms.

### **Summary of Model Testing of the Ameliorative Model of Alternative/Complementary Therapy Use**

A moderate level of model fit was observed in the Ameliorative Model of ACT Use (Model 2e), with close to one third of the variance in the primary outcome concept, *Commitment to ACT Use*, being explained by the structural model. While the Health Belief Model concepts were of no relevance in predicting the use of ACTs in the context of symptom and side effect management, women's prior history of ACT use and the encouragement they received to use ACTs were found to be significantly associated with their commitment to ACT use.

## **Restorative Model of Alternative/Complementary Therapy Use**

### **Structural Model 3a**

Figure 15 illustrates the initial Restorative Model of ACT Use (Model 3a) to be tested using structural equation modelling. This model hypothesizes that selected health beliefs, including perceived risk of harm, perceived efficacy of ACTs in restoring well being, perceived barriers to using ACTs, and perceived control over one's well being, influence the level of women's commitment to ACTs. The above health beliefs, along with women's prior history of ACT use and the encouragement they received from significant others to use ACTs, were hypothesized to directly affect the manner in which ACTs were used by women with breast cancer. Demographic characteristics, including age and education, women's previous use of ACTs, and the social support received with regards to ACT use, were also postulated to indirectly influence women's commitment to ACT use through their effects on selected health beliefs.

The initial Restorative Model (Model 3a) had poor overall fit with the data (see Table 60), with a  $\chi^2 = 271.75$  (df = 107),  $p = .00$ . The RMSEA for Model 3a (0.07; 90% CI: 0.06 - 0.08) was just under the criterion value of 0.08 for a reasonable fitting model (Browne & Cudeck, 1993). Except for the GFI, the remaining fit indices were under the accepted criterion values. Of the 15 structural parameters estimated in Model 3a, only 9 effects were statistically significant ( $t > 1.96$ ;  $p < .05$ ). These pathways included (1) *Age* and *Perceived Risk of Harm*, (2) *Age* and *Perceived Efficacy of ACTs*, (3) *Previous Use of ACTs* and *Perceived Efficacy of ACTs*, (4) *Previous Use of ACTs* and *Commitment to ACTs*, (5) *Encouragement to Use ACTs* and *Perceived Efficacy of*

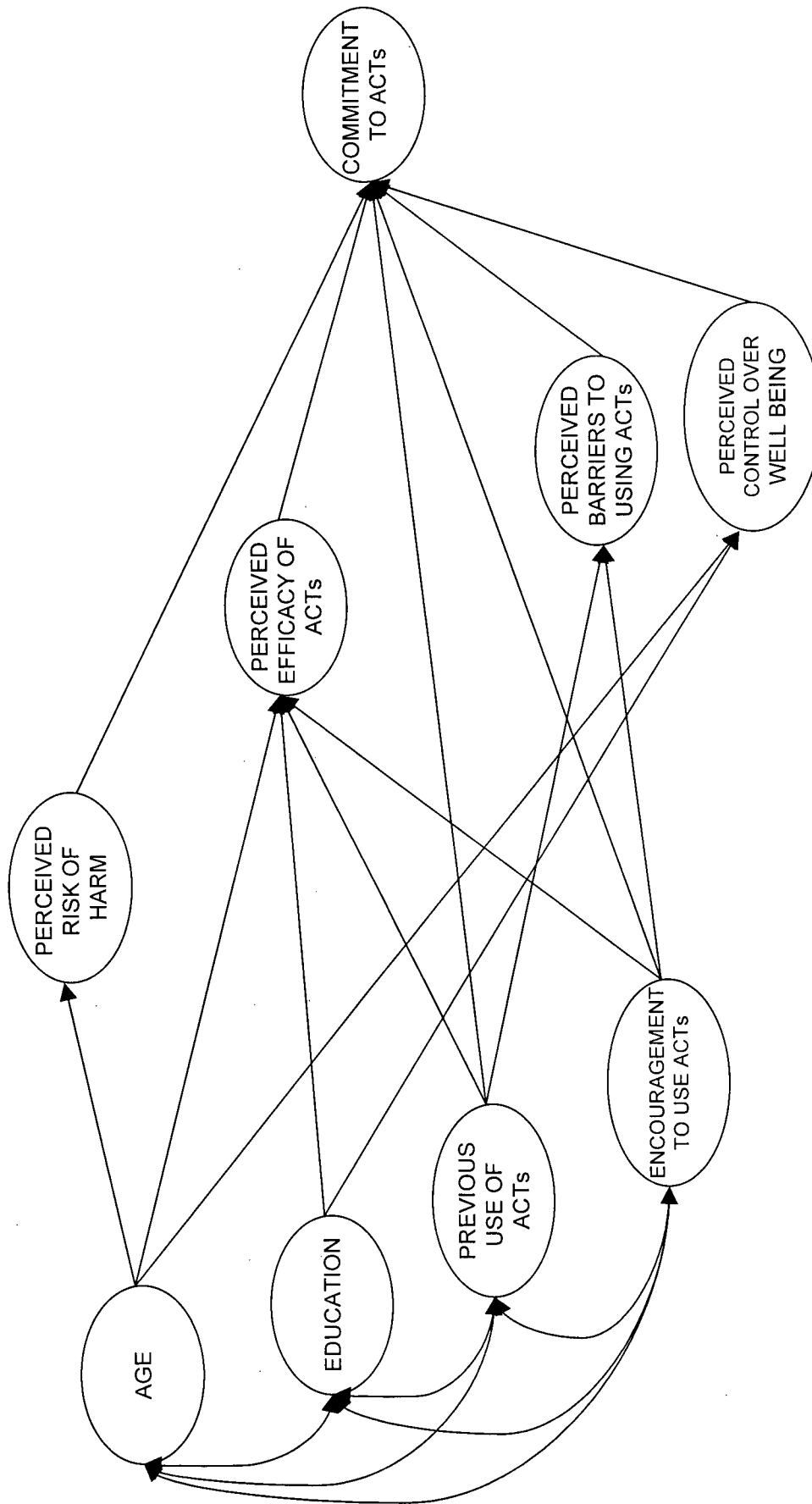


Figure 15. Structural Model 3a - Restorative Model of Alternative/Complementary Therapy Use

ACTs, (6) *Perceived Encouragement to Use ACTs* and *Perceived Barriers to Using ACTs*, (7) *Perceived Encouragement to Use ACTs* and *Commitment to ACTs*, (8) *Perceived Efficacy of ACTs* and *Commitment to ACTs*, and (9) *Perceived Control over Well Being* and *Commitment to ACTs*. All statistically significant associations were in the direction originally hypothesized in Chapter Three for the Restorative Model of ACT use.

#### Model Modifications to Model 3a

Similar to the process used in the Preventive and Ameliorative models, theoretically plausible model modifications were performed incrementally following an examination of the standardized residuals and modification indices (MI)<sup>65</sup> to address possible structural misspecifications and to improve the fit of the model. In Model 3, just over 20% of the standardized residuals were beyond the criterion range of  $\pm 2.00$ . The largest standardized residuals were found between the following indicators: PRHS2 and CONTRL8 (6.81) and PRHS1 and CONTRL7 (4.98). Examination of the modification indices further supported the addition of a relationship between the *Perceived Risk of Harm* and *Perceive Control* concepts, with the largest expected change in model fit (MI = 38.76) occurring with the freeing of the structural coefficient between these concepts. This association suggests that as women's sense of control over their physical and mental well being increases, their perception of the likelihood of harm to their well being correspondingly decreases. Previous research on the relationship between control and perceived risk has provided evidence of the validity of this relationship (Greening, 1997; McKenna, 1993; Weinstein, 1984), with individuals who express high levels of perceived control over their health to optimistically perceive themselves to be at lower risk of negative health outcomes. The addition of this effect further suggests that the influence of women's perceived control over well being on their commitment to ACTs was mediated by their perception of how likely their well being had been harmed by their breast cancer experience – with increasing levels of perceived risk, the effect of perceived control on health behaviour would be inhibited. Given the plausibility of the direct and indirect relationships implied by the respecification of an effect between *Perceived Control over Well Being* and *Perceive Risk of Harm*, this structural coefficient was freed in the model (Model 3b).

#### **Structural Model 3b**

With the addition of the effect between *Perceived Control over Well Being* and *Perceived Risk of Harm*, the chi-square statistic decreased significantly ( $\chi^2$  difference test = 41.91, 1 df,  $p < .001$ ). Improvement in the fit indices was also noted, with the RMSEA, CFI, and GFI being beyond the accepted criterion values for these fit indices (see Table 60).

<sup>65</sup> Standardized residuals greater than  $\pm 2.00$  and modification indices resulting in  $\chi^2$  difference tests significant at the  $p < .05$  level were used as criteria to guide model modifications.

### Model Modifications to Model 3b

In Model 3b, 23% of the standardized residuals remained beyond the accepted criterion range of  $\pm 2.00$ . The largest standardized residuals were identified between the following indicator dyads: PRHS1 and PBACT1 (3.69) and PRHS2 and CONTRL7 (-3.61). The largest modification index (15.29) was also noted between the *Perceived Risk of Harm* and *Perceived Barriers to ACT Use* concepts, supporting the possibility of a misspecification between these two constructs. This misspecification was comparable to the one identified in the Preventive Model of ACT Use (Model 1e) and, given the lack of evidence supporting the direction of the relationship between these two concepts, the decision was made to allow *Perceived Risk of Harm* and *Perceived Barriers to ACT Use* to covary through their disturbance terms (Model 3c). This association hypothesizes that a woman's perceived risk of harm to well being is related to the barriers she perceives to exist to accessing and using ACTs, and visa versa. This association allows for the possibility of an unspecified common cause, or concept, that influences both *Perceived Risk of Harm* and *Perceived Barriers to ACT Use*.

**Table 60. Goodness-of-Fit Indices for Sequential Modifications of the Restorative Model of Alternative/Complementary Therapy Use**

Models	$\chi^2$ (df)	<i>p</i>	RMSEA (90% CI)	CFI	NFI	AGFI	GFI
Model 3a - initial model	271.75 (107)	.00	0.07 (0.06 – 0.08)	0.94	0.91	0.87	0.91
Model 3b - Control $\rightarrow$ Risk	229.84 (106)	.00	0.06 (0.05 – 0.07)	0.96	0.92	0.89	0.92
Model 3c - Risk $\curvearrowright$ Barriers	219.58 (105)	.00	0.06 (0.05 – 0.07)	0.96	0.93	0.89	0.93
Model 3d - Control $\curvearrowright$ Barriers	208.25 (104)	.00	0.06 (0.04 – 0.07)	0.96	0.93	0.90	0.93

<sup>a</sup>The model modifications (i.e., effects or covariances) that were added to the Restorative Model in a sequential manner are listed. In total, three modifications were made to the Restorative Model of ACT Use. For example, the first modification was an added directed effect from *Control* to *Risk*.

### **Structural Model 3c**

A significant improvement was seen in model fit with the addition of the covariance between *Perceived Risk of Harm* and *Perceived Barriers to ACTs*, with a  $\chi^2$  difference test equal to 10.26 (1 df),  $p < .001$ . Slight improvements in the fit indices were apparent (see Table 60).

### Model Modifications to Model 3c

Nearly 21% of the standardized residuals in Model 3c remained beyond the criterion level of  $\pm 2.00$ . The largest standardized residuals were found in the following indicator dyads: PRHS2 and CONTRL8 (3.96), and PBACT2 and CONTRL8 (3.62). The modification indices also indicated misspecification between *Perceived Control over Well Being* and *Perceived*

*Barriers to ACT Use* (MI = 12.40) and *Perceived Control over Well Being* and *Perceived Risk of Harm* (MI = 10.56). Given that a direct effect between perceived control and perceived risk of harm had already been added to the model (Model 3b) as a theoretically plausible respecification, the decision was made to allow the concepts *Perceived Control over Well Being* and *Perceived Barriers to ACT Use* to covary (Model 3d). A direct effect was not specified, as there is insufficient evidence of the direction of the relationship between these two health beliefs. Theoretically, however, it is not unreasonable to hypothesize that individuals who are optimistic about their ability to manage their physical and mental well being may perceive fewer barriers to their use of ACTs than individuals who are more pessimistic about their control over their health. Preliminary research on the effect of optimistic bias on the components of the Health Belief Model within the context of breast and prostate cancer screening provides support for this decision, as optimism was found to influence all health beliefs (Clarke, Lovegrove, Williams, & Machperson, 2000). It is plausible that the influence of optimistic biases on health beliefs would extend to beliefs related to perceived control.

### **Structural Model 3d**

With the addition of the covariance between the disturbance terms *Perceived Control* and *Perceived Barriers*, a significant improvement in model fit was observed ( $\chi^2$  difference test=11.33, 1 df,  $p < .001$ ). A slight improvement was also observed in the AGFI, reaching the criterion value of 0.90. No other changes in fit indices were found (see Table 60).

### **Model Modifications to Model 3d**

No theoretically justifiable model modifications were apparent following the testing of Model 3d. Just over 13% of the standardized residuals were beyond the criterion range of  $\pm 2.00$ , with the highest standardized residuals being found between the following indicator dyads: PRHS1 and CONTRL8 (-3.41), and PRHS2 and CONTRL8 (3.14). A closer examination of the difference between the observed and model-implied correlations for these indicator pairs revealed minimal discrepancies, which were .11 and .09, respectively. Theoretically, the respecifications suggested by the residuals were not theoretically plausible within the context of the Health Belief Model and general health behaviour theory. With regards to the modification indices, the largest modification index that would result in a significant improvement in model fit<sup>66</sup> was between *Perceived Risk of Harm* and *Perceived Efficacy* (MI = 5.01). This association, however, was not consistent with the Health Belief Model. As such, no further modifications were made to the Restorative Model and Model 3d was retained as the final model. The covariance matrix for the Restorative Model of ACT Use (Model 3d) is provided in Appendix 9.

<sup>66</sup> The criterion value for a significant chi square difference test was 3.84.

### Bootstrapping of Model 3d

Bootstrapping was used following testing of the Restorative Model to evaluate the stability of the parameter estimates. As done in the Preventive and Ameliorative Models, a total of 100 replications were conducted using a sample fraction of 100% resulting in 100 samples of size  $n = 313$ . A comparison of the unstandardized and standardized parameter estimates prior to bootstrapping and the mean unstandardized structural coefficients following bootstrapping for Model 3d is provided in Table 61. Minimal biases in parameter estimates were observed, with all

**Table 61. Parameter Estimates for Model 3d (Restorative Model)**

Parameters	Std. Parameter Estimates (before bootstrap)	Unstd. Parameter Estimates (before bootstrap)	Mean Unstd. Parameter Estimates (after bootstrap)	SE of Mean Unstd. Parameter Estimates (after bootstrap)
<b>GAMMAS<sup>a</sup></b>				
Age – Perceived Risk	-.31*	-.03*	-.03*	.01
Age – Perceived Efficacy	-.14*	-.01*	-.01*	.00
Age – Perceived Control	.07	.00	.00	.00
Education – Perceived Efficacy	.08	.03	.03	.02
Education – Perceived Control	.03	.01	.00	.02
Previous Use – Perceived Efficacy	.20*	.65*	.66*	.14
Previous Use – Perceived Barriers	-.09	-.21	-.22	.16
Previous Use – Commitment to ACTs	.29*	.25*	.25*	.07
Encouragement – Perceived Efficacy	.43*	.45*	.45*	.06
Encouragement – Perceived Barriers	-.34*	-.26*	-.27*	.05
Encouragement – Commitment to ACTs	.16*	.05*	.05	.03
<b>BETAS<sup>b</sup></b>				
Perceived Risk – Commitment to ACTs	.10	.03	.02	.03
Perceived Efficacy – Commitment to ACTs	.18*	.05*	.05*	.02
Perceived Barriers – Commitment to ACTs	-.07	-.03	-.03	.03
Perceived Control – Commitment to ACTs	.19*	.07*	.07*	.03
Perceived Control – Perceived Risk	-.46*	-.71*	-.72*	.17
<b>PSI<sup>c</sup></b>				
Perceived Risk – Perceived Barriers	.16*	.10*	.09*	.04
Perceived Control – Perceived Barriers	-.24*	-.09*	-.09*	.03

Note. bootstrap N = 100

<sup>a</sup>Gammas represent the relationships between exogenous and endogenous factors

<sup>b</sup>Betas represent the relationships between endogenous factors

<sup>c</sup>PSI are the covariances between the disturbance terms of the endogenous factors

\*  $p < .05$ ;

of the parameter estimates in Model 3d being within  $\pm 0.01$  of the bootstrapped results. The only difference to note was the shift in significance of the *Encouragement to Use ACTs* and *Commitment to ACTs* direct relationship. In the Model 3d results, the t-value for this relationship was 2.10, just beyond the criterion value of 1.96 for significance at the level of  $p < .05$ . Following bootstrapping, the t-value for the *Encouragement to Use ACTs* and *Commitment to ACTs*

association was 1.82. This suggests that in a larger population sample, social support does not have a significant effect on women's commitment to use ACTs within the context of restoring well being. That this relationship remained significant in the Preventive and Ameliorative Models of ACT Use following bootstrapping is a point that will be discussed in greater detail in the following chapter. Notwithstanding this discrepancy, given the limited bias in the remaining parameter estimates in Model 3d, the decision was made to use the unstandardized and standardized structural coefficient estimates from Model 3d to describe the Restorative Model of ACT Use. The final model with its unstandardized and standardized parameter estimates is shown in Figure 16.

#### Direct and Indirect Effects in Structural Model 3d

A summary of the direct and indirect effects hypothesized in the Restorative Model of ACT Use as well as the total variance (i.e.,  $R^2$ ) explained by the model for each concept is provided in Table 62.

A total of 32% of the variance in the *Commitment to ACT Use* concept was explained by one health belief (*Perceived Efficacy*) and other exogenous and endogenous concepts. The direct relationship between *Perceived Efficacy* and the *Commitment to ACT Use* concept was in accordance with the originally hypothesized model parameter. Women who perceive ACTs to be efficacious in improving their physical and mental well being report higher levels of commitment to ACTs. *Perceived Control over Well Being* was found to be significantly associated with the *Commitment to ACTs* concept, with women who perceive themselves to have greater control over their physical and mental well being expressing higher levels of commitment to ACTs than women with less sense of control. As in the Preventive and Ameliorative models, the effect of *Previous Use of ACTs* on women's commitment to ACTs was significant and accounted for the largest total effect on women's use of ACTs. Women who had used ACTs prior to their breast cancer diagnosis expressed greater commitment to ACTs than women who had not used ACTs before diagnosis. Women who received encouragement to use ACTs were also found to report greater use of ACTs, however, as previously mentioned, this relationship was not significant in the larger, bootstrapped sample.

Several other significant relationships were also found in the Restorative Model of ACT Use. The *Perceived Risk of Harm* concept was well explained by the model, with 33% of the variance being explained by the effects of *Age* and *Perceived Control* on women's perceptions of risk of harm to their physical and mental well being following diagnosis and treatment for breast cancer. Younger women and those who perceived little or no control over their well being were more likely to believe that their physical and mental health had been harmed by their illness.

*Perceived Efficacy* was also reasonably well explained, with close to 40% of the variance for the concept being accounted for by the Restorative Model. Women's age, their prior history of ACT use, and the social support they received with regards to ACTs were all significantly associated with how efficacious women perceived ACTs to be in improving physical and mental well being. Younger women who had previous experience with ACTs and were encouraged to use ACTs reported higher levels of therapy efficacy for ACTs.

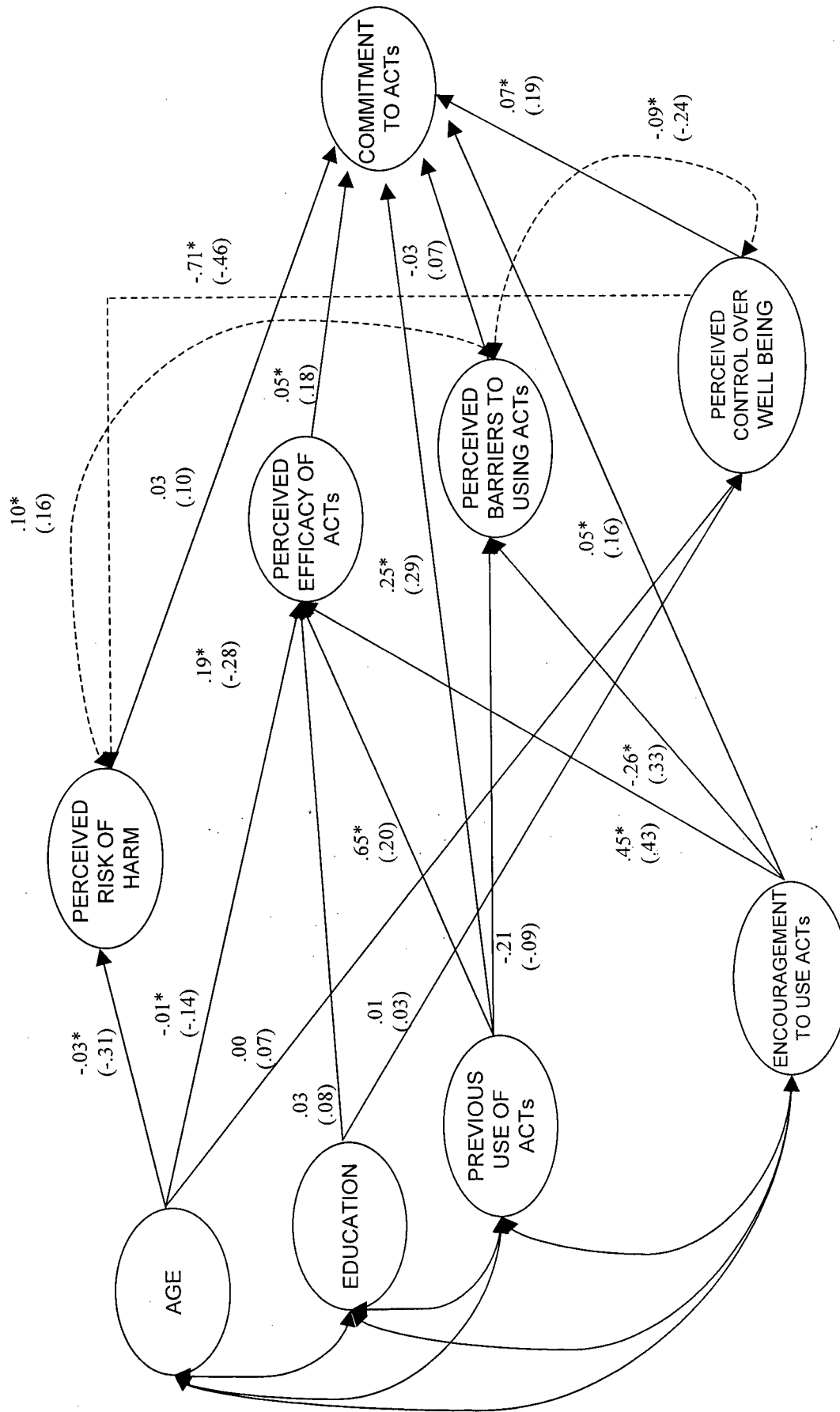
**Table 62. Direct and Indirect Effects from Structural Model 3d (Restorative Model)**

Effects	Std. Direct Effects  Gammas/ Betas	Std. Indirect Effects	Std. Total Effects	R <sup>2</sup>
Effects on Perceived Risk of Harm:				.33
Age	-.30*	-.03	-.33	
Education	--	-.01	-.01	
Perceived Control	-.47*	--	-.47	
Effects on Perceived Efficacy of:				.39
Age	-.14*	--	-.14	
Education	.08	--	.08	
Previous use of ACTs	.20*	--	.20	
Encouragement to use ACTs	.43*	--	.43	
Effects on Perceived Barriers of:				.15
Age	--	-.09	-.09	
Education	--	.00	.00	
Previous Use of ACTs	-.10	--	-.10	
Encouragement to use ACTs	-.38*	--	-.38	
Perceived Control	--	-.13	-.13	
Effects on Perceived Control of:				.00
Age	.06	--	.06	
Education	.01	--	.01	
Effects on Commitment to ACTs:				.32
Age	--	-.04	-.04	
Education	--	.02	.02	
Previous use of ACTs	.29*	.04	.33	
Encouragement to use ACTs	.16*	.11	.27	
Perceived Risk of Harm	.10	-.02	.08	
Perceived Efficacy	.18*	--	.18	
Perceived Barriers	-.08	--	-.08	
Perceived Control	.19*	-.04	.15	

\*  $p \leq .05$  two-tailed

The concept *Perceived Barriers to ACT Use* was not as well explained in the model as the other health beliefs, with only 15% of the variance in the concept explained by the model. Women who reported receiving encouragement to use ACTs perceived fewer barriers to using ACTs than those women who had received less social support in their treatment choice. A





**Figure 16. Model 3d - Restorative Use of Alternative/Complementary Therapy Use**

NOTE: \*  $p < .05$  two-tailed; Standardized parameters in brackets; Modifications shown with dashed lines

significant positive association was also found between the *Perceived Barriers* and *Perceived Risk of Harm* concepts, with a standardized covariance of 0.16 (unstandardized covariance = 0.10). A significant correlation was also found between the *Perceived Barriers* and *Perceived Control over Well Being* concepts, with a standardized covariance of -0.24 (unstandardized covariance = -0.09). Women who perceived many barriers to ACTs also reported themselves as having less control over their physical and mental well being. The source of either of the relationships between *Perceived Barriers to ACT Use* and the *Perceived Risk of Harm* and *Perceived Control* concepts, however, cannot be determined from the model (it could be causal, although the directional of the effect is unclear or it could arise from a common cause).

The Restorative Model of ACT Use poorly explained women's perceptions regarding the degree of control they held over their well being, with less than one percent of the variance being accounted for.

#### **Summary of Model Testing of the Restorative Model of Alternative/Complementary Therapy Use**

The overall fit of the Restorative Model of ACT Use (Model 3d) was reasonable, with a substantial amount of the variance in women's commitment to ACT use being explained by the structural coefficients included in the model. Younger women who perceived ACTs to be efficacious in improving their physical and mental well being, believed they had some degree of control over their health, had a prior history of ACT use, and were supported in their decision to use ACTs were found to be significantly more committed in the manner in which they used ACTs.

## Chapter 8

### Discussion and Implications

The purpose of this study was to add to current knowledge about the use of alternative/complementary therapies (ACTs) by women with breast cancer and to increase understanding of the beliefs and sociobehavioural factors that influence women's decisions to use therapies beyond the realm of conventional medical care. This final chapter provides an overview of the major study findings, the contributions of this study to the larger body of ACT research, the potential limitations of the research, and the implications of the findings, particularly in relation to supporting women with breast cancer and their family members in making informed choices related to ACT use. Recommendations for future research conclude this chapter.

### Discussion of the Findings

The findings of this study can be separated into two distinct areas. The first set of findings describes women's experiences with ACTs following their breast cancer diagnosis. The second set of results focusses on the associations among health beliefs, sociobehavioural factors, and ACT use by women with breast cancer that were tested using structural equation modelling procedures.

#### **Alternative/Complementary Therapy Use by Women Living with Breast Cancer**

It was postulated at the beginning of this work that women living with breast cancer were a relevant and interested population in which to conduct ACT research. The findings of this study support this presumption, with a significant number of women reporting the use of a variety of therapies following their breast cancer diagnosis. A continuum of commitment to ACTs was revealed, based on the amount of time, effort, and expense women afforded ACTs. Women were most likely to seek the advice and knowledge of individuals who were not part of the conventional health-care system, with approximately one quarter of women remaining cautious about sharing their treatment decisions with their primary care physician or cancer specialists.

These findings are discussed in further detail in the following sections; the major inferences are positioned within the context of relevant published literature.

#### Prevalence of Alternative/Complementary Therapy Use

Using a liberal definition<sup>67</sup> of ACTs, the majority of women (79.9%) had used at least one type of ACT or alternative practice since their breast cancer diagnosis. Given the broad range of therapies assessed in this study, it is not surprising that this prevalence is higher than that found in other studies examining ACT use in breast cancer populations (Boon et al., 2000; Crocetti et al., 1998; Rees et al., 2000). Using a more restrictive range of therapies (i.e., 27 therapies), Boon et al. (2000) found only 66.7% of women with breast cancer reported using ACTs. When a more conservative estimate<sup>68</sup> of ACT use was calculated, the prevalence of ACT use was comparable to previous findings in the literature, with approximately one half of the sample using some type of ACT in the period following diagnosis. Prevalence rates reported in other breast cancer studies conducted in developed countries (i.e., Austria, Canada, Finland, Italy, United Kingdom, and United States) have ranged from 17% to 67% (Balneaves et al., 1999; Boon et al., 2000; Burstein et al., 1999; Crocetti et al., 1998; Morris et al., 2000; Moschèn et al., 2001; Rees et al., 2000; Salmenperä, 2002; VandeCreek et al., 1999). These estimates, however, must be compared with caution because the time period over which ACT use was assessed varied considerably across studies and study participants were also younger than in the present study (Burstein et al., 1999; Crocetti et al., 1998; Morris et al., 2000; Moschèn et al., 2001).

Of the studies examining ACT use by women with breast cancer, only Crocetti et al. (1998), Salmenperä (2002), and Rees (2000) measured ACT use since diagnosis, reporting prevalence rates between 16.5% and 31.5%. These rates are lower than that reported in this study for two plausible reasons. First, the definition of ACTs in these studies was more restrictive, limiting ACT use to a small set of therapies (Crocetti et al., 1998) or consultations with alternative practitioners (Rees et al., 2000). Second, these studies were all conducted in European countries, where access to, and interest in, ACTs may differ substantially from North America. Although Ernst and Cassileth (1998) were skeptical about variations in prevalence rates being related to regional variations, no firm conclusions are possible given the lack of specificity and inconsistency in ACT definitions across international studies. These discrepancies point to the need for standardized surveys that incorporate a comprehensive definition of ACT use related to therapy type and period of use.

<sup>67</sup> The liberal definition included all therapies listed in the Ontario Breast Cancer Information Exchange Project's (1994) *A Guide to Unconventional Cancer Therapies*, spiritual therapies, and those additional therapies listed by the women themselves in the study questionnaire.

<sup>68</sup> The more conservative definition excluded those therapies that were integrated into the conventional health care system or that represented lifestyle choices (e.g., vitamin therapies).

Few women in this study were using therapies that were physically invasive, associated with curative claims, or were part of an alternative health-care system with an explicit belief paradigm. These types of therapy often raise the most concern within conventional care settings because they are viewed as being the most likely to result in negative interactions with biomedical treatments or to result in the abandonment of conventional health care. This finding suggests that few women with breast cancer in British Columbia are choosing the "far", or most alternative end of the therapy spectrum and have been minimally influenced by advertising espousing the curative properties of select therapies (i.e., shark cartilage or Essiac).

#### Commonly Used Therapies

Of the therapies listed in the survey or mentioned by women participating in this study, over-the-counter supplements, including vitamin/mineral supplements and herbal and plant products, were the most frequently reported ACTs used following women's breast cancer diagnosis. Similar findings were reported by Boon et al. (2000) and Salmenperä (2002), however, the proportion of women using these types of supplements was considerably lower than that found in the present study. This discrepancy may be a consequence of the way in which ACTs were assessed. In contrast to other research, the questionnaire used in this study included a list of all vitamin/mineral and herbal supplements as individual therapies rather than therapy categories. This assessment method may have prompted women to recall therapies that they had initially forgotten or would not have necessarily classified under the different therapy categorizations.

The specific vitamin/mineral and herbal supplements that were most popular with women in this study included Vitamins B, C, D, and E, calcium, selenium, and echinacea. The popularity of these ACTs may reflect the widespread availability of these products and their integration into mainstream health care. In follow-up interviews, the women spoke of using such therapies to promote their general well being and as part of their self-care regimen. The innocuous nature of this type of ACT was presumed in their commentary and has been suggested within the literature (M. Miller et al., 1998). Many of these types of therapies have become so commonplace within Western societies that it is considered controversial to categorize them as a form of complementary therapy. However, recent clinical research and discussion papers that have unveiled both potentially harmful (L. G. Miller, 1998; Omenn et al., 1996) and beneficial effects of vitamin and herbal supplements (Cassileth, 2000; Tagliaferri et al., 2001) support the importance of monitoring the use of these therapies within breast cancer populations, notwithstanding whether these therapies are classified as ACTs in clinical practice.

While supplements were the most common ACT used by women in this study, over one third of the respondents reported using some form of spiritual therapy, most often prayer, in the period following diagnosis. The importance of spirituality in assisting women cope with their

breast cancer experiences has been acknowledged in the literature (Fredette, 1995; Halstead & Fernsler, 1994) but has been rarely assessed in studies examining ACT use. The exclusion of spiritual therapies, such as prayer and laying on of hands, from studies of ACT use has been motivated, in part, by disagreement in the literature regarding the appropriateness of including spiritual practices under the rubric of ACTs (Eisenberg et al., 1993; Risberg, Wist, Kaasa, Lund, & Norum, 1996). Pilot studies conducted in general and cancer populations, however, have revealed that spiritual therapies are often perceived as playing a meaningful role in health care and well being (Bennett & Lengacher, 1999; Eisenberg et al., 1993). In population-based studies that have included prayer and other spiritual therapies in assessments of ACT use, prevalence has ranged from 21% to 42% (Eisenberg, 1997; Eisenberg et al., 1993; Ramsay et al., 1999). In breast cancer populations, the proportion of women using spiritual therapies has varied widely (i.e., 21% to 76%, Alferi et al., 2001; Lee et al., 2000; VandeCreek et al., 1999), reflecting differences in therapy assessment methods. Notwithstanding this uncertainty, for many women, a breast cancer diagnosis marks the beginning of an existential journey that is explored through the use of spiritual therapies (Halstead & Hull, 2001). Although spiritual therapies are often available in conventional clinical settings through pastoral care departments, how women would like spiritual therapies incorporated into their conventional cancer care, if at all, remains unexplored.

A substantial proportion of women in the present study also reported using either physical/movement therapies or psychological expressive therapies. It is not surprising that the latter group of therapies was prevalent because many women had access to programs, such as art and music therapy and relaxation and meditation sessions, through their conventional cancer treatment centre. In many ways, this type of therapy has become 'mainstream' in that it is frequently recommended by conventional health-care providers and is readily acknowledged as being beneficial (Petersson, Berglund, Brodin, Glimelius, & Sjoden, 2000; Predeger, 1996; Walker et al., 1999). The large number of women using chiropractic care and massage therapy compared to other studies (Burstein et al., 1999; VandeCreek et al., 1999) may reflect the fact that both these therapies were partially funded through the provincial medical insurance at the time of the survey.<sup>69</sup> Recent changes to medical coverage in British Columbia to stop this funding, however, may have a substantial impact on the utilization of these services and their accessibility to select groups, including women living with breast cancer.

The therapies that were least frequently mentioned by women in this study were those included under the dietary changes and miscellaneous categories, the latter including such

<sup>69</sup> Until December 31, 2001, the Medical Service Plan of British Columbia reimbursed provincial residents for 12-15 visits annually to a chiropractor or massage therapist (the latter with a physician referral). A \$10.00 service charge per visit was applicable. See BC Ministry of Health press release at <http://www.healthservices.gov.bc.ca/cpa/newsrel/services/231.html> for further details.

therapies as chelation or colonic irrigation. While many women wrote about increasing their consumption of fruits and vegetable or changing to a low-fat diet, few women radically altered their diet following their diagnosis. The lack of interest in time-consuming, restrictive diets (e.g., macrobiotic diets) has been documented in other recent research with breast cancer and general cancer populations (Bennett & Lengacher, 1999; Boon et al., 2000; Lee et al., 2000; Rees et al., 2000). In summary, these findings suggest that women living with breast cancer in British Columbia may have limited interest in, or access to, therapies that are highly invasive and demanding. Instead, women appear to be attracted to therapies they perceive as accessible and easily incorporated into their lives and believe could be used along with conventional cancer treatments.

### Patterns of Use

The women in this study appeared to be involved in limited polytherapy, reporting the use of between 1.2 to 3.5 therapies<sup>70</sup> following their breast cancer diagnosis, depending on the definition of ACT used (i.e., conservative versus liberal). This finding is comparable to previous research with women living with breast cancer (Alferi et al., 2001; Burstein et al., 1999; Moschèn et al., 2001), which has found that the majority of women use up to three different therapies following diagnosis. There were outstanding exceptions, however, with a few women reporting the use of between 10 to 23 therapies. The experiences of women such as these, as they attempt to coordinate a multitude of ACTs alongside their conventional cancer treatments, may provide unique insights into the treatment decision-making processes of women deeply ingrained in alternative health care practices.

In striking contrast to literature that suggested less than 20% of women with breast cancer have experience with ACTs before breast cancer diagnosis (Crocetti et al., 1998; Rees et al., 2000; Salmenperä, 2002), over 60% of women in this study reported previous ACT use. The therapies women reported using before diagnosis were those most prevalent in the general population in Canada (Ramsay et al., 1999), including vitamin/mineral supplements, prayer, echinacea, chiropractics, and massage therapy. Extending the findings of the Fraser Institute's survey (Ramsay et al., 1999), it can be hypothesized that the main purposes of therapies used before women's diagnosis were to improve wellness and to prevent illness. The discrepancy between this study and previous research with regards to the prevalence of previous ACT use may be a reflection of the manner in which ACT use was assessed. Also possible is that Canadian women living in British Columbia are more inclined towards using ACTs as a form of

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<sup>70</sup> The average number of therapies used was calculated following the collapse of vitamins/mineral supplements into one category.

self-care than women surveyed in other regions and countries. Both the Angus Reid Group (1997) and Fraser Institute (Ramsay et al., 1999) surveys provide support for this hypothesis.<sup>71</sup>

As found in previous studies (Salmenperä, 2002), women who had exposure to ACTs before their diagnosis were significantly more likely to report ACT use following diagnosis than women with no prior history of ACT use. Only 20% of the women reporting ACT use following diagnosis could be considered to be "new" users of ACTs. This finding holds relevance for clinicians caring for women newly-diagnosed with breast cancer because a history of ACT use can be used as a marker for future intentions related to ACTs. Of therapies that women had used before diagnosis, approximately 45% were continued afterwards. While not included in the initial questionnaire, over one third of the 159 women contacted for follow-up interviews indicated therapies they continued using following diagnosis were also an important part of their breast cancer recovery. This suggests that many women maintained an orientation towards well being following their breast cancer diagnosis.

Similar to observations made by Crocetti et al. (1998), differences between the types of therapy initiated before and after diagnosis were found. Although the majority of vitamin/mineral supplements and spiritual therapies were initiated before diagnosis, greater than 80% of the therapies included in the pharmacological/biological supplements, dietary therapies, and energy therapies classifications were initiated following diagnosis. This association is interesting in that it suggests that a significant health crisis is needed before the initiation of therapies that are further removed from conventional medical care with regards to evidence and philosophy. The fear and uncertainty experienced by some women following diagnosis may motivate them to access more radical treatments. In addition, the alleged intent of some of these therapies (e.g., shark cartilage, Essiac) related to recurrence of breast cancer and amelioration of adverse effects of conventional cancer treatment may further explain the timing of initiation following diagnosis. Further research is needed to establish the rationale underlying the use of specific therapies.

Despite a breast cancer diagnosis being a motivating factor in the decision to use ACTs for some women, their sustained use of ACTs one to three years following diagnosis indicated that the majority of women have, to some extent, incorporated ACTs into their daily lives. This hypothesis is supported by the fact that 60% of the therapies initiated after diagnosis were reported to be currently in use at the time of data collection. It was interesting to note that the women had discontinued almost one half of the therapies classified as "most alternative". The

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<sup>71</sup> Additional evidence of the geographic difference in ACT utilization in cancer populations were found in a recent survey conducted by the National Cancer Institute of Canada's Sociobehavioural Cancer Research Network (SCRN). See Leis, A. Use of complementary therapies by cancer patients in six Canadian provinces. Presented at the annual meeting of the Canadian Association of Psychosocial Oncology, Winnipeg, May 2001.



prolonged use of ACTs by women in the years following their diagnosis and treatment for breast cancer is relevant for conventional health professionals providing follow-up care for this population of women.

With regards to the amount of time and energy women were willing to expend in using ACTs, the majority of women reported using ACTs on a daily basis. Given that the most popular therapies were vitamin/mineral supplements and herbal and plant products, this finding was not a surprise. Despite the frequent use of ACTs, the physical and psychological impact on women's lives appeared to be limited as the majority of therapies were reported to require minimal effort. Similar findings were reported by M. Miller et al. (1998).

#### Cost of Alternative/Complementary Therapy Use

The average monthly cost associated with ACTs ranged considerably, with most women spending less than \$50.00 a month on ACTs. The amount spent on ACTs by women in this study appears comparable to previous research examining ACT use by women with breast cancer (Morris et al., 2000; Rees et al., 2000), however, differences in currency and medical insurance coverage make comparisons difficult. In Canada, Boon et al. (2000) found slightly higher cost estimates for ACT use by women with breast cancer. When contrasted to the average out-of-pocket expenses of Canadians using ACTs (Ramsay et al., 1999),<sup>72</sup> women with breast cancer appear to spend approximately twice as much as the general public on ACTs.

Close to 8% of the sample reported spending more than \$200 a month on ACTs, including such therapies as vitamin/mineral supplements, herbal/plant products, and physical therapies. For some women, the financial costs associated with ACTs were a deterrent to incorporating selected therapies into their self-care regimens or following treatment protocols as recommended (i.e., stopping therapy before relief of symptoms). Previous work has also identified cost as being a primary barrier to ACT use by women living with breast cancer (Boon et al., 2000). While national surveys have found the general public disinclined to favour coverage for ACTs in provincial medical insurance plans (Ramsay et al., 1999), some women in this study expressed their displeasure at the exclusion of many ACTs from British Columbia's Medical Service Plan. As one woman wrote, "[My] diet therapy costs about \$900 per year. If this cost was for prescription drugs it would be mostly paid by BC Medicare or at least be an income tax medical expense deduction". With over 20% of the women in the present study using ACTs that have been recently delisted from the British Columbia Medical Service Plan (i.e., chiropractics, massage therapy, naturopathy), it is plausible that many more women will

<sup>72</sup> When costs of alternative practitioners visits, vitamin and diet programs, books, classes, equipment and other material associated with ACT use were added together, the average annual total cost of ACT use was \$127.92 per capita (Ramsay et al., 1999).

experience financial difficulties in accessing and using ACTs. The impact of these restrictions on women's health and recovery from breast cancer will require further investigation.

#### Sources of Information about ACTs and Disclosure of Use

In the present study, close to one half of the women reported learning about ACTs from a family member or friend. Similar results have been reported in previous research within breast cancer populations (Boon et al., 2000; Crocetti et al., 1998; Moschèn et al., 2001). The women's information sources also included print and visual media, health food stores, and support groups. Given the plethora of information about ACTs available on the Internet (Cassileth, 2000), it was surprising that only a small percentage of women (5.7%) reported using web-sites as a resource in their search for information about ACTs.

The reliance on lay resources pertaining to ACTs has raised concerns in the biomedical community regarding the accuracy and reliability of information that individuals are using to make treatment decisions (Cassileth, 2000). Concerns about the vulnerability of cancer patients to unscrupulous advertisement led one researcher to conduct covert participatory observations within health food stores in Oahu, Hawaii (Gotay & Dumitriu, 2000). Posing as the daughter of a breast cancer patient, Gotay and Dumitriu (2000) found store personnel to be persuasive in their recommendations of ACTs, using biomedical language to discuss the benefits of selected therapies, focussing on the non-toxic and natural qualities of their products. Rarely did health food store workers refer to the potential side effects of ACTs or advise that a conventional health professional should be consulted regarding the possible interactions with conventional cancer treatments. In summarizing the ubiquity of such lay resources, Gotay and Dumitriu (2000) explained that, "the phenomenon of self-care, in consultation with retailers, has emerged from the underground and can be found at the mall and corner grocery" (p. 696). The prevalence of such resources in our society emphasizes the importance of assisting individuals to become savvy and informed consumers of ACTs who balance scientific skepticism with hopeful optimism.

Although studies such as Gotay and Dumitriu's (2000) evoke images of ill-informed cancer patients making rash treatment decisions, it is important to note that in the present study and in other research (Crocetti et al., 1998), nearly one quarter of women with breast cancer sought information about ACTs from their physicians. There is insufficient data to comment on the quality and content of the discussions held between women and medical doctors or on the types of therapies that women are most likely to discuss with their conventional health-care providers. Nevertheless, this finding suggests that some women in this study perceived physicians to be knowledgeable about ACTs and open to discussions about therapy choices beyond the scope of conventional medicine. Although the latter supposition has been supported by the literature, there is some suggestion that cancer patients do not necessarily expect

physicians to hold extensive knowledge about ACTs (Verhoef, White, & Doll, 1999). Physicians themselves have identified their knowledge of ACTs to be poor (Goldszmidt, Levitt, Duarte-Franco, & Kaczorowski, 1995). Select demographic and social characteristics, such as being female and born outside of Canada (Goldszmidt et al., 1995), using active listening skills in discussing ACTs (Truant, 1998), and having received some training in alternative medicine (Verhoef & Sutherland, 1995) may predispose some physicians to becoming more involved in women's treatment decisions related to ACTs.

Nurses appear to play a limited role in treatment decisions specific to ACTs. In the present study, only 5% of the women sought information about ACTs from nurses. Given the profession's proclivity towards such concepts as holism, autonomy, and caring (Kikuchi & Simmons, 1994) and its involvement in recognized ACTs (i.e., therapeutic touch), nursing is well positioned to take a more active role in supporting patients in making informed decisions about ACTs. Previous research examining the attitudes of oncology nurses towards ACTs has found the majority of nurses perceive themselves to play a supportive role in patients' treatment decisions related to these types of therapies (Damkier et al., 1998). Nurses experience conflict, however, when faced with patients who chose to abandon conventional cancer treatments or conceal their use of ACTs from other conventional health-care providers. Further, the lack of evidence supporting the efficacy of many ACTs hinders nurses from providing accurate and reliable information to patients. The ethical and professional dilemmas faced by nurses in relation to ACTs point to the need for further education and research on the increasing interface between the profession and alternative healing traditions and practices.

In discussing communication between patients using ACTs and conventional health-care providers, it is important to make the distinction between seeking information about ACTs and disclosing actual ACT use. In the present study, over 70% of the women reported that they had disclosed their use of ACTs to at least one of their physicians (family physician and/or cancer specialists). With only one quarter of women identifying physicians as sources of information about ACTs, this finding suggests that while women are willing to inform their physicians about their treatment decisions, they are not necessarily seeking or receiving information about ACTs from their conventional health-care providers. In the literature, rates of disclosure have varied widely, with between 12% and 71% of women with breast cancer indicating that they had disclosed their use of ACTs to their physicians (Boon et al., 2000; Burstein et al., 1999; Lee et al., 2000; Morris et al., 2000; VandeCreek et al., 1999). The perception that disclosure of selected ACT use (e.g., prayer, vitamins) is not pertinent to conventional medical decisions has been suggested as an explanation for lower disclosure rates (Adler & Fosket, 1999; VandeCreek et al., 1999). Although the majority of women participating in this study appeared comfortable sharing their treatment decisions with their physicians, some women did express

hesitation related to disclosure. Similar to the results of a qualitative study that explored the disclosure experiences of women with breast cancer who were using ACTs (Adler & Fosket, 1999), these women perceived their physicians to be uninterested or biased against ACTs. For other women, use of ACTs was a personal decision that reflected responsibility for their own health and health care. As one woman wrote:

We are our bodies own doctors - we are responsible for the first step and must listen to our bodies and learn what more we can do - by reading, listening, not being afraid to keep asking questions.

These findings emphasize the importance of developing open, non-judgmental communication strategies that foster discussion between patients and conventional health-care providers about the use of ACTs. Eisenberg (1997) and others (Adler & Fosket, 1999; Mackenzie, Parkinson, Lakhani, & Pannekoek, 1999) have provided recommendations for conventional health professionals in the hope of ending the 'don't ask, don't tell' phenomenon surrounding disclosure of ACT use. Further work is needed, however, to elucidate how conventional health professionals can best meet the information and support needs of women with breast cancer interested in ACTs.

### **The Role of Health Beliefs in Alternative and Complementary Therapy Use**

The primary aim of this study is to contribute theoretical knowledge regarding the causal relationships among selected health beliefs, sociobehavioural factors, and ACT use in women living with breast cancer. This purpose was addressed through the development and testing of three cognitive models that examined women's use of ACTs within the context of preventive, ameliorative, and restorative health behaviour. The Health Belief Model (HBM) was used as a guiding framework in the development of the models of ACT use and the associations postulated among the study variables. Two questions that directed the structural equation modelling process were: (1) How are health beliefs and selected sociobehavioural factors associated with the use of ACTs by women living with breast cancer across preventive, ameliorative, and restorative health contexts? and (2) To what extent do the preventive, ameliorative, and restorative models explain ACT use in a breast cancer population? The following sections provide a discussion of the relationships between variables of interest and ACT use in each of the three models, contrasting the model results to relevant literature in fields of treatment decision making and health behaviour. A final summary is provided that compares and contrasts the three models and the relevance of the HBM and other sociobehavioural factors in explaining ACT use.

### Preventive Model of Alternative/Complementary Therapy Use

The application of the HBM in the context of preventive health behaviour has been well established, particularly with regards to explaining breast cancer screening behaviour, including breast self-examination (BSE) and mammography screening (Champion, 1991; Champion & Miller, 1996; Fulton et al., 1991; Holm, Frank, & Curtin, 1999). In this study, the HBM was used to explain women's use of ACTs within the context of preventing a breast cancer recurrence. In the Preventive Model, it was hypothesized that women who reported a higher risk of breast cancer recurrence, stronger belief in the efficacy of ACTs in preventing recurrence, and fewer barriers to using ACTs would be more committed to ACTs. It was also predicted, based on past research focussing on the role of locus of control in health behaviour (Hallal, 1982; Holm et al., 1999; Murray & McMillan, 1993), that women who perceived themselves to have control over their health, namely a recurrence of breast cancer, would be significantly more committed to ACTs. Cues to action were also incorporated into the Preventive Model with the addition of effects that postulated that previous use of ACTs (i.e., before diagnosis) and encouragement to use ACTs would be significantly related to women's commitment to these types of therapies. Demographic characteristics of women, including age and education, were included in the model, with younger, more educated women hypothesized to use ACTs in a more committed manner.

While the Preventive Model of ACT Use was found to be a reasonable representation of the data and explained close to 30% of the variation in women's commitment to ACTs, the relationships between women's health beliefs, their perceived sense of control over breast cancer recurrence, and ACT use were not significant. This finding suggests that women's treatment decisions related to ACTs were minimally influenced by their fears related to breast cancer recurrence and their beliefs about the ability of ACTs to prevent breast cancer from returning. Further, beliefs about the difficulties faced in using ACTs did not appear to dissuade women from their treatment decisions, nor were differences in ACT use found between women with high perceived control over recurrence versus those with a lesser sense of control. What was influential in women's treatment decisions was their exposure to ACTs before their breast cancer diagnosis and having family, friends, and physicians support their decisions related to ACTs. Women's previous use of ACTs and the encouragement they received were also found to affect selected health beliefs. No significant relationships were found between women's demographic characteristics and ACT use.

The positive, significant associations found between previous ACT use and encouragement to use ACTs and women's commitment to ACTs highlight the importance of personal experience and social support in women's treatment decisions. Past ACT research in women with breast cancer has established a link between women's treatment histories before

diagnosis and their decision to use ACTs (Crocetti et al., 1998; M. Miller et al., 1998; Rees et al., 2000). The importance of including prior behaviour in causal models of health behaviour has been further supported within the breast cancer screening literature (Calnan & Rutter, 1986; Champion, 1994; Fajardo et al., 1992; Fulton et al., 1991). For example, in Calnan and Rutter's (1986) exploration of the predictors of BSE, women's past behaviour was found to be a stronger predictor of subsequent screening practices than their health beliefs associated with breast cancer risk and the benefits of and barriers to practicing BSE.

Although no research has been conducted that has considered the association between encouragement to use ACTs and treatment decisions by women with breast cancer, there has been some suggestion that women who choose ACTs are strongly influenced by their social networks. In VandeCreek et al.'s (1999) comparison of ACT use in breast cancer and general populations, individuals who used ACTs reported being persuaded by "family folklore" and the expectations of family members in making their treatment decisions. Lee et al. (2000) also found that women who were active in community, religious, and social groups were more likely to report ACT use than women who were more socially isolated. The importance of social norms and networks in preventive health behaviour, such as breast cancer screening (Champion, 1991; Champion & Miller, 1996; Lewis, Corcoran-Perry, Narayan, & Lally, 1999), has provided further evidence that women's treatment choices are a product, in part, of their social networks. Champion and Miller's (1996) research on mammography screening is of particular relevance to this study because it incorporated social influence into the HBM. Taken together, the present study's findings along with previous research suggest that women rarely make treatment decisions in a social vacuum; treatment decisions are a reflection of the norms and preferences that exist in social groups.

In the present study, it is surprising to note that the three health beliefs held little relevance in predicting women's treatment decisions related to ACTs. Previous research examining ACT use in women with breast cancer has found the fear of recurrence to be a motivating factor in some women's decisions to use ACTs (Burstein et al., 1999). Other studies have found that the prevention of breast cancer recurrence is an important treatment expectation of women using ACTs (Boon et al., 2000; Moschèn et al., 2001). Notwithstanding these findings, there has been inconsistent evidence in the HBM literature regarding the relationship between perceived susceptibility (i.e., perceptions of risk) and preventive health behaviour. Some researchers have found perceived susceptibility to be a significant predictor of health behaviour (Champion, 1991; Stein et al., 1992), while others have reported no substantial associations (Hallal, 1982; Hyman et al., 1994; Rutledge, 1987; Stein et al., 1992).

There have been several explanations why perceptions of risk may be of limited importance in models of preventive health behaviour. First, it has been suggested that because

secondary screening behaviour cannot reduce the risk of disease, there is little motivation to participate in health prevention activities (Rutledge, 1987). Second, it has been implied in the literature that a curvilinear relationship may exist between perceived risk and preventive health behaviour, in which individuals who perceive themselves to be at either very low or very high perceived risk are unlikely to take preventive action (Hallal, 1982). Hallal (1982) further suggested that individuals who perceive themselves to be at low risk of disease may pursue preventive health behaviour simply because the benefits are seen to outweigh the associated costs. In the context of the present study, women with breast cancer may not perceive ACTs to be efficacious in preventing a recurrence of breast cancer, and as such, are not compelled to use these therapies as a form of prevention. Women with early stage disease may also perceive themselves to be at a level of risk of recurrence that is unlikely to motivate ACT use.

There has been stronger support in the ACT and breast cancer screening literature of the importance of perceived benefits and barriers in predicting preventive health behaviour. Furnham and Vincents' program of research has provided considerable evidence of the role of perceived efficacy of ACTs in treatment decisions (Furnham & Bond, 2000; Vincent & Furnham, 1994, 1996, 1997). In cancer populations, both Boon et al. (2000) and Yates et al. (1993) found users of ACTs to hold strong beliefs related to the efficacy of ACTs. Participants in these studies viewed ACTs as being safer than conventional cancer treatments and better able to support the body's natural healing process. Further, researchers examining the influence of perceived benefits and barriers in breast cancer screening have found strong effects between these health beliefs and women's screening behaviour (Champion & Miller, 1996; Clarke et al., 2000; Holm et al., 1999; Rutledge, 1987).

In the present study, the insignificant effects of perceived efficacy and perceived barriers on ACT use may be attributed to several factors. Foremost, there has been some discussion in the HBM literature that the perceived benefit concept is more a reflection of knowledge about a treatment or screening practice than an assessment of personal outcomes of therapy use (Clarke et al., 2000). With many ACTs lacking substantial empirical evidence and women with breast cancer reporting uncertainty related to the safety and effectiveness of ACTs (Truant & Bottorff, 1999), the women in this study may have lacked sufficient knowledge to answer the benefits and barriers survey items in an informed and consistent manner. Second, the instruments used to measure perceived efficacy and barriers may not have adequately captured women's beliefs related to ACTs in the context of preventing breast cancer recurrence. For example, in contrast to the one item used in this study to assess the efficacy of ACTs in preventing a recurrence, Yates et al. (1993) included three additional items that assessed the

perceived outcomes of ACTs.<sup>73</sup> The addition of these items may have improved the reliability of this measure and more fully captured women's beliefs related to the efficacy of ACTs. With regards to the barriers to ACT use, numerous studies have identified financial costs as a significant obstacle to accessing alternative health care (Boon et al., 2000; Lee et al., 2000; Montbriand, 1995b; Salmenperä, 2002; Swisher et al., 2002). The absence of an item that assessed finances as being a potential barrier to therapy use may have been a limitation in this study.<sup>74</sup> Finally, the lack of significant relationships among perceived benefits and barriers and ACT use may have reflected the reality that women with breast cancer who use ACTs do not perceive these therapies as being effective in preventing the recurrence of disease and see few barriers to using these treatments.

One final point of discussion related to the Preventive Model is the insignificant role the *Perceived Control over Breast Cancer Recurrence* construct played in explaining women's commitment to ACTs. There has been extensive qualitative (Brown & Carney, 1996; Kelner & Wellman, 1997a; Montbriand, 1995a; Montbriand & Laing, 1991; Truant & Bottorff, 1999) and quantitative research (Balneaves et al., 1999; Boon et al., 2000; Furnham & Bhagrath, 1993; Hiratzka, 1985; Yates et al., 1993) supporting the importance of perceived control in treatment decisions in cancer and general populations. The manner in which control has been operationalized, however, has varied across studies. In the present study, control was measured using the internal locus of control subscale of the Multidimensional Health Locus-of-Control Scale (MHLC) (Wallston et al., 1978), which was modified to measure women's perceived control over breast cancer recurrence. The use of an annotated and altered version of the MHLC may have reduced the reliability and validity of the control measure, thus influencing the effect of the concept of control on women's ACT use. It is also possible that a different conceptualization of control, for example, preferred decisional role in treatment decisions, may have resulted in a more significant relationship with ACT use. Further, there has been some debate in the ACT literature regarding the potential reciprocal relationship between ACT use and perceived control. For example, in one study of women with breast cancer (Truant & Bottorff, 1999), ACTs were used by respondents as a means of regaining control in the biomedical health-care system and over their health. In the present study, the recursive nature of the structural models prevented the testing of reciprocal effects between these concepts and limited conclusions regarding the role of control in women's use of ACTs. This limitation may prove to be a productive area of study in future research on ACT use.

<sup>73</sup> These items included: "ACTs prevent a spread of the cancer", "ACTs assist other treatments to work", and "ACTs provide a boost to the body's immune system".

<sup>74</sup> The decision was made not to include an item assessing the costs of ACT use in the barriers subscale because women's total household income had been originally included in the model.



### Ameliorative Model of Alternative/Complementary Therapy Use

In the Ameliorative Model of ACT use, women's use of therapies beyond the scope of conventional medicine was considered within the context of sick role behaviour in which an individual is faced with overt symptomatology or disease. In this study, sick role behaviour was defined as women's use of ACTs as a form of symptom management to address their physical and mental distress resulting from conventional cancer treatment. Similar to the Preventive Model, women who believed ACTs to be efficacious in ameliorating the adverse effects of breast cancer were predicted to demonstrate higher levels of commitment to ACTs. Perceived control was also included in the Ameliorative Model, with a higher level of reported control over adverse effects postulated to result in greater commitment to ACTs. The *Previous Use of ACTs*, *Encouragement to Use ACTs*, and *Perceived Barriers* constructs and the demographic characteristics, *Age* and *Education*, were transferred from the Preventive Model without modification, with similar effects on women's commitment to ACTs being hypothesized within the model.

The fit of the Ameliorative Model was nearly identical to the Preventive Model, with approximately 30% of the variation in women's commitment to ACTs explained by the model constructs and parameters. Women's health beliefs, including perceived symptom distress (i.e., severity), perceived efficacy of ACTs (i.e., benefits), and perceived barriers to ACT use, were found to have insignificant influence on women's commitment to ACTs. Women's perceived control over adverse effects was also found to be an insignificant predictor of women's treatment decisions. The effects of prior treatment history and social influence on women's commitment to ACTs, however, remained significant in the Ameliorative Model, with women who had used ACTs before their diagnosis and who had received encouragement to use ACTs being more committed to ACTs. No significant relationships were found between women's demographic characteristics and ACT use.

With the items measuring women's previous use of ACTs and encouragement received related to ACTs being transferred from the Preventive Model without modification, it was not surprising that both variables were predictive of ACT use. Accordingly, the above discussion regarding the role of past behaviour and social support in treatment decision making has application within the Ameliorative Model. Empirical evidence of the importance of social support in sick role health behaviour, however, has been found within audiology (van den Brink, Wit, Kempen, & van Heuvelen, 1996) and cardiology (Oldridge & Streiner, 1990) research. These studies provide additional support for the relevance of prior experiences with ACTs and social support in women's decisions related to ACTs within the context of symptom management.

The limited role of perceived symptom distress, perceived efficacy, and perceived control over adverse effects on women's commitment to ACTs is not consistent with previous breast cancer research, which has identified symptom management as a motivating factor in women's treatment decisions related to ACTs (Burstein et al., 1999; Crocetti et al., 1998; M. Miller et al., 1998; Morris et al., 2000). For example, in Burstein's (1999) study of women's treatment decisions one year after surgery, women who began using ACTs following their diagnosis reported significantly more somatic and emotional symptoms (measured using the Medical Outcome Study's SF-36 (Ware & Sherbourne, 1992)) than women who had never used ACTs. There has been some suggestion, however, in research examining the relevance of the HBM in sick role behaviour, that the theory does not adequately capture the emotional arousal, or anxiety, associated with higher levels of perceived severity of disease (Oldridge & Streiner, 1990). This criticism of the HBM suggests that in the Ameliorative Model of ACT Use, women's anxiety related to the prolonged side effects of conventional cancer treatment may have been a more appropriate predictor of ACT use than their perceived symptom distress. The Symptom Distress Scale (McCorkle & Young, 1978) itself has been criticized for confounding frequency and intensity of symptoms in adult patients with cancer with the degree of distress experienced (McClement, Woodgate, & Degner, 1997). Considering the time frame of Burstein et al.'s (1999) study, it is possible that women's beliefs about the amelioration of adverse effects were less relevant to ACT use because women were farther removed from their initial diagnosis and conventional treatment. An additional explanation is that a curvilinear relationship exists between symptom distress and women's decisions related to ACTs, with women experiencing no or extremely high symptom distress being either unmotivated in their decision to use ACTs or too ill to expend the energy researching treatment options. Another explanation for the lack of significant effect between perceived symptom distress and women's use of ACTs is that treatment decisions related to ACTs are independent of the symptom distress experienced by women living with breast cancer. Further research is needed with women who are undergoing or who have recently completed conventional cancer care to determine if ACTs are being used, in part, to address the side effects and symptoms of the breast cancer experience.

Past research examining the use of ACTs in the management of a variety of benign symptoms has found perceived barriers to be influential in determining individuals' treatment decisions related to ACTs (Furnham & Forey, 1994; Furnham & Smith, 1988). In the Ameliorative Model, however, no significant relationship was found between women's perceived barriers to ACT use and their commitment to ACTs. Because items measuring perceived barriers were transferred without modification from the Preventive Model, the same limitation related to the measurement of perceived barriers in the Preventive Model and its relevance in explaining ACT use apply.

### Restorative Model of Alternative/Complementary Therapy Use

The Restorative Model of ACT Use examined the treatment decisions of women with breast cancer when faced with an ambiguous threat to their general well being following their breast cancer diagnosis and treatment. There has been limited HBM research that has explored such illness behaviour. However, studies that have examined clinic utilization (Hsu & Gallinagh, 2001; Kirscht et al., 1976; Norman, 1995; van de Kar, Knottnerus, Meertens, Dubois, & Kok, 1992) and self-care in the context of chronic illness (Connelly, 1993; McDonald-Miszczak, Wister, & Gutman, 2001) have provided some evidence of the role of health beliefs in explaining actions to enhance general well being. In the present study, it was hypothesized that women recovering from breast cancer used ACTs as a means of improving their general well being following diagnosis and treatment and coping with a "future of uncertainty" (Pelusi, 1997, p. 1345). Within this context, women who believed it was highly likely that their well being had been substantially harmed by their breast cancer experience, and believed ACTs to be efficacious in improving their general well being and saw few barriers to using ACTs, were postulated to be more committed to ACTs. In addition, it was hypothesized that women who believed they had a high level of control over their well being were more likely to use ACTs than women who had less perceived control. Similar to the Preventive and Ameliorative Models, women's age, education, previous use of ACTs, and encouragement to use ACTs were included in the Restorative Model without revision.

The overall fit of the Restorative Model was slightly better than the Preventive and Ameliorative Models and 32% of the variation in women's commitment to ACTs was explained. All significant associations among the health beliefs and ACT utilization were in the predicted direction of effect, with perceived efficacy of ACTs found to be significantly positively associated with women's commitment to ACTs. Significant positive effects were also found among women's previous use of ACTs and perceived control over well being and the level of commitment expressed towards ACTs. Age was also significantly negatively associated with women's commitment to ACTs through its effect on perceived efficacy, with younger women holding more positive beliefs about the efficacy of ACTs in restoring well being. No other significant relationships were found among perceived risk of harm, perceived barriers to ACT use, or education and women's commitment to ACTs.

With no modifications being made to the constructs *Previous Use of ACTs* and *Encouragement to Use ACTs* in the Restorative Model, little explanation is needed regarding the influence of treatment history on women's commitment to ACTs. Similar to the previous two models, women who were familiar with ACTs before being diagnosed with breast cancer reported using ACTs in greater number and frequency and were willing to spend more energy and money on such therapies.

In contrast to the previous models of ACT use, social support was not found in the bootstrapped Restorative Model to be a significant predictor of ACT use by women with breast cancer. This finding is of interest because it implies that social support related to ACTs offers no unique contribution to explaining women's commitment to ACTs beyond that provided by beliefs related to efficacy of ACTs in restoring general well being. In other words, the mechanism through which social support influences ACT use is via its effect on women's perceived efficacy of ACTs in relation to improving physical and mental well being. It can be concluded from this study finding that the type of messages received by women from their friends and families about using ACTs following breast cancer diagnosis are centred on the health promotion aspects of ACTs and their ability to address concerns related to well being.

That cancer patients, including women with breast cancer, are concerned about the impact of diagnosis and treatment on their general well being has been well supported in the literature (Boon et al., 1999; Cassileth et al., 1984; Crocetti et al., 1998; Downer et al., 1994). In the present study, however, women's treatment decisions related to ACTs appeared not to be correlated with their perceived risk of harm to well being. The absence of an effect may be explained, in part, by the difficulties experienced in operationalizing women's perceived risk of harm. The high correlation between items measuring perceived risk and perceived severity suggested that women were unable to distinguish between the two concepts and that ambiguity in the wording of the items may have been present. Further instrument development is needed to better elucidate women's perceptions of risk in relation to harm to their well being within the context of breast cancer recovery. Quality of life measures, such as the multidimensional European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993), may provide a more reliable method of assessing women's current well being.

Despite ACT use not being strongly associated with women's perceived risk of harm, a significant effect was observed between perceived efficacy of ACTs in improving physical and mental well being and women's commitment to ACTs. Women who believed that ACTs are efficacious in addressing wellness issues were more likely to use ACTs in a committed manner than women who did not consider ACTs to be helpful in improving their general health. This relationship is important because it suggests that ACTs are being used by women with breast cancer in the spirit of self-care and wellness rather than as a means of "curing" cancer or ameliorating the adverse effects of cancer treatment. The strength of this belief as a predictor of ACT use may also reflect the prevalence of opinion, both lay and professional, that emphasizes the supportive nature of ACTs in advancing general health. In the context of the larger breast cancer literature, the use of ACTs to address general health concerns has been well documented (M. Miller et al., 1998; Morris et al., 2000; Moschèn et al., 2001; Salmenperä,

2002), with therapies notably used to improve general health rather than to address disease-specific concerns. This finding is in contrast to the fears expressed within the biomedical literature that cancer patients are vulnerable to unwarranted treatment claims and hold unrealistic expectations related to ACTs (Brigden, 1995; Salmenperä, Suominen, & Lauri, 1998). Instead, women appear to be taking a realistic and conservative view of the benefits of ACT use in relation to breast cancer recovery. Thus, although the women were not found to be overly concerned about the impact of breast cancer on their well being in relation to their decision to use ACTs, they were using these therapies with the expectation that their overall well being would be improved.

No significant association was found between women's perceived barriers to ACT use and their treatment decisions specific to ACTs. Because the items assessing perceived barriers were used across the three models without modification, the limitations of the perceived barriers scale and the implications of this non-significant association discussed in relation to the previous two models pertain to the Restorative Model.

Women who were highly committed to using ACTs were also found to report higher perceived control over their physical and mental well being. This finding is significant because it suggests that treatment decisions specific to ACTs are influenced by the amount of confidence women have in their ability to manage, or take responsibility, for their general health. The use of ACTs by women with breast cancer can thus be seen as an enactment of perceived control in the context of restorative health behaviour. Accepting responsibility for one's health is a theme that occurs throughout the literature examining ACT use, reflecting the centrality of personal empowerment and self-care within many alternative and complementary paradigms. In women with breast cancer, Boon et al. (2000) also identified acceptance of personal responsibility for treatment decisions and overall health as being a key factor in influencing women's treatment decisions. It is important to note that due to the limitations of cross-sectional research, it was not possible in this study to determine whether women's beliefs related to perceived control over well being were long-standing beliefs that existed prior to their breast cancer diagnosis or were a consequence of their cancer experience. If the women's perceptions of control were a reflection of their overall attitude towards health and self-care, then the relevance of this construct to explaining ACT use within the context of breast cancer may be minimal. On the other hand, it is also possible that the experience of being diagnosed and treated for breast cancer may influence the manner in which women conceptualize their personal role and responsibility in maintaining their well being. Prospective research is required to fully elucidate the impact of breast cancer on women's perceived control over their well being.

### Comparison of the Three Models of Alternative/Complementary Therapy Use

The decision to develop three distinct cognitive models that explored ACT use within a preventive, ameliorative, and restorative context was motivated, in part, by previous qualitative research and the researcher's experiences with women with breast cancer that suggested ACTs were being used for a multitude of reasons. That treatment decisions related to ACTs are complex, multidimensional processes is highlighted in the following quote provided by one woman in this study:

I have started green tea, soy tablets and vitamins in hope that it will keep me in better health to prevent a recurrence and to try to build my mental and physical [health] back to what it was before my problems began. I only hope it will help.

The three models of ACT use in women with breast cancer, however, were remarkably similar with regards to the proportion of variation in women's commitment to ACTs that was explained. Irrespective of the context of women's use of ACTs, approximately 30% of the variation in commitment to ACTs was predicted by the complex interplay of health beliefs, sociobehavioural factors, and demographic characteristics. Outstanding across the Preventive, Ameliorative, and Restorative Models of ACT Use was the significant influence of women's past treatment history and social networks on their decision to use therapies not traditionally offered as part of conventional cancer treatments. Women who had used ACTs before they had been diagnosed with breast cancer and who had been encouraged by people important to them to use ACTs were found to express higher levels of commitment to ACTs. Consequently, women who express familiarity with ACTs and are surrounded by a supportive social group can be predicted to use ACTs in larger numbers, more frequently, and at greater costs, both financially and in terms of effort.

Also striking in comparing the three cognitive models was the limited relevance of health beliefs in explaining women's decisions to use ACTs. With the exception of perceived efficacy and perceived control in the Restorative Model, threat perceptions, beliefs related to the efficacy of ACTs, perceived barriers to ACT use, and locus of control were not informative in predicting ACT use within the context of breast cancer. These findings suggest that women with breast cancer are not using ACTs in the hope of preventing a recurrence of breast cancer or ameliorating the side effects of conventional cancer treatments. Instead, women are choosing to use ACTs as a reflection of their acceptance of responsibility for their overall well being and commitment to self-care. The failure of the health beliefs in the Preventive and Ameliorative models to influence ACT use may further express women's reservations related to the effectiveness of ACTs in addressing disease-specific concerns. Considering the importance of previous ACT use in predicting women's treatment choices, it is likely that women's use of ACTs

within the Restorative Model was for most women a continuation of treatment decisions made before they were diagnosed with breast cancer. The use of ACTs in breast cancer populations, therefore, may not be a disease-related decision but a reflection of the trend in the general population towards more holistic and comprehensive health care.

The absence of significant effects among the majority of health beliefs tested in this study and ACT utilization raises the question of whether the HBM is an appropriate theory to explore the treatment decisions of women living with breast cancer. Similar questions have been raised in the health behaviour literature. For example, in a review of breast cancer screening studies that have used the HBM as a theoretical guide, Yarbrough and Braden (2001) found that the predictive power of the HBM was low, with the majority of research explaining between 15% to 27% of the variance in screening behaviour. Sheeran and Abraham (1995) further concluded that while the HBM components are often significant predictors of health behaviour, their effects are small. The explanatory power of the four HBM constructs of perceived susceptibility, perceived severity, perceived benefits, and perceived barriers in the context of ACT use is negligible. Despite this finding, given the nascent stage of theory development in explaining ACT use, the HBM provided a valuable framework on which to coalesce previous research findings that have highlighted the role of cognitions in treatment decisions. As stated by Mikhail (1981):

As for usefulness of the HBM for research and theory building, the model helps in unifying the unrelated findings from previous investigations, provides a clearer presentation of ideas, and demonstrates some of the relationships between variables. It also serves as a framework of variables and concepts that can direct future research in a fruitful way. (p. 73)

Despite the theoretical contribution made by the HBM in explaining why women with breast cancer use ACTs, one cannot help wonder what other factors may have accounted for the remaining 70% of variance in women's commitment to ACTs. Clues to these determinants are found within critiques of the HBM and in recent empirical research exploring the use of ACTs in women with breast cancer. In reviews of the HBM, it has been suggested that the HBM has been restricted in its predictive ability because of the absence of several key social and cognitive elements, including cues to actions, health motivation, unrealistic optimism, and causal attributions (Clarke et al., 2000; King, 1983; Sheeran & Abraham, 1995; Yarbrough & Braden, 2001). Beyond encouragement to use ACTs, other cues to action that may hold relevance in explaining women's commitment to ACTs include media or advertising influences and the availability and visibility of alternative practitioners within one's community (Kelner & Wellman, 1997a). Women who are assailed by ACT marketing strategies may be more predisposed towards these therapies than women who have less exposure to these messages.

Sheeran and Abraham (1995) also criticized the HBM for not including measures of general health motivation. Previous research has found small, but significant effects of individuals' attitudes towards health on their subsequent health behaviour (e.g., Champion, 1984), however, whether these beliefs influence behaviour directly or indirectly through their effect on health beliefs has not been conclusively determined. Similarly, Clarke et al. (2000) suggested that women's breast health behaviours are indirectly affected by their unrealistic optimism related to their subjective risk of breast cancer and perceived barriers to accessing regular breast screening. Further research is needed to determine the influence of these cognitive factors on health beliefs and health behaviours.

A strong case also has been made for the importance of illness attribution in predicting health behaviour (King, 1983; Lavery & Clarke, 1996). In her examination of high-blood pressure screening, King (1983) found health behaviour was influenced both directly and indirectly by individuals' perceptions of the cause of disease. The role of causal attributions in predicting ACT use also has been explored within the cancer literature. The effect of beliefs about cause of cancer on therapy use, however, has been inconsistent (Balneaves et al., 1999; Moschèn et al., 2001; Risberg, Wist et al., 1998; Yates et al., 1993).

Other factors that may have increased the predictive power of the HBM and that have received preliminary support within the ACT literature are those related to individuals' overall health status, coping strategies, and attitudes towards conventional medicine. With regards to general health status, a number of studies have explored the impact of quality of life, including mental health, on cancer patients' decisions related to ACTs (Balneaves et al., 1999; Burstein et al., 1999; Maskarinec et al., 2000; Moschèn et al., 2001; Paltiel et al., 2001). Despite contradictory evidence, there is some suggestion that individuals in poorer health are more likely to use ACTs. The directionality of the effect between health status and ACT use, however, has not been definitively determined because of the lack of prospective studies. Moschèn et al.'s (2001) study of ACT use in women with breast cancer also provided evidence of a possible relationship between using active, problem-focused coping strategies and the decision to use ACTs. This suggests that ACTs may be one way women with breast cancer are able to assume an active role in their health care. Finally, there has been extensive consideration within both general and cancer populations about whether individuals choosing ACTs are being "pushed" away from conventional medicine as a consequence of their dissatisfaction with, and skepticism of, the biomedical paradigm (Downer et al., 1994; Furnham & Forey, 1994; Furnham & Kirkcaldy, 1996; Himmel, Schulte, & Kochen, 1993; McGregor & Peay, 1996). Although not consistent across all studies, individuals dissatisfied with the care they receive from conventional health professionals or skeptical about the efficacy of conventional medicine are more likely to use ACTs than individuals more favourably inclined towards biomedicine. Further



investigation is needed to determine what unsatisfactory aspects of conventional medicine (e.g., waiting lists to receive conventional treatment) may lead to alternative health care choices.

To summarize, the decisions made by women with breast cancer related to ACTs occur within the context of restorative health behaviour and are motivated, in part, by the belief in one's personal control over one's health and the perception of ACTs as being efficacious in the promotion of well being. Treatment decisions are further influenced by women's previous health behaviour and by the norms and preferences expressed by their social group in relation to therapy choice. With the addition of key social constructs to the HBM, a moderate amount of variation in women's commitment to ACTs was explained. The predictive power of the HBM, however, may be extended by the inclusion of other social and cognitive factors that have received preliminary support within the field of ACT research.

## **Contributions and Strengths of the Study**

### **Theoretical Considerations**

While much research has been conducted on the use of ACTs in a variety of populations and clinical settings, this present study advances the science of ACT research in several ways. First, this is one of the few research studies that has examined ACT use within a comprehensive theoretical framework that integrates the effects of health beliefs, perceived control, previous treatment history, social support, and selected demographic characteristics on treatment decisions. Using the HBM (Becker, 1974) as a foundation, this study was able to explain individual differences in treatment behaviour in a manner that accounted not only for personal cognition, but also the social context of decision making. To date, only three studies have been published that examine ACT use from an overt theoretical perspective. Kelner and Wellman (1997a) used Andersen's Behavioural Model (1968, 1995) to explain why consumers made the decision to attend conventional medicine or one of four alternative practitioners. Although this study provided interesting insights into the antecedents, social variables, and beliefs that motivated individuals to seek ACTs, it failed to examine specific hypotheses related to the nature of effects among study variables and the ability of the Behavioural Model to predict ACT use. Similar limitations were noted in studies by Yates et al. (1993) and Boon et al. (2000), who both used illness behaviour theory to explore differences among users and non-users of ACTs rather than to test the complex effects among health beliefs, social factors, and treatment behaviour.

Another unique characteristic of this study is consideration of the use of ACTs by women with breast cancer within the context of preventive, ameliorative, and restorative health behaviour. Rather than approaching ACT use as a homogenous concept, health beliefs were used to differentiate therapy use that was directed towards the prevention of breast cancer

recurrence, the amelioration of lingering adverse effects of conventional cancer treatment, or the restoration of general well being. No studies are known that have attempted to classify ACT use in such a manner. Although some researchers have explored the rationale of ACT use by women living with breast cancer (e.g., Boon et al., 2000; Crocetti et al., 1998), they have not adjusted the manner in which health beliefs were assessed. In this study, beliefs related to severity, susceptibility, and efficacy were modified to reflect the underlying motivation of use across the three health contexts. In doing so, the heterogeneity of health behaviour theory specific to ACTs was addressed.

### **Methodological Considerations**

The use of structural equation modelling (SEM) to test the application of the HBM in predicting ACT use is a further strength of the study. In using this statistical method, the complexity of the treatment decisions specific to ACT use could be adequately modelled and tested. The level of specification and intricacy that can be incorporated into structural equation models provides a more rigorous and flexible test of phenomena than comparable methods, such as multiple regression, could provide (Kelloway, 1998). Moreover, inherent to research utilizing SEM is a strong commitment to theory, in which relationships among study concepts are hypothesized a priori. In using SEM to test three models of ACT use that were derived from the Health Belief Model, the tenability of the theory in the context of ACTs was able to be examined (Mueller, 1997). To the researcher's knowledge, this is the first study to use SEM to explore the cognitive and sociobehavioural predictors of ACT use and to test a comprehensive theory of alternative/complementary health behaviour.

With regards to the measurement of ACT use, the majority of researchers have measured ACT utilization as a dichotomy, with ACTs being either used or not used. This lack of precision and refinement in the conceptualization of ACTs has been identified as a limitation of ACT research (Low, 2001). In this study, an effort was made to better capture the diversity of ACT use through the development of the construct, *Commitment to ACTs*. This construct conceptualized ACT use as a "commitment", assessing the amount of time, energy, and money women were willing to expend in using ACTs. In measuring ACT use in this manner, women who had used only one therapy that was easily incorporated into their lives and had little financial, physical, or emotional cost associated with it, were differentiated from women who had used several therapies that were highly invasive in nature and required extensive time, energy, and money. While researchers such as Kelner and Wellman (1997b) have attempted to differentiate among users of ACTs based on the type of therapy used and social and health indicators, this appears to be the first time ACT use has been measured on a continuum of commitment.

The manner in which ACT prevalence rates were calculated in this study was a further methodological strength. Rather than including all therapies under the general rubric of ACTs, therapies were differentiated based on their legitimacy within the conventional health-care system and their degree of "alternativeness". The idea that therapies exist on a spectrum that varies from "less alternative" to "more alternative" was first expressed by Eisenberg et al. (1998). Factor analytical work by Furnham (2000) has provided additional support that ACTs can be classified in a manner that reflects the degree of acceptance and visibility within society. In calculating ACT prevalence rates using liberal, conservative, more conservative, and most conservative classifications of the therapies, more precise and rigorous estimates of ACT use were achieved.

## **Limitations of the Study**

### **Study Design**

The primary limitation of this research arises from its correlational design, in which all study variables were measured simultaneously. Such measurement precludes the postulation of causal relationships among study concepts and the directionality of such effects (Knapp, 1998). Instead, one can, at best, make statements related to the strength of the associations among the variables of interest. While a strong association may provide support for a possible causal pathway, it cannot be used as definitive proof. For example, in the Restorative Model of ACT use, perceived control over well being was found to be significantly associated with the manner in which ACTs were used. While this relationship is persuasive evidence of the effect of perceived control on ACT use, it cannot be accepted as fact. An alternative model in which the use of ACTs leads to an increased perception of control over one's health and well being is equally plausible. As stated by Hayduk (1996), "Models are unrepentant and unapologetic fictions" (p. 2) and require that one retains a healthy dose of skepticism when considering their validity. With clear conceptualization, a sound theoretical framework, and reliable measurement, however, one can have confidence that the "fiction" that is being tested is of the highest quality and grounded in reality.

### **Retrospective Data**

A second limitation of this study is the use of data that were retrospective in nature. Recall errors may have occurred as women were asked to reflect on treatment decisions that were made one to three years previously. For women who had used a considerable number of therapies following their breast cancer diagnosis, this task may have been especially difficult. To limit the influence of memory biases on treatment information that was subsequently used in the structural equation modelling, only therapies that were currently in use were included in the dataset. In limiting therapies to those presently being used, data related to frequency of use,

effort, and monthly expenditures were likely to be more accurate. This decision was also motivated by the fact that women were asked to answer survey items measuring their health beliefs, symptom distress, perceived control, and social support within the context of their present lives. For example, when asked to rate their level of distress on a variety of symptoms, women were asked to indicate how they had been feeling lately. With all variables, including ACT use, being measured at the same time, relationships among study constructs could be made with greater confidence and with minimal bias. It must be acknowledged that in measuring current beliefs and treatment use, the women's responses may have been influenced by events that had occurred since their diagnosis that were unrelated to their breast cancer experience. For instance, one woman wrote on her survey that her use of relaxation and meditation therapies following her diagnosis was more a consequence of her divorce than her breast cancer experience.

### **Measurement Issues**

The use of investigator-developed scales or items that were modified from well-established measures also must be recognized as a potential limitation of this research. Given the nascent stage of ACT research, it is not surprising that there is a lack of instruments with sound psychometric properties that have been developed with the specific purpose of measuring the role of health beliefs in explaining ACT use. Of particular concern is the Perceived Risk of Harm Scale (PRHS), which was derived from Champion's Susceptibility Scale (1984, 1999). While this scale was found to have acceptable internal consistency (with Cronbach's alpha equal to 0.75), the need to omit items measuring harm to relational and spiritual aspects of well being because of a lack of variability was troubling. Researchers examining the long-term impact of breast cancer on women's relationships and spirituality (Dorval, Maunsell, Taylor-Brown, & Kilpatrick, 1999; Latimer, 1998; Taylor-Brown, Kilpatrick, Maunsell, & Dorval, 2000), however, have found few negative effects. Accordingly, the relevance of these items to women who are several years removed from initial diagnosis and conventional cancer treatment may be minimal.

The measurement of women's symptom distress is also of concern because of the relatively low reliability estimate (Cronbach's alpha = 0.66) of the modified three-item scale (SDS4, SDS5, and SDS10). Although the original 13-item Symptom Distress Scale (McCorkle & Young, 1978) was developed in a population of patients with chronic illness (including cancer), much of the later validity and reliability work was completed with cancer patients currently undergoing conventional treatment (Holmes, 1989; McCorkle & Quint-Benoliel, 1983; Sarna & Brecht, 1997). The relevance of many of the symptoms for women who had completed their conventional cancer therapy more than a year earlier was questionable and may have resulted in lower variability across several items. There is some empirical support, however, that breast

cancer patients continue to experience moderate symptom distress more than a year following treatment completion, with the most commonly reported symptoms being pain, insomnia, and fatigue (Winer et al., 1999). This research supports the inclusion of the three items as indicators of the *Perceived Symptom Distress* concept in the present study.

Several steps were taken to address concerns related to measurement. First, the univariate and bivariate statistics of all study items were subjected to careful review to ensure sufficient variability across the study measures and to minimize substantial violations to normality. Second, exploratory factor analyses were conducted, where necessary, to assess the factor structure of the modified and investigator-developed scales. Items that failed to meet a set criterion value were dropped from the dataset. Third, following in the traditions of two-step structural equation modelling, confirmatory factor analyses were conducted on each of the three measurement models. This step established the extent to which the observed indicators represented the hypothesized latent concepts they were to measure (Schumacker & Lomax, 1996). Together, these three steps increased confidence in the reliability and validity of the measurement models across the Preventive, Ameliorative, and Restorative Models of ACT Use.

An additional measurement issue confronted in this study was how to define and measure ACT use by women with breast cancer. This issue has been a source of debate in previous survey research exploring the prevalence of ACT use across general and disease-specific populations (Ernst & Cassileth, 1998; Harris & Rees, 2000; Wootton & Sparber, 2001). Most commonly, study participants are presented with a list of therapies from which they are asked to select those treatments or practices they have used during a specified period of time. For example, Eisenberg et al.'s (1993) list of 16 "unconventional" therapies has been replicated in a range of populations and disease groups (e.g., Burstein et al., 1999). While this approach has provided some consistency across prevalence studies and has allowed comparisons between different groups, researchers have been cautioned from becoming over-reliant on this assessment method (Wootton & Sparber, 2001). In particular, researchers must be sensitive to the nuances of the population of interest and be aware of trends in ACT use across different groups and geographic locations. The use of checklists may further bias prevalence rates, depending on the number and type of therapies listed (Harris & Rees, 2000).

In this study, respondents were presented with a list of over 65 therapies and asked to select those that they had used since being diagnosed with breast cancer. Although it must be acknowledged that the women's responses may have been influenced by the inclusion or exclusion of selected therapies, care was taken to use a comprehensive inventory of treatments that had been reviewed in the Ontario Breast Cancer Information Exchange Project's (1994) *Guide to Unconventional Cancer Therapies*. In using this patient resource, which had been developed specifically for Canadian women living with breast cancer, it was hoped that the

unique treatment decisions of this group of women would be acknowledged. Women were also invited to list any additional therapies not included in the inventory that they had used since being diagnosed. It was believed that in listing such a broad range of therapies, a comprehensive description of ACT use would be achieved.

Because of the concern of burdening women with an excessively long questionnaire, particularly for those individuals who were using many ACTs (i.e., > 10), the number of questions asked regarding each therapy was limited. In retrospect, including an item about the perceived purpose of each therapy would have been helpful in providing a more detailed understanding of the motivation of ACT use and the influence of the breast cancer experience on treatment decisions. The way in which therapy use was modelled in the three cognitive models of ACT use, however, provided important insight into the underlying beliefs that motivated women's treatment choices (i.e., prevention of recurrence, amelioration of adverse effects of conventional treatment, or restoration of well being). In addition, women's comments during the follow-up telephone interviews suggested that they had used ACTs for a multitude of reasons and would have had difficulty establishing one reason as being primary. In asking women about their therapy use following their breast cancer diagnosis, regardless of the purpose of the therapy, a realistic picture of ACT use in this population was achieved.

A final measurement issue that must be acknowledged is that a total of 188 questionnaires were returned with missing data, with the majority of missing information being associated with items assessing women's use of ACTs. Women who used a substantial number of ACTs since their breast cancer diagnosis had particular difficulty in providing information about the initiation, frequency, effort and costs associated with each therapy. Often, the women would provide information for some therapies, but not all. Recall biases may have been responsible for some of the missing data, with women having difficulty remembering detailed information for therapies that may have been used up to three years previously. In addition, the women might have felt burdened by the repetitive nature of the questions that addressed each therapy used since diagnosis (Knapp, 1998). It was also possible that the women required more explicit instructions in completing the section on ACT use. To minimize the effect of missing data, follow-up telephone interviews were successfully completed with 159 women. This allowed the investigator to complete missing information and to address conflicting data.<sup>75</sup> The success of this follow-up method suggests that the collection of treatment-specific information related to ACT use might be best accomplished through verbal interviews. There has been some suggestion in the literature that researcher-prompted interviews may provide more complete and detailed information about ACT use than mailed questionnaires (Balneaves et al., 1999). A

<sup>75</sup> An example of a conflict was if a woman reported that she had not used ACTs before her diagnosis but then proceeded to list a number of therapies when asked to list her previous experience with ACTs.

combination of mailed survey and verbal interview also has been found to be effective in eliciting detailed information regarding previous ACT use in cancer populations (Downer et al., 1994).

### **Generalizability**

A final study limitation is the generalizability of the findings to the larger population of women with breast cancer living in British Columbia.<sup>76</sup> Attempts were made through random sampling of the British Columbia Cancer Registry to recruit a representative sample of women with early-stage breast cancer who were within 9 to 29 months post-diagnosis. Because cancer-staging information was limited to those individuals who had been referred to the British Columbia Cancer Agency for treatment,<sup>77</sup> the sample was further restricted to those individuals who had received some form of conventional cancer care. Consequently, the study findings cannot be generalized to those women who refused conventional breast cancer treatment or received treatment from health care institutions not associated with the British Columbia Cancer Agency (either by choice or because of accessibility of services). Research by Montbriand (1998) has suggested that individuals who abandon conventional medicine may hold unique beliefs related to their disease and the effectiveness of conventional and alternative treatments. Individuals who seek or receive conventional care outside of the British Columbia Cancer Agency may also differ with regards to their treatment experiences and their contact with other cancer patients, which may in turn influence treatment decisions.

With approximately 90% of the sample reporting their ethnicity/culture to be either "Caucasian" or "Canadian/Nothing in particular", the treatment experiences and beliefs of women from different ethnocultural communities prevalent in British Columbia (i.e., Asian, South Asian, and First Nations) may not have been adequately captured by the survey. In addition, because only an English version of the survey was used, study findings are limited to those individuals able to read English.

Women who responded to the survey may be different than those women who chose not to participate in the study. Women interested in ACTs and with prior treatment experience may have been more likely to respond to the survey than women who had limited exposure to these types of therapy. However, with between 58% and 72% of eligible participants (see Table 3 for discussion of completion rates) completing the study questionnaire, the response rate in this study is similar to previous survey research utilizing Dillman's Total Design Method (1978, 1983). The use of probability sampling in generating the study sample further increases the

<sup>76</sup> Because previous prevalence research has suggested geographical differences in ACT use across Canada, the results of this study cannot be generalized beyond British Columbia.

<sup>77</sup> It is important to note that the British Columbia Cancer Agency serves all areas of the province of British Columbia and women from both urban and rural areas are included in the British Columbia Cancer Registry.

confidence in the generalizability of the study findings. Comparison of respondents and non-respondents on disease information available from the British Columbia Cancer Registry revealed minimal differences, with the exception of respondents being more likely to have been prescribed hormone cancer therapy (i.e., Tamoxifen). Due to the data limitations of the provincial cancer registry and restrictions of the data collection process, additional demographic information for non-respondents was not available. Accordingly, it is possible that the women who participated in the study differed from non-respondents with regards to their educational attainment, income, and marital status. While these biases may have influenced the validity of the descriptive results related to ACT use, it was expected to have little impact on the modelling results.

The generalizability of the study findings to all types of ACTs must also be considered with caution because of the grouping of "more conservative" ACTs with those therapies that were classified at the far end of the alternative continuum. Further study is needed to distinguish the cognitive and social variables associated with the use of therapies that are invasive and farthest removed philosophically and empirically from conventional medicine.

## **Implications for Practice**

Although the main aim of this study was to develop theoretical knowledge of the relationships among health beliefs, sociobehavioural factors, and ACT use in women with breast cancer, several key implications for conventional practice and education are suggested by the study findings. Table 63 provides a summary of the major study findings as well as the clinical implications.

Foremost, it should be recognized by nurses and other conventional health professionals that a significant number of women living with breast cancer are interested in, and use, therapies that are alternative or complementary to conventional cancer care. Acknowledging the pervasiveness of these therapies across demographic groups is an important first step to dialogue with breast cancer consumers about their treatment decisions. It is also important to recognize the wide range of therapies women living with breast cancer may use following diagnosis, and that they often use more than one therapy at a time. In this study, the women reported using over 70 different types of therapy, with the majority of women using between three and five therapies following their breast cancer diagnosis. The popularity of natural health products such as vitamins, minerals, and herbal supplements in breast cancer populations is of particular interest for conventional health professionals because of the risk of interactions with conventional cancer treatments (Decker, 2000; Tagliaferri et al., 2001). These risks, as well as the possible benefits, created by women's use of ACTs emphasize the importance of communicating with women about their use of therapies not included in their conventional



treatment plan and of developing an accurate, documented treatment history<sup>78</sup>. The use of an inventory was shown in the present study to elicit a broad range of therapies and to encourage women to recall therapies that they may have forgotten or not necessarily considered to be "alternative" or "complementary". In addition to assisting with the development of a comprehensive history of ACT use, the presentation of an inventory may help to normalize the use of ACTs and facilitate more open discussion about ACTs within conventional care settings. This study also emphasized the importance of assessing not only current ACT use but previous use of ACTs as well. This information may help predict those women who may be most likely to require support in making treatment decisions related to ACTs following diagnosis.

In communicating with women about their use of ACTs it is important to appreciate that not all women may be interested in discussing their treatment choices with conventional health-care providers. This decision may be a result of women perceiving health professionals within conventional care settings as lacking adequate knowledge about ACTs or being uninterested in therapies not included as part of conventional medicine. Still other women may have accepted responsibility for their well being and health care and may be unwilling to share control with their doctor, nurse, or other care provider. These hesitations stress the need for patient-provider communication that is open, non-judgmental, and respectful of the choices made by women with breast cancer. Given the range of therapies used by the women in this study and the lack of effect of disease-specific health beliefs on ACT use, it is important to use broad, open-ended questions that are not restricted to the breast cancer experience. The inclusion of family members and significant others in discussions about ACTs also may be important given the notable effect social groups have on women's decisions about ACTs. Further, communication about ACTs needs to be a continuous process because therapy utilization changes over time as some therapies are initiated and others discontinued. Although nurses were not identified in this study as playing a central role in women's decisions about ACTs, they are well positioned by their close interactions with patients and by their commitment to patient advocacy to become more involved in supporting informed treatment decisions. Discussions with women with breast cancer about their complex treatment decisions related to ACTs may be further supported with the development of decision-making interventions. There is emerging evidence that interventions, such as decisional aids, may increase satisfaction with decisions, reduce decisional conflict, and improve psychosocial functioning (Goel, Sawka, Thiel, Gort, & O'Connor, 2001; O'Connor et al., 1999; O'Connor et al., 2001).

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<sup>78</sup> Having ACT use documented in medical charts would be a valuable resource for clinicians caring for women with breast cancer as well as a preliminary database of ACT utilization and potential interactions and benefits in relation to conventional cancer care (Eisenberg, 1997; Tataryn & Verhoef, 2001).

Essential to supporting informed decision making about ACTs is improved educational opportunities for both women with breast cancer and conventional health professionals. Provincial cancer agencies and other groups have begun to offer information to patients about selected therapies and practices,<sup>79</sup> but some women may require further assistance in sorting through the abundant and often contradictory advice about ACTs. Conventional health professionals may be able to assist women by providing them with resources that offer a balanced assessment of the efficacy and safety of ACTs (e.g., *A Guide to Unconventional Cancer Therapies* (Ontario Breast Cancer Information Exchange Project, 1994) and the Canadian Breast Cancer Research Initiative's information packages on ACTs (Kaegi, 1998a, 1998b, 1998c, 1998d, 1998e, 1998f)). Nurses and other professionals can help by becoming more knowledgeable about the therapies that are commonly used by women with breast cancer or are receiving attention within the lay and scientific literature. Recognition of the importance of ACTs within the Canadian health care system has motivated many nursing and medical schools in Canada to incorporate knowledge about ACTs into their curricula. However, relatively few professional schools have offered full courses on ACTs in their program (de Bruyn, 2001). Given the prevalence of ACTs and the breadth of this field of study, more attention and resources need to be committed to ACTs in conventional health professionals' basic and continuing education programs. Beyond providing basic information regarding different types of therapies, future educational strategies need to acknowledge the ethical, legal, and professional issues that surround ACTs and their possible integration into conventional health care (Gaydos, 2001).

## Recommendations for Future Research

The findings and limitations of this study, along with current knowledge in the ACT and treatment decision-making literature, provide direction for future inquiry into ACT utilization in women living with breast cancer and other clinical populations. This final section provides a brief discussion of six key research recommendations that may further our understanding of the complex treatment choices faced by women following a breast cancer diagnosis and the personal and social contexts in which treatment decisions are made.

As noted earlier in this thesis, women with breast cancer represent one of many populations that have been identified as being advocates and consumers of alternative and complementary health care. Replication of the present study in other clinical populations would increase confidence in the relationships found in this research and possibly uncover

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<sup>79</sup> For example, see the British Columbia Cancer Agency's web site at <http://www.bccancer.bc.ca/PPI/UnconventionalTherapies/default.htm>.

**Table 63. Major Study Findings and Related Implications**

Study Findings	Implications
<ul style="list-style-type: none"> <li>• ACT use is a prevalent and diverse phenomenon in women living with breast cancer</li> <li>• Vitamin/mineral supplements and herbal remedies are the most commonly used therapies, with few women using therapies on the far end of the alternative continuum</li> <li>• ACT use changes as women move through the breast cancer trajectory</li> <li>• Previous experience with ACTs is predictive of ACT use following breast cancer diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Frequently assess and document women's use of ACTs prior to and following breast cancer diagnosis and treatment</li> <li>• Develop a treatment history through the use of a therapy inventory and open-ended questions that explore the types of therapies being used and the associated costs and effort</li> <li>• Recognize that women are using therapies that are accessible and easily incorporated into their lives and often reflect lifestyle choices rather than curative claims</li> <li>• Increase awareness of the possible benefits and negative interactions with conventional cancer treatments associated with selected ACTs</li> </ul>
<ul style="list-style-type: none"> <li>• Majority of women with breast cancer seek information about ACTs from lay sources</li> <li>• Some women may be hesitant about sharing their treatment history with conventional health-care providers</li> <li>• Significant others play an important role in influencing women's treatment decisions related to ACTs</li> </ul>	<ul style="list-style-type: none"> <li>• Communicate to women about ACTs in an open, non-judgmental, and respectful manner</li> <li>• Acknowledge and include family members and other individuals important to women in discussions about ACTs</li> <li>• Offer assistance with treatment decision-making process (i.e., decisional aids, ACT resources)</li> <li>• Educate women and health-care providers so that they become better informed about the potential benefits and costs of ACTs</li> </ul>
<ul style="list-style-type: none"> <li>• ACT use occurs within the context of restoring of general well being, with women who perceive ACTs to be efficacious in improving well being and who perceive themselves to have control over well being to be more committed in their use of ACTs</li> <li>• Women's use of ACTs was minimally influenced by their fears related to breast cancer recurrence and their distress associated with adverse effects of conventional cancer treatments</li> </ul>	<ul style="list-style-type: none"> <li>• Acknowledge that women's use of ACTs may reflect their acceptance of responsibility for self-care and well being</li> <li>• Recognize that the majority of women hold realistic and conservative expectations of the outcomes of ACTs</li> </ul>
<ul style="list-style-type: none"> <li>• Limited relevance of the HBM in explaining ACT use in women living with breast cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Acknowledge the limited relevance of health beliefs in explaining ACT use</li> <li>• Explore the role of other cognitive and social factors in predicting ACT use in women with breast cancer</li> </ul>

unique differences in treatment decision making and health behaviour across disease groups and gender. This research would require the careful tailoring of study concepts and associated questionnaire items to ensure the salience of the variables to the population of interest (Sheeran & Abraham, 1995). In addition, the expansion of the theoretical model to include other cognitive and contextual factors, such as causal attributions of illness, coping strategies, satisfaction with care, and visibility of ACTs, may help increase the explanatory power of the model. Testing of these cognitive models of ACT use within the general population would provide additional insight into the germaneness of health beliefs, sociobehavioural factors and other non-health constructs to treatment decisions across the health-illness trajectory. The opportunity also exists to compare models of ACT use with those focussing on decision making about conventional medical treatments to assess whether the underlying motivations differ across health paradigms. Finally, duplication of this study with women at different stages in the breast cancer trajectory, from diagnosis to palliation, may reveal shifts in the beliefs and motivations that underlie women's decisions to seek ACTs. Such cross-validation is essential to the development of rigorous structural models (Schumacker & Lomax, 1996).

Although reference was made throughout this study to factors that "predicted" or "motivated" ACT use, the correlational nature of the data prevented causal associations from being conclusively determined (Weinstein & Nicolich, 1993). Prospective, longitudinal research is needed that examines not only differences in therapy utilization and health beliefs across women with breast cancer but explores how women's individual treatment decisions change as they move from diagnosis, through treatment, to survivorship and beyond. Advanced statistical techniques, such as growth curve modelling (Willett & Sayer, 1996) and hierarchical linear modelling (Byrk & Raudenbush, 1992), can be used to analyze temporal change in constructs as well as differences among study groups. Such analysis would provide additional insight into whether health beliefs and perceptions of control act as predictors of ACT use, are a consequence of women's treatment decisions and health behaviour, or are part of a complex feedback loop. Descriptively, longitudinal research would offer conventional health professionals a clearer picture of what types of therapies and practices are most prevalent at different stages of the cancer trajectory, providing the opportunity to collect vital information about potential interactions between ACTs and conventional cancer treatments.

The strong influence of social support on the therapy choices made by women with breast cancer provides further evidence of the need for ACT research that examines the social context of treatment decision making. In particular, qualitative research is needed that elucidates the process by which family members, friends, conventional and alternative health professionals, and other individuals become involved in, and contribute to, women's treatment decisions specific to ACTs. To date, limited research has examined the family decision-making

processes experienced by women with breast cancer (Hilton, 1994), and no studies are known that have explored family decision making specific to ACTs. Such research would shed light on how women balance the conflicting treatment advice and social norms that exist between and within the biomedical and alternative practice arenas and their social networks. Also of interest would be understanding which treatment messages are most persuasive to women with breast cancer and whether encouragement to use ACTs functions as a cue to action or mediates the effect of selected health beliefs on women's health behaviour. Further, by involving women and their significant others in treatment decision-making research, the social implications of treatment choice can be clarified (Balneaves & Long, 1999) as well as how to best include family members in educational and counselling strategies. Because this study was limited in terms of accessing women from diverse ethnocultural groups, it may be worthwhile to explore the influence of culture on women's treatment decisions with regards to types of therapies used, integration of therapies into conventional medical care, and the intent of traditional therapies. For example, in a recent ethnographic study of traditional health practices of South Asian women in British Columbia (Hilton et al., 2001), women used a range of therapies in response to health concerns. In addition, the therapies provided a means of preserving their cultural heritage and reflected their past treatment experiences, belief systems, and acculturation to Canadian society. Traditional therapies were such an integrated part of these women's lives, that they had difficulty distinguishing their traditional healing practices from everyday practices.

The reliance by women with breast cancer on lay sources of information about alternative and complementary practices highlights the need for research that examines the potential role of nurses and other conventional health professionals in treatment decision-making specific to ACTs. With some study participants choosing not to disclose their therapy choices to their primary care physician or cancer specialist, it cannot be assumed that educational and counselling strategies offered by conventional practitioners would necessarily be welcomed. However, research that has investigated cancer patients' information-seeking behaviour related to ACTs has suggested that some individuals are seeking "permission" from the conventional medical establishment prior to incorporating ACTs into their personal treatment plans (Eng, Monkman, Verhoef, Ramsum, & Bradbury, 2001). In addition, nurses and physicians are obligated under their professional and ethical standards of practice to assist individuals in making informed decisions while respecting their autonomy. Insights into why women with breast cancer choose not to disclose or discuss ACTs within conventional practice settings may be gleaned by examining current patient-provider communication patterns. This research would uncover valuable information about the barriers and facilitators of communication, the type of information being sought by patients, and the expectations of both patients and providers. Such investigations would provide a foundation for the development of

counselling and educational resources that could be offered to women willing to include conventional health professionals in their treatment decisions. Decisional aids (e.g., O'Connor et al., 1999; O'Connor et al., 2001) may be one strategy through which women and their family members can be supported in making complicated therapy decisions, incorporating recent research evidence with advice of how to be "smart" consumers of ACTs.

In any study on ACT utilization, what becomes abundantly clear is the urgent need for research that examines the efficacy and safety of ACTs. This recommendation is fuelled, in part, by the large proportion of women with breast cancer who were using therapies for which there is inconclusive evidence of the possible harmful or beneficial effects. It is also motivated by the numerous anecdotal requests for information and guidance about ACTs that the researcher received during follow-up telephone calls with study participants. Although the therapies that were most prevalent in this study are considered by both lay and professional audiences to be relatively innocuous (Thorne, 2001), the potential for harmful interactions with conventional cancer treatments has been acknowledged (Jacobson & Verret, 2001). In the absence of sound, empirically-based knowledge regarding the actions, outcomes (both positive and negative), and potential interactions of ACTs with biomedical therapies, patients are unable to make informed treatment decisions and conventional health professionals are stymied in their attempts to provide accurate and reliable advice. Which therapies might be the most advantageous for researchers to investigate is indicated in the study findings, with women being most committed to vitamin/mineral supplements, herbal remedies, and spiritual therapies. What level of evidence is needed, however, to support or disclaim ACTs is still under debate (Bell et al., 2002; Thorne, 2001). Flexibility and innovation in research methodology is needed to accurately assess the safety, efficacy, practice-effectiveness, and cost-effectiveness of selected ACTs (de Bruyn, 2001; Jacobson, 1996). Despite steps being taken in Canada to address the paucity of empirical evidence for ACTs,<sup>80</sup> recent provincial funding cuts to institutions such as the Tzu Chi Institute in Vancouver, BC<sup>81</sup> may pose significant challenges to the future of ACT efficacy research.

Another issue that will require investigation as ACTs become more prominent in cancer and general populations is the implications of these therapies for the Canadian health care system. There has been much discussion within the literature regarding the development of an integrative system of health care in which effective and safe conventional and non-conventional therapies are offered in combination (Bell et al., 2002; de Bruyn, 2001; LaValley & Verhoef, 1995). The economic feasibility of such a model of care, as well as its impact on patient care, health care utilization, and health outcomes, however, have not been adequately evaluated.

<sup>80</sup> In March, 1999, Health Canada announced the establishment of the Natural Health Products Directorate, whose mandate is to assist in the regulation and evaluation of natural health products. See Health Canada's web site at <http://www.hc-sc.gc.ca/hpb/onhp>

<sup>81</sup> Fayerman, P. (2002, June 6) Tzu Chi institute loses funding. *Vancouver Sun*. pp. B1.

## Conclusion

With ACT use burgeoning in the general public and individuals living with cancer, health professionals can no longer ignore this social trend in treatment choice. Through the development and testing of three models of ACT use, the findings of this study contributes knowledge of the sociobehavioural predictors of ACT use in a population-based sample of women living with breast cancer, as well as the underlying health beliefs that motivate treatment choice. Recognizing what health beliefs and personal and social factors influence ACT use is important for nursing and other health professions because it provides a foundation upon which educational and counselling strategies specific to ACTs can be developed. This study also provides a valuable "snap shot" of ACT use within the British Columbian breast cancer population. Understanding the types of ACTs used by women with breast cancer informs clinical practice and will assist conventional health professionals in providing compassionate and comprehensive cancer care and in supporting women in making informed treatment decisions. The prevalence of use of over-the-counter supplements such as vitamins, minerals, and herbal products in this population of women and their beliefs related to the efficacy of ACTs in promoting well being suggest that women with breast cancer may differ little from the general public in relation to their use of ACTs.

In cancer, there is no single right choice for all of us, but there are surely right choices for each of us. There are no certain courses of action, but there are certainly educated and wiser choices, as opposed to uneducated and more foolish ones. The skill is the movement from ignorance toward knowledge and from knowledge towards wisdom. In wisdom, we choose what we are least likely to regret. Accepting pain and sorrow inherent in the fate we have been given, we can seek also the beauty and the joy. (Lerner, 1994, p. 534)

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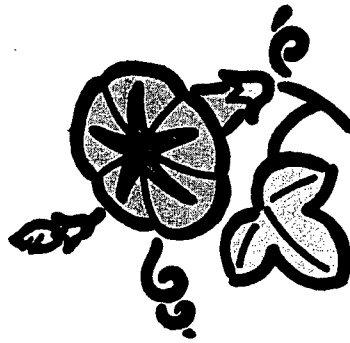
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# Alternative and Complementary Therapy Use by Women Living with Breast Cancer Survey



## APPENDIX 5 STUDY QUESTIONNAIRE

Thank you for agreeing to complete this survey. Please read and answer each item as carefully as possible. There are no right or wrong answers. Your answers will be kept strictly confidential. PLEASE DO NOT PUT YOUR NAME ON THE SURVEY. Once you are finished completing the survey, please return it in the stamped, self-addressed envelope provided to the BC Cancer Agency

UBC School of Nursing

BC Cancer Agency

**Part A:** This first section of the survey lists many of the therapies that people living with cancer may use in addition to their conventional medical treatments (i.e., surgery, chemotherapy, radiation). These therapies are sometimes referred to as alternative and complementary therapies. Please read the following list and CHECK EACH therapy that you have used SINCE YOU WERE DIAGNOSED with breast cancer.

### Natural Health Practices

- ☐ Aromatherapy
- ☐ Ayurvedic medicine
- ☐ Herbalism
- ☐ Homeopathy
- ☐ Native North American healing
- ☐ Traditional Chinese medicine
- ☐ Naturopathy

### Vitamins

- ☐ B vitamins
- ☐ Beta-carotene
- ☐ Megavitamin therapy
- ☐ Vitamin A
- ☐ Vitamin C
- ☐ Vitamin D
- ☐ Vitamin E

### Dietary Therapies

- ☐ Alkaline/acid cleansing diet
- ☐ Gerson therapy
- ☐ Grape cure
- ☐ Metabolic therapy
- ☐ Macrobiotic diet

### Herbal Therapies

- ☐ Aloe
- ☐ Carnivora
- ☐ Coffee enemas
- ☐ Essiac/Flor\*Essence
- ☐ Ginseng
- ☐ Hoxsey herbal treatment
- ☐ Pau d'Arco
- ☐ Iscadora/Mistletoe

### Minerals

- ☐ Calcium
- ☐ Selenium
- ☐ Zinc

### From Earth to Sea

- ☐ Alkylglycerols
- ☐ Canthazanthin
- ☐ Evening Primrose
- ☐ Mushrooms
- ☐ Seaweed
- ☐ Shark Cartilage

### Drugs

- ☐ 714-X
- ☐ Hydrazine Sulfate
- ☐ Bezaldehyde
- ☐ Chelation therapy
- ☐ DMSO
- ☐ Enzyme therapy

### To and From the Body

- ☐ Cell extraction therapy
- ☐ Colonic irrigation
- ☐ urea (urine) therapy
- ☐ Antineoplastons

<b>Immune Boosters</b>	<b>Energy Life Force Therapies</b>	<b>Oxygen Therapies</b>
<input type="checkbox"/> Bestatin	<input type="checkbox"/> Acupuncture and/or acupressure	<input type="checkbox"/> Ozone
<input type="checkbox"/> Chondriana	<input type="checkbox"/> Reiki	<input type="checkbox"/> Hydrogen Peroxide
<input type="checkbox"/> Coley's Toxins	<input type="checkbox"/> Polarity therapy	<b>Psychological Therapies</b>
<input type="checkbox"/> Immuno-augmentative therapy	<input type="checkbox"/> Therapeutic touch	<input type="checkbox"/> Hypnosis
<input type="checkbox"/> Isoprinosine	<b>Expressive Arts Therapies</b>	<input type="checkbox"/> Imagery
<input type="checkbox"/> Echinacea	<input type="checkbox"/> Art therapy	<input type="checkbox"/> Meditation
<input type="checkbox"/> Livingston therapy	<input type="checkbox"/> Music therapy	<input type="checkbox"/> Psychotherapy and counselling
<b>Physical Therapies</b>	<b>Spiritual Therapies</b>	<input type="checkbox"/> Relaxation therapy
<input type="checkbox"/> Chiropractor	<input type="checkbox"/> Prayer	<b>Movement Therapies</b>
<input type="checkbox"/> Massage therapy	<input type="checkbox"/> Laying on of hands	<input type="checkbox"/> T'ai chi
<input type="checkbox"/> Reflexology		<input type="checkbox"/> Yoga

Please list any other therapies not included above that you have used since diagnosed with breast cancer.

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**\*\*If you HAVE checked any of the therapies above or listed additional therapies, please go to the next page, Part B**

**\*\*If you HAVE NOT checked any of the therapies above or listed additional therapies, please go to page 9, Part C.**

**Part B**  
This next section of the survey asks you some specific questions about each therapy you have used since you were diagnosed with breast cancer. For EACH therapy that you have checked or listed on the previous pages, please answer the following questions:

- the date you started using the therapy
- whether you are still using the therapy
- how often you use/used the therapy
- how much effort is involved in using the therapy
- how much it costs to use the therapy

An example of how to complete this section is provided on the right →

Therapy # 1 (please print)		<u>ESSIAC</u>																					
a) When did you start using this therapy (month/year)?		<u>JAN/98</u>																					
b) Are you currently using this therapy?		<input checked="" type="radio"/> Yes <input type="radio"/> No If NO, when did you stop using this therapy (month/year)? _____																					
c) How often did/do you use this therapy? (please check one response)		Less than once a month    Once a month    Once every 2 weeks    Once a week    Every other day    Daily <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/>																					
d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)		<table border="0"> <tr> <td>No Effort</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> <td>6</td> <td>7</td> <td>8</td> <td>9</td> <td>10</td> <td>Great Effort</td> </tr> </table>										No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort												
e) How much did/do you spend each month using this therapy?		\$ <u>30</u>																					

**Therapy # 1 (please print)** \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

Less than once a month	Once every 2 weeks	Once a week	Every other day	Daily
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)

No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
-----------	---	---	---	---	---	---	---	---	---	----	--------------

e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

**Therapy # 2 (please print)** \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

Less than once a month	Once every 2 weeks	Once a week	Every other day	Daily
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)

No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
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e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

### Therapy # 3 (please print) \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

<input type="checkbox"/>	Less than once a month	<input type="checkbox"/>	Once a month	<input type="checkbox"/>	Once every 2 weeks	<input type="checkbox"/>	Every week	<input type="checkbox"/>	Daily other day
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d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle one)

No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
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e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

### Therapy # 4 (please print) \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

<input type="checkbox"/>	Less than once a month	<input type="checkbox"/>	Once a month	<input type="checkbox"/>	Once every 2 weeks	<input type="checkbox"/>	Every week	<input type="checkbox"/>	Daily other day
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d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle one)

No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
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e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

**Therapy # 5 (please print)** \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

<input type="checkbox"/>	Less than once a month	<input type="checkbox"/>	Once a month	<input type="checkbox"/>	Once every 2 weeks	<input type="checkbox"/>	Every week	<input type="checkbox"/>	Daily other day
--------------------------	------------------------	--------------------------	--------------	--------------------------	--------------------	--------------------------	------------	--------------------------	-----------------

d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)

No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
-----------	---	---	---	---	---	---	---	---	---	----	--------------

e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

**Therapy # 6 (please print)** \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

<input type="checkbox"/>	Less than once a month	<input type="checkbox"/>	Once a month	<input type="checkbox"/>	Once every 2 weeks	<input type="checkbox"/>	Every week	<input type="checkbox"/>	Daily other day
--------------------------	------------------------	--------------------------	--------------	--------------------------	--------------------	--------------------------	------------	--------------------------	-----------------

d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)

No Effort	1	2	3	4	5	6	7	8	9	10	Great Effort
-----------	---	---	---	---	---	---	---	---	---	----	--------------

e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_



Therapy # 7 (please print) _____	Therapy # 8 (please print) _____																																
<p>a) When did you start using this therapy (month/year)? _____</p> <p>b) Are you currently using this therapy? <input type="radio"/> Yes <input type="radio"/> No</p> <p style="padding-left: 40px;">If NO, when did you stop using this therapy (month/year)? _____</p> <p>c) How often did/do you use this therapy? (please check one response)</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center;">Less than once a month</td> <td style="text-align: center;">Once a month</td> <td style="text-align: center;">Once every 2 weeks</td> <td style="text-align: center;">Once a week</td> <td style="text-align: center;">Every other day</td> <td style="text-align: center;">Daily</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table> <p>d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center;">No Effort</td> <td style="text-align: center;">Great Effort</td> </tr> <tr> <td style="text-align: center;">1   2   3   4   5   6   7   8   9   10</td> <td></td> </tr> </table> <p>e) How much did/do you spend each month using this therapy? \$ _____</p>	Less than once a month	Once a month	Once every 2 weeks	Once a week	Every other day	Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No Effort	Great Effort	1   2   3   4   5   6   7   8   9   10		<p>a) When did you start using this therapy (month/year)? _____</p> <p>b) Are you currently using this therapy? <input type="radio"/> Yes <input type="radio"/> No</p> <p style="padding-left: 40px;">If NO, when did you stop using this therapy (month/year)? _____</p> <p>c) How often did/do you use this therapy? (please check one response)</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center;">Less than once a month</td> <td style="text-align: center;">Once a month</td> <td style="text-align: center;">Once every 2 weeks</td> <td style="text-align: center;">Once a week</td> <td style="text-align: center;">Every other day</td> <td style="text-align: center;">Daily</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table> <p>d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center;">No Effort</td> <td style="text-align: center;">Great Effort</td> </tr> <tr> <td style="text-align: center;">1   2   3   4   5   6   7   8   9   10</td> <td></td> </tr> </table> <p>e) How much did/do you spend each month using this therapy? \$ _____</p>	Less than once a month	Once a month	Once every 2 weeks	Once a week	Every other day	Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No Effort	Great Effort	1   2   3   4   5   6   7   8   9   10	
Less than once a month	Once a month	Once every 2 weeks	Once a week	Every other day	Daily																												
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																												
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Less than once a month	Once a month	Once every 2 weeks	Once a week	Every other day	Daily																												
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																												
No Effort	Great Effort																																
1   2   3   4   5   6   7   8   9   10																																	

**Therapy # 10 (please print)** \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

Less than once a month	Once a month	Once every 2 weeks	Once a week	Every other day	Daily
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)

No Effort	Great Effort
1   2   3   4   5   6   7   8   9   10	

e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

**Therapy # 9 (please print)** \_\_\_\_\_

a) When did you start using this therapy (month/year)? \_\_\_\_\_

b) Are you currently using this therapy? ☐ Yes ☐ No

If NO, when did you stop using this therapy (month/year)? \_\_\_\_\_

c) How often did/do you use this therapy? (please check one response)

Less than once a month	Once a month	Once every 2 weeks	Once a week	Every other day	Daily
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d) On a scale from 1 to 10, how much effort is involved in using this therapy? (please circle)

No Effort	Great Effort
1   2   3   4   5   6   7   8   9   10	

e) How much did/do you spend each month using this therapy? \$ \_\_\_\_\_

**\*\* If you have used more than ten therapies and require more room to answer the above questions, please use the back of this page.**

Part C. This next section of the survey asks you some general questions about your use of alternative and complementary therapies.

1. Did you use alternative and complementary therapies BEFORE you were diagnosed with breast cancer? Remember, these are therapies such as those listed in the previous section, PART A.

☐ Yes

☐ No

If YES, please list below the therapies you used before you were diagnosed with breast cancer.


If NO, please go to page 11, Part D

2. In general, how often did you use alternative and complementary therapies before you were diagnosed with breast cancer? (please check one response)

Less than once a month	<input type="checkbox"/>	Once a month	<input type="checkbox"/>	Once every 2 weeks	<input type="checkbox"/>	Once a week	<input type="checkbox"/>	Every other day	<input type="checkbox"/>	Daily	<input type="checkbox"/>
---------------------------	--------------------------	-----------------	--------------------------	-----------------------	--------------------------	-------------	--------------------------	--------------------	--------------------------	-------	--------------------------

3. Where did you learn about the alternative and complementary therapies that you have used ? (please check all that apply).

- |  |  |   |
|--|--|---|
| <input type="checkbox"/> Doctor        | <input type="checkbox"/> Support group     | <input type="checkbox"/> Television/radio             |
| <input type="checkbox"/> Nurse         | <input type="checkbox"/> Health food store | <input type="checkbox"/> Internet/web                 |
| <input type="checkbox"/> Family member | <input type="checkbox"/> Magazines/books   | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Friend        |  |   |

4. Have you told your physician(s) about your use of alternative and complementary therapies? (please check one response)

- ☐ Yes, all my physicians know
- ☐ Yes, my family physician knows, but my specialists do not
- ☐ Yes, my specialists know, but my family physician does not
- ☐ No, none of my physicians know

Continue on next page...

**Part D:** This section describes thoughts that some women may have after being diagnosed and treated for breast cancer. Please check the one response that best describes how much you agree or disagree with each statement.

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1. My chances of having breast cancer come back are great.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My physical health makes it more likely that the breast cancer will come back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel that my chances of having breast cancer come back in the future are high.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. There is a good possibility that I will have breast cancer come back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I worry a lot about having breast cancer come back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Within the next year I will have the breast cancer come back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Part E:** Each of the following items list 5 different numbered statements about your health. Think about what each statement says then check the circle beside the statement that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where "1" indicates no problems and "5" indicates the maximum amount of problems. "2" through "4" indicate you feel somewhere in between.

#### Nausea

- ☐ 1. I seldom feel any nausea at all
- ☐ 2. I am nauseated once in a while
- ☐ 3. I am often nauseated
- ☐ 4. I am usually nauseated
- ☐ 5. I suffer from nausea almost continually

#### Nausea

- ☐ 1. When I do have nausea, it is very mild
- ☐ 2. When I do have nausea, it is mildly distressing
- ☐ 3. When I have nausea, I feel pretty sick
- ☐ 4. When I have nausea, I feel very sick
- ☐ 5. When I have nausea, I am as sick as I could possibly be

#### Appetite

- ☐ 1. I have my normal appetite
- ☐ 2. My appetite is usually, but not always, good
- ☐ 3. I don't really enjoy my food like I used to
- ☐ 4. I have to force myself to eat my food
- ☐ 5. I cannot stand the thought of food

#### Insomnia

- ☐ 1. I sleep as well as I always have
- ☐ 2. I have occasional spells of sleeplessness
- ☐ 3. I frequently have trouble getting to sleep and staying asleep
- ☐ 4. I have difficulty sleeping almost every night
- ☐ 5. It is almost impossible for me to get a decent night's sleep

**Pain**

- ☐ 1. I almost never have pain
- ☐ 2. I have pain once in a while
- ☐ 3. I frequently have pain several times a week
- ☐ 4. I am usually in some degree of pain
- ☐ 5. I am in some degree of pain almost constantly

**Pain**

- ☐ 1. When I do have pain, it is very mild
- ☐ 2. When I do have pain, it is mildly distressing
- ☐ 3. The pain I do have is usually fairly intense
- ☐ 4. The pain I have is usually very intense
- ☐ 5. The pain I have is almost unbearable

**Appearance**

- ☐ 1. My appearance has basically not changed
- ☐ 2. My appearance has gotten a little worse
- ☐ 3. My appearance is definitely worse than it used to be, but I am not greatly concerned about it
- ☐ 4. My appearance is definitely worse than it used to be, and I am concerned about it
- ☐ 5. My appearance has changed drastically from what it was

**Bowel**

- ☐ 1. I have my normal bowel pattern
- ☐ 2. My bowel pattern occasionally causes me some discomfort
- ☐ 3. I frequently have discomfort from my present bowel pattern
- ☐ 4. I am usually in discomfort because of my present bowel pattern
- ☐ 5. My present bowel pattern has changed drastically from what was normal for me

**Concentration**

- ☐ 1. I have my normal ability to concentrate
- ☐ 2. I occasionally have trouble concentrating
- ☐ 3. I often have trouble concentrating
- ☐ 4. I usually have at least some difficulty concentrating
- ☐ 5. I just can't seem to concentrate at all

**Fatigue**

- ☐ 1. I am usually not tired at all
- ☐ 2. I am occasionally rather tired
- ☐ 3. There are frequently periods when I am quite tired
- ☐ 4. I am usually very tired
- ☐ 5. Most of the time, I feel exhausted

**Breathing**

- ☐ 1. I usually breathe normally
- ☐ 2. I occasionally have trouble breathing
- ☐ 3. I often have trouble breathing
- ☐ 4. I can hardly ever breathe as easily as I want
- ☐ 5. I almost always have severe trouble with my breathing

**Outlook**

- ☐ 1. I am not fearful or worried
- ☐ 2. I am a little worried about things
- ☐ 3. I am quite worried, but unafraid
- ☐ 4. I am worried and a little frightened about things
- ☐ 5. I am worried and scared about things

**Cough**

- ☐ 1. I seldom cough
- ☐ 2. I have an occasional cough
- ☐ 3. I often cough
- ☐ 4. I often cough, and occasionally have severe coughing spells
- ☐ 5. I often have persistent and severe coughing spells



**Part F** This part of the survey lists beliefs some women may hold about HOW LIKELY it is that their well being has been harmed by their breast cancer experience. Please check the one response that best describes how much you agree or disagree with each statement.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. There is a good possibility that my physical health has been harmed by my breast cancer experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. There is a good possibility that my mental health has been harmed by my breast cancer experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. There is a good possibility that my relationships with others have been harmed by my breast cancer experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. There is a good possibility that my spiritual well being has been harmed by my breast cancer experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page...

**Part G.** A number of statements that people have used to describe themselves are given below. Please read each statement and then check the one response that indicates how you **GENERALLY** feel. There are no right or wrong answers.

	Almost Never	Sometimes	Often	Almost Always
1. I feel pleasant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I feel nervous and restless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel satisfied with myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I wish I could be as happy as others seem to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel like a failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel rested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am "calm, cool, and collected"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel the difficulties are piling up so that I cannot overcome them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I worry too much over something that really doesn't matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I am happy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I have disturbing thoughts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Almost Never	Sometimes	Often	Almost Always
12. I lack self-confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I feel secure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I make decisions easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel inadequate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I am content	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Some unimportant thoughts run through my mind and bother me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I take disappointments so keenly that I can't put them out of my mind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I am a steady person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I get in a state of tension or turmoil as I think over my recent concerns and interests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Part H:** This next section lists beliefs that some women may hold about **HOW MUCH** their well being has been harmed by their breast cancer experience. Please check the one response that best describes how you feel about each statement.

	Not at all	A little	Quite a bit	Very Much
1. How much do you think your physical well being has been harmed by your breast cancer experience?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How much do you think your mental well being has been harmed by your breast cancer experience?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How much do you think your relationships with others have been harmed by your breast cancer experience?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How much do you think your spiritual well being has been harmed by your breast cancer experience?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page...

**Part I** This part of the survey lists beliefs some women may hold about alternative and complementary therapies. Please check the one response that best describes how much you agree or disagree with each statement, even if you have not used alternative and complementary therapies.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Alternative/complementary therapies will prevent a recurrence of my breast cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Alternative/complementary therapies will relieve some of my symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Alternative/complementary therapies will relieve some of my side effects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Alternative/complementary therapies will improve my physical well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Alternative/complementary therapies will improve my mental well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Alternative/complementary therapies will improve my relationships with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Alternative/complementary therapies will improve my spiritual well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Part J:** This next section of the survey lists beliefs some people may have about using alternative and complementary therapies. Please check the one response that best describes how much you agree or disagree with each statement even if you have not used alternative and complementary therapies.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. In order to use alternative/complementary therapies, I would have to give up a lot.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Using alternative/complementary therapies would be uncomfortable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Using alternative/complementary therapies would be time consuming.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My family would make fun of me if I used alternative/complementary therapies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Using alternative/complementary therapies would interfere with my activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Using alternative/complementary therapies would require me starting a new habit, which is difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am afraid that I would not be able to use alternative/complementary therapies the way they should be used.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Part K** This part of the questionnaire lists beliefs some women may have about the amount of control they have over their health and well being. Please read each item and check the one response that best describes how you feel.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I am in control of whether I have breast cancer again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. If I take care of myself, I can avoid having breast cancer again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. If I take the right actions, I can prevent having breast cancer again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I am in control of whether I experience side effects from medical cancer treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. If I take care of myself, I can avoid the side effects of medical cancer treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. If I take the right actions, I can manage the side effects of medical cancer treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am in control of my physical well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I am in control of my mental well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am in control of my relationships with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I am in control of my spiritual well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part L: This part of the survey asks about the encouragement you have received to use alternative and complementary therapies during your breast cancer experience. Please check the one response that best describes how much encouragement you received:

	Not at All	A Little	Quite a Bit	Very Much
1. My family has encouraged me to use alternative and complementary therapies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My friends have encouraged me to use alternative and complementary therapies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My doctor has encouraged me to use alternative and complementary therapies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Other health professionals have encouraged me to use alternative and complementary therapies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page...



**Part M.** This final section of the survey tells us some important general information about you and your family. This information will help us better understand which individuals may hold certain beliefs and use selected therapies and what possible barriers to treatment may exist.

What is your birth date (month/day/year)? \_\_\_\_\_

What is your marital status? (please check one response)

- ☐ Married
- ☐ Living with a partner/common-law
- ☐ Single (never married)
- ☐ Widowed
- ☐ Separated
- ☐ Divorced

How would you describe yourself in terms of ethnic or cultural group? \_\_\_\_\_

What is the highest level of education that you have received? (please check one response)

- ☐ Grade 8 or less
- ☐ Some high school
- ☐ High school diploma
- ☐ Some trade, technical, vocational school, or business school
- ☐ Some community college or nursing school
- ☐ Some university
- ☐ Diploma/certificate from trade, technical, or vocational school
- ☐ Diploma/certificate from community college or nursing school
- ☐ Bachelor's degree or undergraduate degree, or teacher's college
- ☐ Master's degree (e.g., MA., MSc, MEd)
- ☐ Degree in medicine, dentistry, veterinary medicine or optometry
- ☐ Earned doctorate (e.g., \_\_\_\_\_)
- ☐ Other (please specify) \_\_\_\_\_

What is your best estimate of the total income, before taxes and deductions, of your household, from all sources, in the past 12 months? (please check one response)

- ☐ \$10,000 to less than \$20,000  
☐ \$20,000 to less than \$30,000  
☐ \$30,000 to less than \$40,000  
☐ \$40,000 to less than \$50,000  
☐ \$50,000 to less than \$60,000  
☐ \$60,000 to less than \$70,000  
☐ \$70,000 to less than \$80,000  
☐ \$80,000 to less than \$90,000  
☐ \$90,000 to less than \$100,000  
☐ \$100,000 or more

When were you first diagnosed with breast cancer? (month/year) \_\_\_\_\_

Have you had a recurrence of breast cancer?

- ☐ Yes  
☐ No

If yes, when was this? (month/year) \_\_\_\_\_

Have you ever been diagnosed with another type of cancer?

- ☐ Yes  
☐ No
- If YES, please indicate what type of cancer. \_\_\_\_\_

What types of medical treatment have you received for breast cancer? (please check all that apply)

- ☐ mastectomy  
☐ lumpectomy  
☐ radiotherapy  
☐ chemotherapy  
☐ hormone therapy  
☐ other (please specify) \_\_\_\_\_

Have you finished your medical treatments for breast cancer? (please check one response)

- ☐ Yes  
☐ No (if NO, go to the next page)  
☐ No Response

What was the date of your last medical treatment for breast cancer? (month/year) \_\_\_\_\_

**\*\* This is the end of the survey. If you would like to comment on your experiences with alternative and complementary therapies, please do so below.**

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**THANK YOU VERY MUCH** for taking the time and effort to participate in this study. Please note that you may be contacted by phone by the principal investigator, Ms. Lynda Balneaves, to clarify any missing information. If you do not wish to be contacted, you may leave a message at (604) 822-7430 (for local calls) or 1-888-553-9977 (toll free). If you are interested in receiving a summary of the results of this study, please let us know at the above telephone numbers.

## APPENDIX 7

## SURVEY ASSESSMENT FORM

**We would be gratefully if you could take a few minutes after completing the questionnaire to answer the following questions. Your answers will help us improve the survey for future use.**

1. How long did it take you to complete the questionnaire? \_\_\_\_\_
2. Were there any questions on the survey that you had trouble understanding?  
(please check one)  
  
☐ Yes  
  
☐ No

If YES, please return to the questionnaire and place an "X" in the margin by the questions that you had difficulty understanding.

3. Did you have any concerns about participating in this study? If so, please tell us what those were below:

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4. If you have any other comments about this study, please write them below:

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**THANK YOU FOR COMPLETING THIS FORM!**

## APPENDIX 8

## Complete Alternative/Complementary Therapy List (Liberal Definition)

Type of Alternative/Complementary Therapy	Frequency (%)
<b>Alternative Medical Systems</b>	
Aromatherapy	19 (5.7)
Ayurvedic	1 (0.3)
Herbalism	6 (1.8)
Homeopathy	4 (1.2)
Naturopathy	25 (7.5)
First Nations Traditional Healing	3 (0.9)
TCM	14 (4.2)
<b>Vitamins and Mineral Supplements</b>	
B vitamins	93 (27.8)
Beta-carotene	60 (18.0)
Vitamin A	71 (21.3)
Vitamin C	154 (46.1)
Vitamin D	93 (27.8)
Vitamin E	166 (49.4)
Megavitamin therapy	27 (8.1)
Multivitamin	43 (12.9)
Calcium	147 (43.7)
Selenium	80 (24.0)
Zinc	61 (18.3)
Magnesium	3 (0.9)
Other vitamin/mineral supplements (e.g., folic acid, iron, chromium)	6 (1.8)
<b>Herbal/Plant Products</b>	
Aloe	7 (2.1)
Coffee enemas	2 (0.6)
Echinacea	88 (26.3)
Essiac	36 (10.8)
Ginseng	14 (4.2)
Hoxsey herbal treatment	3 (0.9)
Pau d'Arco	6 (1.8)
Grape Seed	9 (2.7)
Evening Primrose	26 (7.8)
Seaweed	10 (3.0)
Flaxseed	8 (2.4)
Garlic	11 (3.3)
Black Cohosh/Remifemin	5 (1.5)
St. John's Wort	3 (0.9)
Ginkgo Biloba	2 (0.6)
Milk Thistle	2 (0.6)
Green Tea	7 (2.1)
Noni	2 (0.6)
Other natural health products (e.g., chamomile, cat's claw, oil of oregano, licorice root)	22 (6.6)
<b>Pharmacological/Biological Supplements</b>	
Co-enzyme Q10	22 (6.7)
Shark cartilage	17 (5.1)
Lecithin	5 (1.5)
Omega-3 oils	5 (1.5)
Glucosamine	4 (1.2)
Other Supplements (e.g., citrus pectin, royal jelly, Provox CV, Repo 7)	12 (3.6)

## Complete Alternative/Complementary Therapy List (Liberal Definition) (cont.)

Alternative/Complementary Therapies	Frequency (%)
<b>Dietary Therapies/Changes</b>	
Cleansing/detoxifying diet	3 (1.5)
Juice therapy	4 (1.2)
Mushrooms	13 (3.9)
Soy products	7 (2.1)
Other dietary changes (elimination diets, Korean boiled vegetable stock, almonds, hi fibre diet)	6 (1.8)
<b>Physical/Movement Therapies</b>	
Cranial-sacral massage	2 (0.6)
Chiropractor	35 (10.5)
Manual lymph drainage	3 (0.9)
Massage therapy	66 (19.8)
Reflexology	10 (3.0)
T'ai Chi	17 (4.8)
Yoga	21 (6.3)
<b>Energy Therapies</b>	
Acupuncture/acupressure	15 (4.5)
Reiki	12 (3.6)
Therapeutic/healing Touch	29 (8.7)
Qi Gong	5 (1.5)
Other energy therapies (e.g., magnet therapy, electrical zapping)	5 (1.5)
<b>Psychological/Expressive Therapies</b>	
Art Therapy	13 (3.9)
Hypnosis	4 (1.2)
Imagery	33 (9.9)
Meditation	34 (10.2)
Music Therapy	21 (6.3)
Relaxation	45 (13.5)
<b>Spiritual Therapies</b>	
Prayer	114 (34.1)
Laying on of Hands	26 (7.8)
Other spiritual therapies (e.g., psychic surgery)	2 (0.6)
<b>Miscellaneous Therapies</b>	
Chelation therapy	3 (0.9)
Chondriana	1 (0.3)
Colonic irrigation	3 (0.9)
Hydrogen peroxide therapy	2 (0.6)
Immuno-augmentative therapy	2 (0.6)

Note. N = 334

## APPENDIX 9

Covariance Matrix of the Preventive Model of Alternative and Complementary Therapy Use (Model 1f)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1 PLRS1	1.09																	
2 PLRS2	0.54	1.16																
3 PLRS4	0.86	0.58	1.15															
4 PEACTS1	-0.12	-0.02	-0.12	0.92														
5 PBACT2	0.09	0.12	0.11	0.02	-0.68													
6 PBACTI	0.16	0.21	0.18	-0.13	-0.39	-0.79												
7 PBACTE	0.13	0.07	0.16	-0.14	-0.38	-0.43	-0.65											
8 CONTRL1	-0.33	-0.27	-0.36	0.29	-0.02	-0.14	-0.11	1.17										
9 CONTRL2	-0.33	-0.26	-0.38	0.38	-0.00	-0.13	-0.12	0.76	1.01									
10 CONTRL3	-0.34	-0.26	-0.38	0.40	-0.03	-0.20	-0.15	0.75	0.88	1.01								
11 NUMACT	0.00	0.01	-0.01	0.06	-0.05	-0.04	-0.03	0.02	0.04	0.03	0.06							
12 FQFTOT	-0.01	0.03	-0.03	0.15	-0.12	-0.09	-0.07	0.06	0.09	0.08	0.14	0.36						
13 COSTTOT	0.01	0.05	-0.02	0.17	-0.15	-0.08	-0.07	0.05	0.10	0.08	0.17	0.40	0.52					
14 AGE	-1.62	-1.48	-1.07	-1.25	1.82	-0.10	0.84	0.31	0.56	0.38	-0.44	-1.31	-1.50	122.63				
15 EDUCATE	-0.12	-0.07	-0.22	0.04	-0.36	-0.02	0.20	-0.30	-0.11	-0.20	0.09	0.21	0.27	-5.23	7.40			
16 PREVIOUS	-0.05	-0.03	-0.06	0.07	-0.06	-0.03	-0.04	0.03	0.03	0.02	0.03	0.06	0.08	-0.40	0.13	0.08		
17 ENCOURCM	0.02	0.04	-0.07	0.26	-0.22	-0.17	-0.17	0.09	0.21	0.19	0.08	0.20	0.24	-3.03	0.46	0.08	0.88	
18 ENCOUR3	-0.06	0.01	-0.10	0.22	-0.13	-0.13	-0.10	0.15	0.22	0.21	0.04	0.10	0.10	-0.65	0.14	0.06	0.43	0.68

Covariance Matrix of the Ameliorative Model of Alternative and Complementary Therapy Use (Model 2e)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1 SDS4	1.30																		
2 SDS5	0.41	1.06																	
3 SDS10	0.51	0.44	0.91																
4 PEACTS2	0.03	0.08	0.05	0.82															
5 PEACTS3	0.03	0.04	0.05	0.70	0.87														
6 PBACT2	0.04	-0.03	0.07	-0.15	-0.20	-0.67													
7 PBACTI	0.15	0.07	0.16	-0.05	-0.10	-0.38	-0.78												
8 PBACTE	0.10	0.09	0.07	-0.06	-0.11	-0.37	-0.43	-0.64											
9 CONTRL4	-0.15	-0.11	-0.12	0.10	0.05	-0.00	-0.11	-0.10	1.11										
10 CONTRL5	-0.19	-0.06	-0.11	0.14	0.09	-0.02	-0.14	-0.12	0.77	1.01									
11 CONTRL6	-0.10	0.00	-0.11	0.12	0.09	-0.09	-0.15	-0.05	0.33	0.43	0.77								
12 NUMACT	0.00	0.02	0.01	0.06	0.08	-0.05	-0.04	-0.04	0.01	0.03	0.02	0.06							
13 FQEFTOT	0.02	0.08	0.05	0.15	0.18	-0.12	-0.10	-0.07	0.02	0.09	0.06	0.14	0.37						
14 COSTTOT	0.01	0.09	-0.04	0.17	0.21	-0.15	-0.08	-0.08	0.01	0.07	0.07	0.16	0.39	0.52					
15 AGE	-0.60	-1.32	-0.92	-2.70	-3.11	1.89	-0.02	0.95	1.00	0.70	-1.05	-0.45	-1.40	-1.55	124.16				
16 EDUCATE	-0.05	0.05	-0.07	0.52	0.41	-0.38	-0.05	0.18	-0.35	-0.27	0.04	0.10	0.24	0.28	-5.26	7.35			
17 PREVIOUS	0.02	0.03	0.02	0.08	0.09	-0.06	-0.03	-0.04	0.02	0.04	0.04	0.03	0.07	0.09	-0.39	0.12	0.08		
18 ENCOURCM	0.05	0.15	0.08	0.35	0.34	-0.22	-0.17	-0.17	0.17	0.19	0.14	0.08	0.21	0.25	-2.93	0.48	0.09	0.90	
19 ENCOUR3	0.11	0.08	0.11	0.22	0.20	-0.14	-0.14	-0.11	0.13	0.18	0.04	0.05	0.12	0.13	-0.66	0.17	0.06	0.46	0.72



Covariance Matrix of the Restorative Model of Alternative and Complementary Therapy Use (Model 3d)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1 PRHS1	1.47																
2 PRHS2	0.86	1.43															
3 PEACTS4	0.21	0.13	0.83														
4 PEACTS5	0.14	0.16	0.75	0.94													
5 PBACT2	0.10	0.10	-0.22	-0.20	-0.68												
6 PBACTI	0.20	0.19	-0.14	-0.12	-0.40	0.80											
7 PBACTE	0.12	0.04	-0.11	-0.10	-0.38	0.45	0.66										
8 CONTRL7	-0.33	-0.26	0.04	0.01	-0.11	-0.13	-0.12	0.92									
9 CONTRL8	-0.18	-0.36	0.03	0.04	-0.13	-0.10	-0.07	-0.41	0.61								
10 NUMACT	0.03	0.00	0.09	0.08	-0.05	-0.04	-0.04	-0.03	-0.03	0.06							
11 FQEFTOT	0.10	0.02	0.22	0.18	-0.12	-0.10	-0.07	-0.07	-0.08	0.14	0.37						
12 COSTTOT	0.09	0.02	0.25	0.22	-0.15	-0.08	-0.07	-0.07	-0.08	0.16	0.39	0.51					
13 AGE	-3.90	-3.03	-2.90	-3.23	1.88	-0.06	0.91	-0.99	-0.15	-0.45	-1.39	-1.55	124.33				
14 EDUCATE	0.05	0.01	0.50	0.60	-0.36	-0.06	0.18	0.15	-0.05	0.08	0.22	0.27	-5.25	7.39			
15 PREVIOUS	0.00	0.01	0.10	0.09	-0.06	-0.03	-0.04	-0.01	-0.02	0.03	0.07	0.09	-00.43	0.13	0.08		
16 ENCOURCM	0.20	0.11	0.41	0.43	-0.23	-0.17	-0.17	-0.05	-0.01	0.08	0.21	0.24	-2.94	0.49	0.09	0.88	
17 ENCOUR3	0.05	0.09	0.25	0.26	-0.16	-0.13	-0.12	-0.11	-0.04	0.05	0.12	0.12	-0.77	0.22	0.06	0.43	0.67