COMPLEMENTARY THERAPIES:
THE DECISION-MAKING PROCESS OF WOMEN WITH BREAST CANCER

by

TRACY TRUANT
BSN, The University of British Columbia, 1988

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING
in
THE FACULTY OF GRADUATE STUDIES
(School of Nursing)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA
April, 1998
©Tracy-Lynn Oline Truant
In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of School of Nursing
The University of British Columbia
Vancouver, Canada

Date April 23, 1998
Abstract

Complementary therapy (CT) use by women with breast cancer is increasing in popularity. However, informed decisions about CT use are difficult for women due to limited and conflicting sources of information in the accessible lay literature, and lack of knowledge by health care professionals. The purpose of this grounded theory study was to describe the process by which women with breast cancer make decisions about CTs, including the integration of CTs into orthodox cancer treatment plans.

Open-ended interviews were conducted with 16 women receiving orthodox cancer treatment, from across the breast cancer trajectory, from a variety of cultural groups, and who used a wide range of CTs. Analysis of the interviews involved identification of three interconnected phases of the CT decision-making process: 1) Getting Something in Place: Covering all the Bases, 2) Hand-picking CTs which Fit: Getting a Personalized Regimen in place, and 3) Living with the Security of CTs: Fine-Tuning a Regimen to Live With. All of these phases occurred within the breast cancer trajectory, with the first phase initiated at the time of diagnosis. Phase two usually did not begin until after surgery and lasted throughout orthodox treatment and beyond. The third phase generally began sometime after the completion of orthodox treatment, lasting perhaps for the remainder of one’s lifetime. However, when a recurrence of breast cancer occurred, or a shift from a curative to palliative intent, women returned to the second phase, modifying their existing CT regimen.

The use of CTs was identified as an important means by which to regain control and maintain hope. Relationships with health care professionals were found to be highly influential, both positively and negatively, in the CT decision-making process.

The process described in this study provides a beginning understanding of how women with breast cancer make decisions about CT use. Interventions to support CT decision-making were outlined which help women to maintain control and foster hope. The findings of this study will help nurses and other health care professionals in assisting women to make informed
decisions about their health, including the safe integration of CTs into their cancer treatment plan.
# TABLE OF CONTENTS

Abstract ii  
Table of Contents iv  
List of Tables vii  
List of Figures viii  
Acknowledgments ix  
Chapter One: INTRODUCTION 1  
  Background of the Study 1  
  Purpose and Research Question 5  
  Theoretical Framework 6  
  Significance of Complementary Therapy Use in British Columbia 7  
Chapter Two: LITERATURE REVIEW 9  
  Non Research Literature 9  
    Perspectives on Complementary Therapy Use 9  
    Differences Between Orthodox Medicine and Complementary Therapies 17  
    Types of Complementary Therapies 21  
  Research Literature 23  
    Prevalence and Patterns of Complementary Therapy Use 23  
    Health and Illness Beliefs Related to Complementary Therapy Use 28  
    Knowledge and Attitudes Related to Complementary Therapies 32  
    Decision Making and Complementary Therapies 33  
    The Physician-Patient Relationship 39  
  Comparison Studies: Effectiveness of Complementary versus Orthodox Therapies 41  
Summary 42
Chapter Three: METHODOLOGY 44
Research Design 44
Sample Selection and Criteria 45
Data Collection 47
Data Analysis 48
Ethical and Human Rights 51
Summary 52

Chapter Four: FINDINGS 53
Context of the Women's Descriptions 53
Regaining Control Through Complementary Therapy Use 55
The Complementary Therapies Decision-Making Process 56
  Phase I 58
    Outcomes of Phase I 62
  Phase II 62
    Searching for Information 63
      Sources of Information 64
      Patterns of Searching 71
      Making Sense 74
    Trying Out Complementary Therapies 80
    Evaluating Complementary Therapies 81
    Modifying the Regimen 82
    Outcomes of Phase II 84
  Phase III 86
    Monitoring for New Information 86
    Modifying the Complementary Therapies Regimen 88
    Maintaining a "Security Blanket" 88
LIST OF TABLES

Table 1: Healing Matrix
12

Table 2: Differences Patients Perceive Between Orthodox and Unconventional Therapists
20
LIST OF FIGURES

Figure 1: Kleinman's (1984) Model of Health Care Systems 10
Figure 2: Regaining Control Through CT Use 56
Figure 3: Overview of CT Decision-Making Process 57
Figure 4: Phase I 59
Figure 5: Phase II: Overview 62
Figure 6: Ways of Maintaining Control During the Search Process 68
Figure 7: Patterns of Information Searching About CTs 71
Figure 8: Phase III 86
Acknowledgments

This thesis would not have been possible without the support of colleagues, friends and family members. Foremost, I would like to express my gratitude to my thesis committee members, Dr. Joan Bottorff, Dr. Joy Johnson, and Ms. Rhea Arcand for their ongoing mentorship, encouragement and enthusiasm for my project over the past three years. I would not have achieved this level of study without their support.

To my family, husband Michael and baby Sophie, my biggest cheerleaders, thank you for your understanding and patience while I spent long hours at the computer. Special thanks to my mom, Lois, for teaching me to believe in myself and to reach for the stars.

I would also like to acknowledge the generous support of the British Columbia Health Research Foundation, the Canadian Red Cross Society, the Canadian Nurses Foundation, and Xi Eta Chapter of Sigma Theta Tau. These organizations made it possible for me to pursue my studies full-time and to undertake this project.

Special thanks to Gary Bowman, Media Technician at the UBC School of Nursing for his assistance in creating the figures which appear in this thesis.

Finally, I thank the women who participated in this study. I am forever grateful for their thoughtful insights and willingness to speak frankly about their cancer and complementary therapy use.
Dedication

In memory of my friend and colleague Linda Nixon, who encouraged me to undertake this thesis and taught me about courage, to be passionate about nursing, and the importance of healing.
CHAPTER ONE

Introduction

This thesis describes a grounded theory research study which aimed to identify and describe the process by which women with breast cancer make decisions about whether to use complementary therapies in addition to orthodox cancer therapies for breast cancer. Chapter one provides the background to the study.

Background of the Study

Technologic advances in the diagnosis and treatment of breast cancer have prolonged patients' lives without guarantee of quality of life (Zaloznik, 1994). While conventional treatments such as chemotherapy, radiation therapy, surgery and hormonal therapy have the potential to cure cancer and/or prolong life, they are frequently associated with toxic and irreversible side effects thereby reducing appeal as the treatment of choice for many patients. Changing societal values compound this issue, where patients, as health care consumers, seek a participatory role in formulating their cancer treatment plans (Grant, 1993; Hack, Degner, & Dyck, 1994). Further, current social trends such as the growing holistic health movement which encourages personal responsibility for one's health, the importance of self care and physical fitness, an increased emphasis on diet as a means to health and wellness, and dissatisfaction with organized orthodox medicine creates a context in which patients with breast cancer question their conventional treatments and/or seek supplementary ways in which to aid their healing (Cassileth, 1989). As patients with breast cancer continue to live longer with their chronic illness, these social trends and the desire for quality of life have translated into an increasing interest in complementary therapies as both adjuvants and alternatives to conventional modes of treatment.

Complementary therapies (CTs) are broadly defined as “treatments or methods...that have not been objectively, reliably, responsibly, and reproducibly demonstrated in the peer-reviewed literature to be more effective than no treatment” (Zaloznik, 1994, p. 20). Several terms such as alternative therapies, unconventional cancer therapies, unorthodox cancer treatments,
nontraditional cancer methods, and unproven cancer therapies appear interchangeably in the literature. For the purposes of this thesis, the term complementary therapies (CTs) will be used.

Vitamins and herbal preparations, biologic products, dietary changes, massage, therapeutic touch, chiropractic treatments, acupuncture, and psychologic and spiritual approaches are cited in the literature as complementary cancer therapies, used either in addition to or in lieu of conventional treatments for cancer (Cassileth, Lusk, Strouse, & Bodenheimer, 1984; Lerner & Kennedy, 1992; Montbriand, 1994). Although the physical benefits of CTs remain controversial, promises of a cure "the natural way" without toxic side effects experienced with conventional cancer treatments attract much attention (Cassileth et al., 1984). In some cases, CT use may benefit the patient by participation in their own care, thereby inducing a positive effect on the emotional state of the patient (Speigel, 1992). Lerner (1994) identifies enhanced quality of life as an invaluable outcome of CT use by many patients with cancer. On the other hand, the effect of CT usage may be benign or even harmful if, for example, it interferes with utilization of conventional treatments (Danielson, Stewart, & Lippert, 1988; Hopkins & Brigden, 1991).

A number of recent surveys carried out in the United States (US), Great Britain, Canada and Australia have reported that anywhere from 9% to 50% of cancer patients recount using a CT (Berger, 1990; Cassileth et al., 1984; Cook & Baisden, 1986; Downer et al., 1994; Eisenberg et al., 1993; Kronenfeld & Wasner, 1982; Lerner & Kennedy, 1992; Millar, 1997; Mooney, 1987; Yates et al., 1993). Further, Eisenberg et al. (1993) concluded that in the US, more visits were made to practitioners of CTs than medical doctors in 1990. The mass media reflects this trend, with an increasing number of TV documentaries and articles in popular magazines showcasing CTs as a possible treatment for a number of illnesses including cancer. Nevertheless, informed decisions about CT use are difficult for patients due to limited and conflicting sources of information in the accessible lay literature (Montbriand, 1993b). Lack of knowledge by health professionals regarding CTs is also an issue, reducing the cancer patient's
options for sources of information on which to make informed decisions regarding CT use (Zaloznik, 1994). Montbriand (1993b) emphasizes the importance of nursing’s role in assisting patients to make informed decisions about their health, including the safe integration of CTs into their cancer treatment.

In response to increasing public attention to CTs, a number of organizations have identified the study and research of CTs as a priority. In the United States, the Office of Alternative Medicine (OAM), under the auspices of the National Institutes of Health (NIH), was established in 1992 to facilitate the evaluation of alternative medical treatment modalities. In 1996, 7.4 million dollars were budgeted by the NIH to evaluate the effectiveness of various alternative therapies on illnesses including cancer (Office of Alternative Medicine, 1996). In Canada, the Canadian Breast Cancer Research Initiative, in response to the 1993 National Forum on Breast Cancer, has identified the 10 most common CTs used by women with breast cancer, and has designated research dollars to investigate the effectiveness of these CTs following rigorous scientific principles. In British Columbia (BC), the BC Cancer Agency has participated in a Canada wide pilot study, funded by the National Cancer Institute of Canada, to survey patterns of CT use among Canadians with cancer. The establishment of the Tzu Chi Institute for Alternative and Complementary Medicine at Vancouver Hospital, whose mandate is to scientifically evaluate the effectiveness of CTs, is yet another example of the increasing interest by the traditional health care system to investigate the efficacy of various CTs.

Despite this increasing interest in documenting patterns of use and efficacy of CTs in cancer patients, there is little published research world wide to address why or, more specifically how patients with cancer make decisions to use CTs (Clavarino & Yates, 1995; Yates et al., 1993). Many authors hypothesize that factors such as dissatisfaction with the traditional health care system or fear of side effects of cancer treatments pushes patients into making decisions to use CTs (Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Smith, 1988). While these variables may explain why some patients use CTs, it does not explain the role of these factors in the decision-making process to use CTs. Furthermore, it is unlikely that these are the
only factors that influence this decision-making process. An in-depth understanding of the decision-making process, including the influencing factors and how they affect the process by which patients with breast cancer make decisions whether to use CTs will ultimately facilitate nurses’ effectiveness in assisting patients to incorporate complementary approaches into their cancer treatment.

Why Study Women with Breast Cancer?

The probability of a Canadian woman developing breast cancer in her lifetime is now one in nine. Since 1963, this lifetime risk of developing breast cancer has increased dramatically, from one in every 18 women. Although lung cancer incidence rates in women are rising (one in 21), breast cancer remains the leading cancer diagnosis, accounting for 30% of all new cancers for women in 1996 (National Cancer Institute of Canada, 1996). In 1996, approximately 18,600 women developed breast cancer in Canada (Statistics Canada, cited in National Cancer Institute of Canada, 1996).

Although incidence rates for breast cancer are on the rise in Canada, the mortality rate has remained stable. In 1996, approximately 5,300 women died of breast cancer (National Cancer Institute of Canada, 1996). The increased incidence rate, coupled with a stable mortality rate has resulted in large numbers of women living with breast cancer. In North America, Caldwell (1995) estimates that approximately two million women are currently living with a diagnosis of breast cancer. Based on these statistics, some authors consider breast cancer an epidemic (Love, 1995).

Women with breast cancer were chosen as a subgroup of the cancer population for study due to the high prevalence of this disease among women and the uncertainties surrounding the causes of and treatment for the disease. Goodman and Chapman (1993) state that the unknown etiology and the complex array of treatment options for breast cancer that provide no guarantees of cure cause much uncertainty among women diagnosed with breast cancer. Without knowledge about what caused their breast cancer, women may have difficulty knowing which treatment options they should choose and which behaviors to modify to fight
their cancer. This uncertainty, among other factors may contribute to women with breast cancer turning to CTs and CT practitioners for assistance (Morra & Potts, 1987).

**Purpose and Research Question**

Given the lack of research data regarding why women with breast cancer use CTs, and how they make this decision to use CTs, the main purpose of this study was to identify and provide an in-depth description of the decision-making process to use complementary therapies in addition to orthodox cancer therapies by women with breast cancer. An in-depth understanding of what these motivating factors are, and how they affect the process by which patients with breast cancer make decisions to use CTs will ultimately facilitate nurses’ effectiveness in assisting patients to incorporate complementary approaches into their cancer treatment. The question which guided this research was:

What is the decision-making process used by women with breast cancer to determine whether to use CTs in addition to orthodox treatments for breast cancer?

**Definition of Terms**

1. **Breast cancer** - The abnormal and uncontrolled growth of cells in breast tissue that may invade and destroy the surrounding tissues and/or spread to distant sites (Olivotto, Gelmon, & Kuusk, 1995).

2. **Complementary therapies** - Treatments or methods that have not been objectively, reliably, responsibly, and reproducibly demonstrated in the peer-reviewed literature to be more effective than no treatment (Zaloznik, 1994), which are used in addition to orthodox breast cancer treatments for the purpose of enhancing quality of life and/or achieving a cure for cancer. Complementary therapies may be administered by a range of practitioners, including physicians and non physicians.

3. **Orthodox breast cancer treatments** - Radiation therapy, chemotherapy, hormonal therapy, and surgery used for the purpose of enhancing quality of life and/or achieving a cure for cancer.
Theoretical Framework

Symbolic interactionism, a theory about human behavior, provided the framework which supported the use of grounded theory methodology for this study (Chenitz, 1986a). Symbolic interaction theory, originally developed by Mead (1934) and expanded by Blumer (1969), explains how people define reality, and how their actions are related to their beliefs. Further, the theory explains how it is through interaction with others that one’s reality is expressed and communicated (Chenitz & Swanson, 1986). Therefore, in order for the researcher to understand human behavior, such as that of the decision-making process to determine whether to use CTs by women with breast cancer, an interactive process must be used by the researcher to accurately perceive and present these women’s world (Chenitz, 1986b; Hutchison, 1986).

The following three basic premises of symbolic interaction, according to Blumer (1969), provided a context for this research study examining the decision-making processes to use CTs by women with breast cancer:

1. Human beings act toward things on the basis of the meanings that the things have for them.
2. Meaning of such things is derived from, or arises out of the social interaction that one has with one’s fellows [sic].
3. These meanings are handled in and modified through, an interpretive process used by the person dealing with the things he [sic] encounters (Blumer, 1969, p. 2)

According to the symbolic interactionist theory then, a woman’s decision to use CTs is related to her beliefs, and these beliefs are formed and expressed through an interactive process with her self and others. As such, symbolic interactionism provided the theoretical starting point for this study. Additional theories and/or conceptual frameworks were then identified during data analysis and incorporated into the unfolding grounded theory.

Assumptions

Two assumptions were inherent in the question posed in this study. The first was that women with breast cancer use CTs in addition to orthodox medical treatments. Secondly, it was assumed that these women used a decision-making process to determine whether or not to use CTs in addition to orthodox medical treatments for cancer.
Significance of Understanding Complementary Therapy Use in British Columbia

Exploration of the phenomenon of CT use among patients with cancer in British Columbia (BC) is important. In 1997, the BC Cancer Agency registered approximately 15,000 new cancer patients in British Columbia (BC Cancer Agency, BC Cancer Research Center, & BC Cancer Foundation, 1997). Based on the literature, it is estimated that up to 50% of these 15,000 newly diagnosed patients will use CTs as adjuvants or alternatives to conventional modes of care (Cassileth et al., 1984; Cook & Baisden, 1986; Downer et al., 1994; Eisenberg et al., 1993; Kronenfeld & Wasner, 1982; Lerner & Kennedy, 1992; Mooney, 1987; Yates et al., 1993). Many CT practices, while potentially offering some benefit to patients, have not been scientifically proven to fulfill their promises of cure, are very costly to the individual, and could interfere with the utilization of conventional modes of treatment. Scarcity of information in the lay literature and among conventional health care professionals regarding CT use compounds cancer patients’ ability to make informed decisions about CT use.

It is estimated that CT use is higher in BC than the other provinces. This may be due to the rapid rate of new immigration to BC, resulting in an ethnically diverse province (LaValley & Verhoef, 1995). Along with their own culture and customs, these new immigrants bring certain practices and beliefs about health and illness, such as those based on traditional eastern philosophies of healing. This rapid infusion of eastern approaches into a society of traditional western medicine creates an interesting and unique dichotomy, where a treatment which is unorthodox or alternative in one culture may be fully accepted as conventional therapy in another.

The Closer to Home report (British Columbia Royal Commission on Health Care and Costs, 1991) documents initiatives which identify the importance of respecting individual differences regarding health practices, stating that “within their communities, patients must be accommodated as individuals and given the best care possible” (p. B-21). This statement acknowledges that people and communities are different across BC, where the seasoned native trapper from the Nemiah Valley may have different health beliefs and alternative health
practices than the Greater Vancouver senior. Understanding CT use among British Columbians may aid health care professionals in understanding, respecting, and supporting women in their decision-making process to use CTs in addition to conventional cancer care.

Given the large numbers of ethnically diverse British Columbians who are potentially using CTs as adjuvants or alternatives to their conventional cancer treatments, and the potential for harm when making uninformed decisions about CT use, it is essential that health care professionals begin to play a key role in helping patients to safely integrate CTs into conventional modes of care. The theory generated from this research study will increase understanding of how women with breast cancer make decisions to use CTs in conjunction with traditional treatment for breast cancer. Further, findings from this study will complement findings from other quantitative CT research, such as the National Cancer Institute’s complementary therapies survey currently being implemented across Canada. As the phenomenon of CT use increases, nurses and other health professionals may begin to play a key role in helping women to safely and effectively integrate CTs with conventional approaches to breast cancer care.
CHAPTER TWO: LITERATURE REVIEW

The literature reviewed in this chapter provided a framework for this research study by evaluating the current knowledge base and providing additional background for the study. In keeping with the procedures of grounded theory methodology, this initial review of the literature aimed to identify gaps in the current knowledge about the phenomenon of CT use, thereby providing a rationale for launching this grounded theory study (Chenitz & Swanson, 1986). The following literature review is divided into two major sections: non-research and research literature.

Non Research Literature

Published non research articles were categorized into three types: a) perspectives regarding the phenomenon of CT use by patients with cancer, b) differences between orthodox medicine and CTs, and c) types of CTs used by individuals with cancer and other chronic illnesses. These articles were included to provide a context in which CTs are currently practiced within the traditional health care system. Further, as very little research has been done to address why and how individuals make decisions to use CTs, this review of non-research literature helped to inform and give direction to this study.

Perspectives on the Phenomenon of CT Use

Two types of perspectives are included in this section: theoretical and opinion-based perspectives. Theoretical perspectives provided conceptual explanations for a) the relationship of CT use to Western biomedicine, and b) how individuals interpret illness symptoms and take action to alleviate these symptoms. Opinion-based perspectives, although considered highly subjective, were included to highlight the current controversies and arguments related to CT use which have resulted, due to the lack of scientific evidence to verify the efficacy of various CTs.
**Theoretical Perspectives**

While it is widely assumed that individuals who experience illness symptoms almost always seek out the care of an orthodox physician (e.g., general practitioner), experts investigating illness behavior have shown this assumption to be largely invalid (Kleinman, Eisenberg, & Good, 1978). For example, it is estimated that between 70% to 90% of illness episodes are managed outside of the traditional health care system (Kelner & Wellman, 1997; Wadsworth, Butterfield, & Blaney, 1971; Zola, 1972). In an attempt to explain the social context of health care where individuals use systems other than traditional health care, Kleinman (1984) developed a model of health care systems, which is comprised of three overlapping sectors: professional, popular, and folk (Figure 1).

**Figure 1: Kleinman’s (1984) Model of Health Care Systems**

Kleinman describes the *professional* sector as being comprised of organized and legally sanctioned healing professionals, such as physicians, nurses, pharmacists, midwives, dentists and ancillary workers. The *popular* sector consists of lay non professional, non specialist advice from individuals such as family members (Kleinman, 1984). This advice generally provides a set of guidelines that are specific to each cultural group about the correct behavior.
for managing and/or preventing illness. An example of a treatment within the popular sector includes taking chicken soup for a cold.

The folk sector, which is especially large in non Western societies, consists of individuals who specialize in forms of healing that are either sacred or secular, or a mixture of the two (Kleinman, 1984). These complementary healers are not considered a part of the official orthodox medical system, but occupy an intermediate position between the popular and professional sectors (Furnham & Bhagrath, 1993). Healing activities within the folk sector may include, for example, herbalism, reflexology, naturopathy, homeopathy, Traditional Chinese healing, and Ayurvedic healing. It is within this sector that most CTs are evident.

Kleinman envisions that, due to the overlapping nature of these three health care sectors, individuals may be using any or all of the sectors to manage a particular illness. Although there are other explanatory models of health care systems (for example Bean, 1976; Foster & Anderson, 1978), Kleinman’s model is exceptional in that it clearly includes the biomedical system overlapping with the folk and popular health care systems. As such, Kleinman’s model of health care systems supports the development of a research study, where it is likely that many women with breast cancer who receive conventional treatment for their cancer (from practitioners within the professional sector) also access healers from the popular and/or the folk sectors. However, the model does not explain how individuals choose to use one or more of these overlapping health care sectors, or make decisions about the various treatments and therapies included within each sector.

Engebretson and Wardell (1993) have also proposed a model of health care systems which includes complementary approaches. However, rather than attempting to explain the interrelatedness of various health care systems as in Kleinman’s model, Engebretson and Wardell’s (1993) Healing Matrix (Table 1) classifies modalities of healing according to the degree of acceptedness by biomedicine. This framework conceptualizes health care systems on a continuum, with orthodox medicine based on Western scientific principles at one end, and alternative practices, which largely have not been evaluated according to Western scientific
principles, at the other end. Marginal healing practices, which are situated approximately in the middle of the continuum, are those practices which have a formal curriculum of study and forms of licensure or credentialling. The degree to which these marginal healing practices are considered a part of orthodox medicine largely depends on the country in which it is practiced. For example, homeopathy has a long history of acceptance by the orthodox medical system in Britain, where a number of homeopathic hospitals exist as well as orthodox hospitals have integrated homeopathy into their treatment options for patients (British Medical Association, 1992; Buckle, 1994).

Table 1

Healing Matrix

<table>
<thead>
<tr>
<th>Orthodoxy</th>
<th>Marginal</th>
<th>Alternative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Manipulation</td>
<td>Surgery</td>
<td>Chiropractic</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>Massage Therapy</td>
<td></td>
</tr>
<tr>
<td>Ingested or Applied Substances</td>
<td>Pharmacology</td>
<td>Homeopathy</td>
</tr>
<tr>
<td></td>
<td>Vitamin therapy</td>
<td></td>
</tr>
<tr>
<td>Uses of Energy</td>
<td>Laser Surgery</td>
<td>Acupressure</td>
</tr>
<tr>
<td></td>
<td>Acupuncture</td>
<td>Therapeutic Touch, Reiki</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental / Spiritual</td>
<td>Psychiatry</td>
<td>Spiritual Counseling, Established Support Groups (12 step)</td>
</tr>
<tr>
<td>Psychology</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Although Engebretson and Wardell’s (1993) Healing Matrix and Kleinman’s (1984) model of health care systems provide perspectives to conceptualize CT use in relation to biomedicine, they do not explain how individuals make decisions to use CTs in addition to, or instead of, orthodox medical treatments.

Clavarino and Yates (1995) identify the work by Becker (1974) and Fabrega (1974) as important in beginning to understand the decision-making aspect of CT use. Both Becker and Fabrega have developed models of illness behavior which attempt to explain how individuals’ beliefs and culture may influence decisions to use CTs. Becker purports that an individual’s beliefs about his or her own susceptibility to illness, severity of illness, and likelihood of benefit from or obstacles to seeking treatment will determine that individual’s help seeking behavior. Fabrega, building upon Becker’s work, developed his model of illness behavior from an anthropologic perspective. Rather than focusing on medical care utilization, Fabrega developed a framework which attempts to explain a wider variety of responses to symptoms which are expressed. Fabrega argues that individuals continually monitor their symptoms, interpreting the meaning of those symptoms based on his or her own past experience and cultural background. Dependent on the perceived severity and meaning of the symptom, the individual will choose to consult a range of “healers” from family members to practitioners within orthodox medicine. Upon initial treatment, the individual will assess the efficacy of that treatment, thereby making decisions to continue or seek other treatments. A key point in Fabrega’s model, outlined by Clavarino and Yates (1995), is that individuals frequently revise their treatment plans according to whether they perceive their treatment to be effective, and as to their optimism regarding the likely benefits of the remaining treatments.

Clavarino and Yates (1995) identify the theories of Becker and Fabrega as important as they emphasize the following three themes: a) attention is directed to the individual’s social and cultural background, b) individuals routinely consider a variety of treatment options, where orthodox medicine may be rarely utilized, and c) many individuals may use a rational process
in choosing a particular treatment option. These themes were important to the proposed study in that they supported the use of grounded theory methodology. For example, these themes suggested that choosing a CT involves a decision-making process which is influenced by one’s social and cultural background. As grounded theory aims to uncover social processes, the fit between this methodology and the themes identified by Becker and Fabrega was appropriate (Hutchison, 1986). Further, as Becker and Fabrega’s theories suggest that the process of making decisions about one’s treatment occurs over time, using a qualitative methodology such as grounded theory helped to capture this dynamic process.

Opinion-Based Perspectives

A long history of adversity and controversy in the area of CTs exists, largely due to the lack of research studies attempting to evaluate CTs and the resultant lack of documented scientific efficacy of these treatments and therapies (Boik, 1996; Cassileth, 1989; Cassileth & Chapman, 1996; Office of Alternative Medicine, 1996). Further, very few research studies have identified the factors that motivate patients to use CTs in addition to traditional treatments. As such, without objective, research-based findings, health professionals must rely on anecdotal evidence from their own practice and published discussion papers to form opinions about various aspects of the phenomenon of CT use. The following section reviews the published perspectives of prominent advocates and critics of CT use regarding two common themes: the general efficacy of CTs, including risks and benefits, and factors influencing patients to use CTs.

Efficacy of Complementary Therapies. Expert opinion about the efficacy of CT use varies from those who consider it to be useless to those who believe in the curative powers of various CTs (Cassileth, 1994). Danielson et al. (1988), staunch critics of CT use, propose four major characteristics common to “the problem” of CTs: promise, pseudoscience, profit, and philosophy. The authors state that “Promotors of unproven treatments exploit fear and promise painless treatment with good results...[because] many patients choose unproven treatments simply on the basis of false promises of an unscrupulous practitioner” (p. 1007). The lack of scientific evidence of the efficacy of various CTs is attributed to “...endeavour(s) to avoid
scientifically valid studies that will subject their methods to rigorous scrutiny” (p. 1008). Danielson and colleagues go on to state that profit is the major motivator of proponents of CTs, and that such practitioners promote antiestablishment propaganda to promote distrust of orthodox medicine. Without identifying any benefits of CT use, the authors identify risks such as delaying or stopping orthodox medical treatment in favor of CT use, direct toxic effects of ingested CTs, emotional injury when psychospiritual methods “fail,” false hope, and “exorbitant” cost. Clearly, Danielson and her colleagues paint a one-sided, extremely negative picture of the phenomenon of CT use. Although much of the discussion paper is opinion based, it is the opinion of well respected psychiatrists and oncologists in Toronto. Unfortunately, the paper by Danielson et al. is just one example of many similar papers expounding the dangers of “quackery” (see Brigden, 1998; Brown, 1987; Goldman, 1987; Herbert & Henke-Yarbro, 1986; Hopkins & Brigden, 1991; Jarvis, 1986; Lerner, 1984). Rather than adding clarity, these one-sided perspectives add to the confusion about the phenomenon of CT use.

At the other end of the spectrum, some supporters of CT use believe CTs should be used in lieu of traditional treatment (Cassileth & Chapman, 1996). These practitioners often make promises of cure based on anecdotal rather than scientific evidence, and may or may not benefit monetarily as a result of making the treatment available to patients. Fortunately, the number of practitioners fitting into this category is relatively small (Cassileth & Chapman, 1996).

Somewhere in the middle of the continuum, between those who label CT use as quackery and those who hail CTs as miracle cures, lie those proponents of CTs who envision CT use as a way to promote health and manage symptoms while receiving traditional forms of treatment. These practitioners identify benefits of CT use such as enhanced well being, a sense of control over one’s illness, increased ability to cope with stress, improved physiological outcomes (including enhanced immunity in some cases) and improved quality of life (Cassileth & Brown, 1988; Cassileth & Chapman, 1996; Cronsberry, 1996; Stephens, 1993). Rather than touting CTs as cures for cancer and other illnesses, these practitioners perceive CT use as a
supportive measure and a way to address patients' unique cultures and belief systems related to health and illness.

Factors Influencing Complementary Therapy Use. Cassileth (1989, 1996), a prominent researcher and expert in the area of CT use by individuals with cancer, posits that CTs are not selected in a vacuum. Rather, she states that "...their degree of popularity and the particular types used are functions of their social and cultural context" (Cassileth, 1989, p. 1247). She goes on to suggest that today's popular CTs such as metabolic therapies emphasizing diet, self-care, vitamins, and internal cleansing, along with "immune-enhancing" regimens are reflected in underlying social trends including: a) various rights movements, such as patient's rights, b) consumer movements in medicine, where the patient's role has shifted from dependent and passive to an active partnership in his or her care, c) the holistic health movement, d) self-care and fitness emphases, and e) dissatisfaction with and mistrust of organized medicine (Cassileth, 1989). The relationship between social trends and the use of various CTs is reciprocal and cyclic according to Cassileth, where social trends encourage particular forms of CTs, and, in turn, prevailing social beliefs are reinforced.

Other factors influencing the decision to use CTs have been speculated by a number of health professionals. These factors include: a) the desire for an active role in one's treatment and control over one's life, b) the appeal of "natural" remedies as opposed to chemotherapy, surgery, and radiation (referred to by many CT advocates as poison, slash, and burn), c) pressure from family or friends, d) desire for a supportive relationship with a health practitioner, e) mistrust of the orthodox medical system and treatments, f) better "fit" with patient's beliefs about health and illness, such as those which are culture specific, and g) hope for a cure when all other orthodox treatments have failed (Cassileth, 1986; Dossey, 1991; Holland, 1982; Hopkins & Brigden, 1991; Lerner, 1984; Zaloznik, 1994). These factors, in combination with those trends cited by Cassileth (1989) begin to paint a picture of why individuals choose CTs in addition to, or instead of, orthodox medical treatments. While these factors are based on expert opinion, they have not been generated via scientific methods and
therefore must be interpreted with caution. Further, these may not be the only factors influencing the decision to use CTs. Research to confirm and expand on these factors is necessary to solidify the body of knowledge related to the phenomenon of CT use.

Differences Between Orthodox Medicine and Complementary Therapies

To begin to understand the current climate of confusion and skepticism surrounding the use of CTs by individuals within our Western orthodox health care system, it is important to identify how orthodox medicine and CTs differ. Clavarino and Yates (1995) identify at least three different areas in which CTs and orthodox medicine are divergent: a) philosophical and theoretical underpinnings, b) scope of practice, and c) documented scientific evidence of the efficacy of the different techniques.

The theories and philosophies of health and illness underlying orthodox medicine and CTs are dramatically different. The medical model of illness takes a mechanistic view of the world, where all phenomena can be explained through a reductionist analysis based on a Cartesian mind-body dualism (Clavarino & Yates, 1995). Central to the medical model, then, is the notion that illness is caused by an aberrant biological process, that occurs independently of the mind (Berliner, 1984). Comparing a patient to a clock whose broken parts are fixed or replaced is a common analogy of modern orthodox medicine (Seaward, 1994). Complementary therapies, on the other hand, are generally based on a paradigm of whole systems, suggesting that humans are more than their physical bodies with fixable and reusable parts. Holism involves understanding the interrelationships among the body, mind and spirit, recognizing that the whole is greater than the sum of its parts (Dossey, 1991; Dossey & Guzzetta, 1995). The body, mind and spirit are seen as interacting in a way that can either enhance or suppress one’s health and level of well-being. All CTs, however, do not share the same epistemological base, maintaining knowledge bases that vary along a continuum from those promoting a holistic approach to those whose focus is more specific (Clavarino & Yates, 1995).

The scope of practice of orthodox medicine versus CTs is the second division identified by Clavarino and Yates (1995). Generally, the range of conditions for which CTs claim to be
effective are broad, and the techniques or modalities which are utilized by CT practitioners are numerous. Traditional Chinese healing, for example, utilizes multiple healing practices such as herbs, acupuncture, massage, qi-gong, and T’ai Chi in order to rebalance one’s vital energy (also known as chi) (Ontario Breast Cancer Information Exchange Project, 1995). The cause of the unbalanced chi is less important to the Traditional Chinese healer, but may include illnesses such as cancer and arthritis. In contrast, orthodox medicine is highly specialized, with most practitioners using a very specific technique to treat a very specific illness or condition. For example, radiation oncologists specifically use radiotherapy to treat patients with cancer. As such, patients utilizing the orthodox medical system must see many different specialized practitioners to ensure complete emotional, physical, and spiritual care.

The third division between orthodox medicine and CTs relates to documented scientific evidence of the efficacy of the different techniques (Clavarino & Yates, 1995). The lack of scientific evidence of the efficacy of CTs is well documented and the primary source of many of the controversies surrounding CT use (Cassileth, 1994; Eisenberg, 1993). While the lack of documented scientific evidence of the efficacy of CTs is largely related to the relatively small number of research studies on CTs being implemented, supporters of CTs argue that evaluation of many CTs according to western scientific principles poses paradigmatic as well as procedural difficulties (Collinge, 1996; Patel, 1987). As many CTs have epistemological bases different from those of western orthodox medicine, supporters of CTs maintain that other criteria for determining the efficacy of treatments should be considered (Eisenberg, 1993; Patel, 1987). For example, the concept of chi (vital energy), the cornerstone of Traditional Chinese healing, is difficult to articulate and objectively measure according to western standards. Practitioners who use chi to heal must first spend many years with a master learning to feel their own chi, which is a highly subjective experience, and then how to use their own chi to heal others (Eisenberg, 1993). Currently there are no objective measures to quantify chi, nor is it likely there will be due to the very nature of chi.
Robert Buckman, a Canadian medical oncologist, also attempts to delineate differences between orthodox medicine and CTs (Buckman & Sabbagh, 1993). From Buckman’s perspective, these differences are rooted in how the practitioners of orthodox medicine and CTs interact and care for the patient. For example, development of the therapeutic relationship, which is a key element in CTs, is often not a priority in orthodox medicine, either due to time constraints or a lack of value by the physician (Buckman & Sabbagh, 1993). An overview of the differences cited by Buckman, from the patient’s perspective, as summarized by Brigden (1998), are presented in Table 2. Brigden suggests that it is due to these differences that some individuals may seek out CTs in addition to, or in lieu of, orthodox therapies.
Table 2

Differences Patients Perceive Between Conventional and Unorthodox Therapists\(^1\) (Buckman & Sabbagh, 1993, cited in Brigden, 1998)

<table>
<thead>
<tr>
<th>Perceived Quality</th>
<th>Orthodox Practitioner</th>
<th>CT Practitioner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>May be rushed; average 6-10 minutes per patient</td>
<td>Unrushed; average 90 mins for first consultation, 20 per follow up</td>
</tr>
<tr>
<td>Setting</td>
<td>May be depersonalized &amp; institutionalized</td>
<td>Considerable effort made for patient's comfort &amp; personalization</td>
</tr>
<tr>
<td>Continuity</td>
<td>Patient may see different person on follow-up visits</td>
<td>Patient usually sees same person</td>
</tr>
<tr>
<td>Symptom Handling</td>
<td>Trained to interpret patient’s symptoms in light of knowledge of underlying disease. May “disbelieve” patient’s perceptions</td>
<td>Accepts patient’s symptoms at face value</td>
</tr>
<tr>
<td>Emotional Handling</td>
<td>Empathetic abilities may be lacking</td>
<td>Empathetic abilities central to therapist’s skill</td>
</tr>
<tr>
<td>Dealing with patient’s uniqueness</td>
<td>May try to compensate for or minimize personal idiosyncrasies of the patient</td>
<td>Practitioner regards patient’s personal features as central to the illness and its treatment</td>
</tr>
<tr>
<td>Dealing with social context</td>
<td>Variable. Importance of social context may be ignored or underestimated</td>
<td>Social context regarded as central to understanding the illness</td>
</tr>
<tr>
<td>Ability to provide hope</td>
<td>Variable; may not be a major component of the therapeutic relationship</td>
<td>Usually a major part of the therapeutic relationship</td>
</tr>
</tbody>
</table>

Types of Complementary Therapies

Numerous classification systems exist which attempt to categorize the large number of CTs available today. To bring structure to this rapidly changing universe of CTs, the Office of Alternative Medicine (OAM) at the National Institute of Health in the United States has identified seven categories of CTs: a) diet and nutrition, b) mind-body techniques, c) bioelectromagnetics, d) alternative systems of medical practice (or traditional and folk remedies), e) biologic and pharmacologic treatments, f) manual healing methods, and g) herbal medicine (Workshop on Alternative Medicine, 1992). The following discussion highlights some common CTs used by individuals with cancer, categorized according to the OAM classification system.

Dietary changes and nutritional supplements are among the most common CTs used by patients with cancer (Lerner & Kennedy, 1992). Treatments commonly utilized by individuals with cancer within this category of CTs include megavitamins, and two very popular anticancer diets: the macrobiotic diet, promoted by Michio Kushi (e.g., Kushi, 1982), and metabolic diets, involving a protocol of hair and blood analysis, anticancer diet of raw food with decreased protein and additives, detoxification with coffee enemas, oral and injected enzymes, and vitamin and mineral supplements (Montbriand, 1994).

Mind-body techniques, supported by a holistic healing framework, include treatments such as relaxation techniques, guided imagery, hypnotherapy, support groups, yoga, and meditation. Treatments within this category of CTs generally aim to create balance between the mind, body, and spirit, thereby enhancing wellness. Recently, research by Speigel (1992) has identified enhanced quality and quantity of life in women who attended breast cancer support groups.

Bioelectromagnetics includes using low-frequency electromagnetic sources to treat tumors. These treatments include, for example, electroacupuncture, magnet therapy, blue light treatment, and artificial lighting (Cassileth & Chapman, 1996).
Alternative systems of medical practice are treatments which have epistemological bases which differ from those accepted by modern Western science. These treatments, generally aiming to help individuals achieve "inner balance", include, for example, acupuncture, Ayurveda, homeopathy, naturopathy, Traditional Chinese medicine, shamanism, and Native Indian healing practices (Workshop on Alternative Medicine, 1992). Cassileth and Chapman (1996) identify Ayurveda and Traditional Chinese medicine as the most popular healing systems in this category.

Biologic and pharmacologic treatments include some of the most controversial CTs such as antineoplastic agents, immunoaugmentive therapy, ozone therapy, shark cartilage, and metabolic therapies. Two of the most well known biologic products aimed at cancer patients are the Gerson Diet and Treatment, and the Hoxsey Method. These treatments are illegal in the US and Canada but can be obtained in clinics in Mexico (American Cancer Society, 1990; Cassileth & Chapman, 1996).

Manual healing involves those therapies which utilize a variety of touch and manipulation strategies. Acupressure, aromatherapy, chiropractic medicine, massage, osteopathy, reflexology, rolfing, and therapeutic touch are examples of common manual healing techniques utilized by individuals with cancer.

Herbal medicines can be used alone or in addition to other healing practices such as Traditional Chinese medicine, homeopathy, and naturopathy. Common herbs used by individuals with cancer include essiac, iscador, echinacea, green tea, and ginseng (Ontario Breast Cancer Information Exchange Project, 1994).

The Canadian Breast Cancer Research Initiative (CBCRI) has identified the 10 most popular CTs used among women with breast cancer, including essiac, green tea, hydralazine sulphate, iscador, laetrile, ozone therapy, selenium, shark cartilage, vitamin C, and 714-X (National Cancer Institute of Canada, 1994). Recently, initiatives to investigate these CTs have been undertaken by researchers within the CBCRI, including a Canada wide workshop held in October, 1996 to determine appropriate research methodologies to investigate these CTs.
Research Literature

Much of the CT research literature in the past 20 years has come from medicine, focusing on two features of CTs, including the lack of scientific proof of the clinical efficacy of CTs, and the reported adverse effects of many CTs (Danielson et al., 1988; Hopkins & Brigden, 1991; Yates, 1991). While this research plays an important role for health professionals to inform patients regarding the potential risks of using selected CTs, it does not identify the potential benefits of using selected CTs, and does not help to explain the phenomenon of CT use among patients with cancer, including how individuals make decisions to use CTs. In recent years, however, a growing number of studies from nursing, social work and anthropology have been conducted in an attempt to explain the phenomenon of CT use. Collaboratively, these studies have begun to paint a picture of the phenomenon of CT use by individuals with various illnesses, including cancer.

The following research literature review has been divided into six major categories, including: a) prevalence and patterns of CT use, b) patients’ health and illness beliefs and behaviors related to CT use, c) patient knowledge and attitudes related to CT use, d) decision making and complementary therapies, e) the physician-patient relationship, and f) comparison studies evaluating complementary versus orthodox approaches to cancer treatment.

Prevalence and Patterns of Complementary Therapy Use

A number of studies have measured the extent and patterns of use of CTs, both in the general population, and specifically by cancer patients. These studies have reported that anywhere from 9% (Lerner & Kennedy, 1992) to over 50% (Cassileth et al., 1984) of people with cancer use CTs. The diversity of findings reflect differing conceptualizations and measurements of CTs, and differing populations from which the samples were drawn (Aaronson & Holland, 1990). The following review of the literature related to patterns and prevalence of CT use is divided into four groups: a) studies documenting the increase in CT use over the past decade, b) studies utilizing random samples and survey methodology, c) studies utilizing convenience samples, and d) Canadian survey data.
Documentation of the increase in CT use over the past decade was identified in only one study. Northcott and Bachynsky (1993) surveyed two independent random samples of residents of Edmonton, Alberta, one sample in 1979 (n=439), and another in 1988 (n= 464) regarding the use of chiropractic medicine, prescription medication, non prescription medication, and use of CTs. Findings of these studies indicate that between 1979 and 1988, there was a 31.1% increase in the use of chiropractic services, and a 46.8% increase in the use of CTs. The use of prescription and non prescription medication increased only 1.7% and 11.6% respectively for the same time period. While this survey did not specifically target patients with cancer, it demonstrates the significant increase in utilization of CTs, including chiropractic services since 1979. It is interesting to note that chiropractic medicine is no longer considered a CT, where it is regulated and by a professional body and services are reimbursed by the Medical Services Plan in British Columbia.

Two studies utilizing random samples and survey methods to identify the prevalence and patterns of CT use by cancer patients have been implemented in the United States (US) by Lerner and Kennedy (1992), and in Great Britain by Downer et al. (1994). These are the only large scale studies (N=5,047 and N=415) which evaluate cancer patients' CT use via survey methods. No studies were found which specifically evaluate CT use by women with breast cancer.

In Lerner and Kennedy’s (1992) telephone generated random sample of 5,047 individuals with cancer, only 9% (n=454) of subjects reported using CTs. Nine percent of these users were women with breast cancer (n=42). Most commonly utilized CTs among all CT users in the study included “mind” therapies such as mental imagery and hypnosis (49%), diets (38%), and drugs and biologic products (33%). Users of CTs were found to be white, more affluent, and better educated than non users of CTs. Although it is unclear how CTs were defined in this survey, the authors presented a list of 39 “questionable methods” to subjects over the telephone, expecting that subjects would state which of these methods they currently utilize. Using the title “questionable methods” may have been a methodological flaw in this study,
reducing the likelihood that subjects would report using a treatment which is labeled as questionable by the orthodox health care system. The low prevalence rate of nine percent may be a result of CTs being presented in this manner.

Physicians of a small number of CT users (n=91) were also sampled in the same survey by Lemer and Kennedy (1992) to gain information about the role of the physician related to CT use. Discrepancies between patient and physician perspectives were noted. Although 50% of patients reported that they used CTs with “consent” from their physician, physicians said they opposed the CT in 52% of cases, went along with it in 37% of cases, and recommended it only in 2% cases. While it is difficult to determine whether a true communication gap between patients and doctors existed, or whether a social desirability response influenced reporting, this study highlighted the importance of further exploring this aspect of the phenomenon of CT use.

In Great Britain, Downer et al. (1994) surveyed cancer patients to determine what proportion of patients were using CTs in addition to orthodox treatment. A random sample of 416 subjects revealed that 16% had used CTs, including relaxation, visualization, diets, homeopathy, vitamins, and herbalism. Two or more CTs were utilized by 75% of the CT users. Demographic data supported earlier survey findings where young, females of higher social class were the most frequent users of CTs.

Although Eisenberg et al.’s (1993) random telephone survey of 1,539 American adults is not specific to cancer, it is the most commonly cited and referred to survey in the CT literature. A number of important social trends in CT use were identified in this survey. Findings from this survey identified that 34% of respondents utilized a CT in the past year, with 83% of these users of CTs also seeking treatment for the same condition from a medical doctor. However, of these CT users also seeking medical care, 72% did not inform their medical doctor of their CT use. These results confirm Lerner and Kennedy’s (1992) findings that CT users may not tell their medical doctor about their CT use. Extrapolating survey findings to the US population, the authors predicted that more visits were made to practitioners of CTs than medical doctors in

Findings from previous studies regarding the demographic profile of a typical CT user were confirmed by Eisenberg et al. (1993), showing that young (25-49 years), non black, educated (college level), financially stable females were the most frequent users of CTs. Relaxation techniques, chiropractic, massage, imagery and spiritual healing were the most frequently reported CTs. However, these findings must be examined in light of the fact that respondents were only given a list of 16 different CTs to choose from, which did not include CTs such as Native Indian healing practices, Ayurvedic healing, or Traditional Chinese medicine.

Four studies utilizing convenience samples of cancer patients to determine the prevalence and patterns of CT use were identified in the literature. Three of these studies were implemented in the US by Cassileth et al. (1984), Cassileth (1986), and Goldstein, Chao, Valentine, Chabon, and Davis (1991), and one study in Australia by Yates et al. (1993).

A study by Cassileth et al. (1984) is cited in the literature as a classic CT survey, as it was one of the first large scale studies in the US of the prevalence and patterns of CT use specifically by cancer patients (N=660). The authors found that 54% of individuals surveyed used CTs in addition to orthodox treatments. However, 40% of these individuals using both CTs and orthodox treatments abandoned their orthodox treatments in favor of CTs within eight months of beginning orthodox treatments. The remaining 60% continued to use both CTs and orthodox treatments concurrently. While these statistics seem alarming, methodological shortcomings evident in this study limit the generalizability of these findings. For example, the convenience sample was drawn from two sources, including cancer center outpatients and cancer patients under the care of an unorthodox practitioner. These subjects were largely white, Christian, married women. Further, the definition of CTs in this study included treatments that are used specifically to cure cancer. Therefore, a large number of CTs such as relaxation therapy and massage, which are aimed at managing symptoms and enhancing quality of life versus achieving a cure, were excluded from the possible list of CTs utilized by subjects in this
study. Although this survey by Cassileth et al. (1984) is important in that it raised health care professional’s awareness of the phenomenon of CT use among patients with cancer, generalizability of study findings to the US population is poor due to these sampling limitations and narrow operational definition of CTs.

In an updated study two years later, based on a national sample of 1,000 individuals, Cassileth (1986) reported that approximately 50% of subjects were using CTs. However, this survey was mentioned only briefly in Cassileth's (1986) discussion paper on CT use, without any information reported on sampling procedures and other methodology and analysis components. As such, findings of this study are not useful as they cannot be critiqued regarding rigor.

On a smaller scale, Yates et al. (1993), using a convenience sample of 152 subjects, surveyed patients with incurable cancer who use both orthodox medical treatments and CTs. Forty percent of subjects (n=60) utilized a CT, with the most common CTs used including vitamins/tonics (24%), meditation/relaxation (19%), and special diets (18%). Complementary therapies were broadly defined in this study, including CTs from all categories of the OAM classification system.

In 1988, Goldstein et al. (1991) surveyed 42 patients’ use of CTs in a Radiation Oncology Department in New York. A 12% CT user rate was reported (n=5), where the CTs used included selenium, mental imaging, megadoses of garlic, and Jamaican herbal tea. The use of a convenience sample which consisted largely of white, Catholic, married, well educated women, and the extremely small sample size severely limits the generalizability of these findings.

The Canadian literature on the prevalence and patterns of use of CTs by patients with cancer is sparse. Only three completed studies could be located. Although not specific to cancer, a survey by the Canada Health Monitor found that in 1990, one in five (20%) Canadians used some form of CT (Berger, 1990). Most common CTs utilized included chiropractic (9%), and advice from a health food store (6%).
The National Population Health Survey (1994-1995), using a random sample telephone interview technique (N=17,626), reported that 15% of Canadians over the age of 15 years had consulted an alternative health practitioner within the past 12 months (Millar, 1997). This low CT user rate may not be a true representation of CT use within the population, as only those individuals who spoke with a CT practitioner (e.g., homeopath, chiropractor, massage therapist) were identified as users of CTs. Therefore, those individuals who self prescribed or began using CTs on the advice of a trusted friend were not included in the study as users of CTs.

Survey data on the use of CTs by cancer patients was elicited in a needs assessment survey involving outpatients with cancer at the BC Cancer Agency (Upright, Brown, & Janes, 1996). Of the random sample of 797 subjects, 11% reported simultaneous CT use with their orthodox cancer treatment. Most popular CTs included prayer (33.4%), relaxation (23.4%), herbal teas (23.4%), dietary modifications (21.9%), imagery (19.8%), and meditation (15.8%).

Upon examination of the survey research on patterns and prevalence of CT use completed to date, few solid conclusions can be drawn due to the use of convenience samples and differences in the definition and scope of CTs explored in the surveys. Further, very little survey research has been done with samples of Canadians with cancer. Due to the paucity of survey data on the prevalence and patterns of use of CTs by patients with cancer in Canada, the National Cancer Institute of Canada is currently implementing a large scale Canada wide CT use survey. Although the survey will greatly enhance our knowledge about prevalence and patterns of use of CTs in Canada, it will not provide information on how individuals with cancer make decisions to use CTs.

Health and Illness Beliefs Related to Complementary Therapy Use

Four studies, lead by Adrian Furnham, investigated the role of belief systems in relation to CT use as a potential factor affecting decisions to use CTs using quantitative methods (Furnham & Beard, 1995; Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Smith, 1988). In the first study, Furnham and Smith (1988) investigated the difference in
health and illness beliefs of patients choosing orthodox medicine versus CTs in Britain, hypothesizing that users of CTs may hold different theories as to the cause and cure of illness than users of orthodox medicine. One group visited a general practitioner (GP) (n=45), and the other a homeopath (n=42). The major differences between groups were that the homeopathic group were more critical and skeptical about the efficacy of orthodox medicine, and, in comparison to those visiting GPs, they believed more often that their general health could be improved. No differences between groups were noted regarding beliefs about illness susceptibility or preventative measures. These results suggest that people who choose CTs may do so related to disenchantment with orthodox medical practitioners, rather than because of a beliefs that orthodox medicine itself is ineffective. Due to the small sample size, the authors caution against generalizing these results to the larger population.

In a subsequent larger study, Furnham and Bhagrath (1993) also sought to compare and contrast the beliefs and expectations of two groups: one visiting an orthodox medical practitioner (GP) (n= 80), and the other a homeopath (n=80). Results showed that compared to patients of orthodox medicine, homeopathic patients claimed to a) hold stronger beliefs about “healthy lifestyle” methods of preventing illness, b) trust more in their chosen primary health professional, c) be dissatisfied with orthodox medicine, and d) believe in potential self control over health. Although these findings support and extend Furnham and Smith’s (1988) earlier work, these findings are limited only to users of homeopathy as a CT. More research is necessary to determine generalizability to users of CTs other than homeopathy.

Furnham and Forey (1994) built upon previous health belief studies by comparing users of orthodox medicine (n=80) with users of a variety of CTs (n=80) visiting 10 large established CT centers in and around London. Differences between groups indicate that users of CTs a) were more critical and skeptical about the efficacy of modern medicine, b) believed their health could be improved, c) stayed loyal to their chosen practitioner, d) believed that treatment should concentrate on the whole person and greater knowledge of the physiology of the body, and e) had a more optimistic outlook on life, believing that they had a degree of control no
matter how bad the illness. These findings show definite differences between groups regarding beliefs about health and illness, which is contrary to previous findings (Furnham & Smith, 1988; Furnham & Bhagrath, 1993). Furnham and Forey (1994) suggest that the motivational force for choosing a CT is not necessarily dissatisfaction with the orthodox system alone, but a choice related to wider belief systems and a consequence of the CT practitioner-patient relationship.

Again building on previous work, Furnham and Beard (1995) investigated differences between users of orthodox medicine (n=81) and users of CTs (n=65). To add variability to the CT user group, subjects were sampled from general practices within orthodox medicine, shiatsu, and acupuncture clinics. This sampling procedure allowed for the creation of a third group of CT users who were concurrent users of orthodox medicine (n=39), not included in previous studies. Results indicated that the CT only and combined CT/orthodox treatment group stressed emotional well being and lifestyle factors as being major influences on their current state of health more often than the orthodox treatment only group. Further, all CT users, regardless of group, believed that psychological lifestyle and self-medication were important factors that influence one’s future health, more often than did the orthodox treatment only group. These findings suggest that one’s health beliefs may influence health behavior, including the choice of CTs versus orthodox medicine.

Furnham and his colleagues have added to the body of knowledge regarding the phenomenon of CT use by examining the role of health and illness beliefs as they relate to CT use. Although it is an important contribution, none of the studies specifically targeted patients with cancer. Further, questions must be raised regarding the validity of the findings by Furnahm and colleagues when only quantitative methods such as questionnaires were used to measure individuals’ beliefs systems. Utilizing questionnaires which include predetermined sources of health and illness beliefs assumes that one knows which beliefs are important to measure related to CT use. Without qualitative research to inductively discover which health beliefs are related to CT use, one cannot be sure that questionnaires utilized in the studies by
Furnham and colleagues are indeed valid. As such, a grounded theory research study which investigates how women with breast cancer made decisions to use CTs in addition to their traditional cancer could add to the body of knowledge concerning the relationship of health beliefs to the use of CTs by inductively uncovering those health beliefs from the patients', rather than the researcher's perspective.

Two other studies were reviewed which examined belief systems of cancer patients as a potential factor affecting decisions to use CTs. In a study by Yates et al. (1993), both quantitative and qualitative methods were used to survey terminal cancer patients in Australia regarding beliefs and attitudes about cancer, its treatment, and the practitioners providing that treatment. Analysis of findings suggest that important predictors of CT use include a) belief in "alternative" causes of cancer, b) desire for control over treatment decisions, and c) will to live. In addition to questionnaires to elicit data about health and illness beliefs, Yates et al. also included spontaneous comments from subjects completing the questionnaires, and included data from nine in-depth interviews eliciting information about how the subjects came to use CTs, and their beliefs and attitudes about cancer as it relates to using CTs. These findings support other research in the area of CT use, such Furnham and Beard's (1995) finding that health beliefs influence behavior, and Montbriand and Laing's (1991) finding that choosing a CT may be a way of increasing control over the disease of cancer. While Yates et al. (1993) have expanded our understanding of various aspects of CT use including health beliefs, more research is necessary to investigate cancer populations other than terminally ill patients regarding the relationship of health beliefs and CT use.

Balneaves (1996) also investigated the relationship of CT use to a number of individuals' beliefs, including beliefs about the cause of cancer, orthodox medical treatment, CTs, satisfaction with health care providers, and the will to live, in a convenience sample of 52 women with breast cancer. Contrary to findings by Furnham and his colleagues, and Yates et al. (1993), no relationships were found in Balneaves' study between CT use and the aforementioned variables. Insufficient sample size was cited as rationale for a lack of
significant association among the variables. Due to the conflicting results of this study with the findings from previous studies, more research is necessary with larger groups of women with breast cancer.

**Knowledge and Attitudes Related to Complementary Therapies**

Only four studies could be located which have focused on evaluating cancer patients' knowledge and attitudes about CT use and its relationship to other variables. In a study to determine patient's insight into their disease, treatment, prognosis, and the use of CTs, Eidinger and Schapira (1984) selected a convenience sample of 190 patients with advanced cancer. Findings specific to CT use indicate that about 25% of patients believed that treatments such as laetrile were effective in curing cancer, and about 40% were unsure if they were effective. Only 33% of subjects had accessed the biomedical literature to determine that laetrile was ineffective in curing cancer.

In another study, Hiratzka (1985) randomly sampled 125 subjects from patients attending an outpatient cancer clinic to determine if cancer patients' attitudes toward self-use of CTs related to a) their knowledge of these CTs, and b) a belief in their control over their health outcomes (locus of control). A significant relationship was found between an internal locus of control and knowledge of, and attitudes toward CTs. According to Hiratzka (1985), individuals who believe that their actions control their health outcomes knew more about, and had more positive attitudes toward CTs. These findings must be examined in light of methodological problems, related to the use of the health locus of control scale. In recent criticisms of the scale it has been suggested that the assumption may not be valid that people adopt a single explanatory system for all aspects of health and illness. Further, people may have both internal and external explanations for health and illness (Furnham & Beard, 1995). In light of these criticisms of the locus of control scale, the findings must be interpreted cautiously.

Skinn (1994) investigated the relationship of belief in control and purpose in life to the adult lung cancer patient's inclination to use CTs. A convenience sample of 40 lung cancer patients
completed a number of questionnaires and scales, including the health locus of control scale. No significant associations among belief in control, purpose in life, and the degree of inclination to use CTs were found. The controversy surrounding the use of the health locus of control scale also applies in this study, suggesting caution in interpreting the results of this study.

Lastly, in a study by Vincent, Furnham, and Willsmore (1995), patients attending a variety of CT practitioners were compared to those attending general practitioners regarding their perceived efficacy of both complementary and orthodox medicine. The most significant predictor of CT use was found to be a belief in the importance of psychological factors in illness. Similarly, in a follow-up study by Vincent and Furnham (1997) a belief in psychological factors in health and illness was strongly related to preferences for CT use. While the findings of these two studies may begin to help explain common attitudes about CT use, they are based on small sample sizes and must be interpreted cautiously.

In summary, very little research has targeted cancer patients' knowledge and attitudes as they relate to CT use. Further, methodological constraints limit the applicability of these findings in any meaningful way. Additional studies which evaluate the relationship of knowledge and attitudes with potential and actual CT use will be important in further explaining the phenomenon of CT use.

Decision Making and Complementary Therapies

This section on decision making is divided into three parts: a) studies investigating orthodox treatment decision-making preferences of women with breast cancer, b) studies investigating decision making to use CTs as a control mechanism by patients with cancer, and c) the decision-making process related to CT use.

Decision Making and Orthodox Treatment for Breast Cancer

Research findings about cancer patients' preferences for involvement when making treatment decisions have been inconsistent (Hack et al., 1994). Although some researchers have found that most patients want to actively participate in the decision-making process, rather than have the physician decide the treatments (Blanchard, Labrecque, Ruckdeschel, &
Blanchard, 1988; Brandt, 1991; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Degner & Russell, 1988), others have found that a majority of patients prefer that their physicians choose their treatments (Beaver et al., 1996; Degner & Sloan, 1992; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). Differences in these findings may be attributable in part to different disease sites across the samples, and the use of small convenience samples in a number of the studies.

Decisional roles of women with breast cancer have been explored by a number of researchers including Hughes (1993), Hack et al., (1994), Bilodeau and Degner (1996), Beaver et al. (1996), and Balneaves (1996). Two of these studies investigated some aspect of the role of information as it relates to women’s degree of preferred decisional control (Bilodeau & Degner, 1996; Hack et al., 1994), and one study by Hughes (1993) explored the role of information in selecting treatments. Balneaves (1996) compared preferred and actual decision-making roles in women with breast cancer who use CTs to women who use orthodox treatments only, and another study compared women with breast cancer to women with benign breast disease to determine their preferences for decisional control in selecting treatments (Beaver et al., 1996). As was evident with previous studies evaluating decisional roles in patients with all types of cancer, researchers demonstrated differences related to degree of preferred decisional control, with 43% of women in Bilodeau and Degner’s (1996) study preferring a more passive role in treatment selection, compared to only 20% of women in Hack et al.’s (1994) study who preferred a passive role. Hack et al. (1994) identifies small sample size as a major limitation to interpretation of these findings. One major drawback of these studies as they relate to the proposed research study exploring the decision-making process of women with breast cancer to use CTs, is that only one of these decision-making studies included CTs as a treatment option. Balneaves (1996) found that 94.3% of the women using CTs preferred an active or collaborative decision-making role with their physician. However, it is unclear from the findings of this study if this preferred decisional role was specific to both CT and orthodox treatment decisions, or orthodox treatment decisions only. Gaining clarity on
this issue will help to identify whether women with breast cancer prefer different decision-making roles in relation to the types of treatment decisions they make. Despite the groundbreaking work by Balneaves regarding preferred decision-making roles of women with breast cancer who use CTs, little is known about decisional roles related to CTs in addition to orthodox treatments for cancer, including breast cancer.

**Decision Making as a Control Mechanism**

Decision making regarding CT use has been explored by Montbriand and Laing (1991) as a mechanism to enhance feelings of control over one's illness. The authors argue that in the orthodox medical system, the doctor, not the patient, is responsible for health care. As such, patients desiring a high level of control over their illnesses may seek out CTs as a control strategy. Seventy-five Caucasian patients of European descent were selected from a hospital surgical unit to participate in this phenomenological study to uncover the patient's experience of making decisions to use CTs. Analysis revealed that patients may choose to maintain control either by choosing a direct action such as ingesting vitamins or herbs, or by non-action, such as performing visualizations. Further, when the freedom obtained by taking control seemed too much for some individuals, they gave it away to CT healers or God. Analysis of control themes also revealed an internal-external orientation, where individuals may concurrently choose CTs and orthodox medicine, simultaneously taking control and giving it away.

In a follow-up study investigating the use of CTs as control behaviors by cancer patients, Montbriand (1995a) uncovered major ambiguities concerning the control behaviors of cancer patients. Through secondary qualitative analysis of previous research data (Montbriand, 1993a), Montbriand (1995a) applied existing control theories to explain CT use as it relates to the desire to have control of health care. While on one hand previous research has suggested that patients choose CTs as a control mechanism (Montbriand & Laing, 1991), results of Montbriand's (1995a) more recent study suggest that use of CTs could be a sign of inability to cope. The act of searching for and utilizing various CTs, according to Montbriand (1995a), may be a stalling mechanism to prevent conclusive decision making about orthodox cancer
treatments or cancer acceptance. Montbriand (1995a) agrees that more research is necessary to unravel the complex phenomenon of decision making about CT use, and the role that desire for decisional control plays in this process.

More recently, Montbriand (1997) expanded her program of CT research to explore the concept of control as it relates to those individuals who leave biomedicine to use CTs. In this ethnographic study, anger with orthodox health care professionals and feelings of abandonment were described as residual forces which initially precipitated individuals to seek control of their health care outside of the biomedical health care system. While taking control of their health care was an attempt to reduce feelings of stress, many of the subjects found the responsibility of being in control ultimately increased their stress. As such, most gave the responsibility to an alternative healer. These findings support the notion that the concept of control related to CT use is more complex that originally thought, where subjects may both take control of their health care and give it away to alternative healers. However, it is important to note that some characteristics of these subjects were slightly different than those in earlier studies. In Montbriand’s 1997 study, subjects used CTs only and were searching for a cure for their cancer. Earlier studies (Montbriand, 1991, 1993a, 1995a, and 1995b) included subjects who used both biomedicine and CTs, but the aim of using CTs was not reported. It can be rationalized that individuals who use CTs only with the aim of curing their cancer bear a heavy burden of responsibility and, in turn, experience more stress, when compared to those individuals who use both CTs and biomedicine. Individuals who use both CTs and biomedical treatments share the responsibility for their health care with biomedicine and may not use CTs with expectations of cure. Instead, CTs in this situation may have been used to enhance the beneficial effects and/or manage unwanted side effects of orthodox treatments. As such, these individuals who use orthodox medicine and CTs may indeed use CTs to regain control over their health care. Further qualitative studies need to be done to explore the relationship of control to the aims of CT use in populations who use both orthodox medicine and CTs.
The use of CTs as a control mechanism has also been identified in other populations facing a life-threatening illness such as AIDS (Abrams, Dilley, Maxey, & Volberding, 1986; Fryback & Reinert, 1997; Kendall et al., 1989). Complementary therapies were used by individuals in these studies to manage the side effects of conventional treatments and to give the individual a sense of active participation in his or her treatment. Further, they felt that CT use functioned to promote their health while living with AIDS, which was not addressed by orthodox medicine. Further qualitative studies to examine the CT use as a means to maintain control in women with breast cancer is necessary to determine this phenomenon is similar to those individuals with AIDS.

Decision Making and Complementary Therapies: The Process

Two qualitative studies were located which outline aspects of the treatment decision-making process by individuals living with breast cancer and other chronic life-threatening illnesses (Kelly-Powell, 1997; Pierce, 1993). While these studies include decisions related to orthodox treatments only, they help to explain how treatment decisions may be a dynamic rather than static phenomenon. Further, findings from the study by Kelly-Powell (1997) indicate that treatment decisions are personalized to correspond with one’s beliefs and lifestyle, rather than solely based on statistical data regarding treatment outcomes. Additional studies need to be conducted with populations making both CT and orthodox treatment decisions to determine the applicability of the above aspects of treatment decisions to other populations such as breast cancer.

Montbriand (1995b) has made a major contribution to understanding the phenomenon of decision making related to CTs through development of a decision tree model of alternative health care choices made by oncology patients. Using a large (N=300) sample of patients with respiratory or digestive system cancer, Montbriand (1995b) utilized an ethnographic methodology to develop a decision model which describes a pattern of how choices about CTs are made. Factors affecting decisions to use CTs included desired decisional control, considerations of cost, perceived stress, judgments about cure, change, and searching, and
faith in the practice. While this decision tree helps to explain how patients with cancer choose to use or not to use CTs, it does not explain how patients choose among the various CTs. Further, only individuals with respiratory and digestive cancers in Saskatoon were included in the sample. More research is therefore necessary to determine whether this model also explains the patterns of choices for patients with other cancers, such as breast cancer.

In another study examining choices of CTs by patients with cancer, Montbriand's (1993b) findings raise questions about whether patients truly have freedom of choice regarding CTs. Although informants felt that they were making health care choices through rational decision making, they were limited by the inaccessibility of biomedical literature which evaluates the efficacy of various CTs, and by the lay literature which is often ambiguous, exploitive, and confusing. As such, Montbriand (1993b) concluded that most individuals with cancer who choose CTs make decisions based on inadequate information.

A major strength of Montbriand's research related to CT use lies in her choice of various qualitative methodologies which has allowed her to begin documenting the process of decision making as it relates to CT use from the patient's perspective. Previous research reflects health care providers' perspectives, which may or may not encompass all of the elements of the phenomenon of decision making as it relates to CT use. A qualitative approach such as grounded theory, which was utilized in the current research study, ensured that the phenomenon under study is understood from the patient's perspective.

Although Montbriand has begun to explore cancer patients' decision-making process to use CTs from the patient's perspective, her research does not explore the potentially dynamic nature of the decision-making process. As with most of the previous research on CTs, a static view of CT use is presented which represents only one point in time in that patient's cancer trajectory. Research focusing on the CT decision-making process as patients move through the cancer experience needs to be implemented, thereby providing a broad perspective on the phenomenon of CT use.
The Physician-Patient Relationship

Findings from two studies cited earlier in this literature review by Furnham and Forey (1994) and Furnham and Beard (1995) suggest that in addition to a patient’s beliefs about health and illness, the physician-patient relationship may play an important role in that patient’s decision to use CTs. Further, a great deal of opinion-based literature on the topic of the physician-patient relationship has surfaced in the past five years. As such, studies investigating levels of patient satisfaction regarding the physician-patient relationship are reviewed here.

Donnelly, Spykerboer, and Thong (1985) found that 76.4% of patients using both CTs and orthodox treatments for asthma and minor surgical problems were satisfied with both forms of treatment. Only 2.7% of patients using CTs were dissatisfied with conventional treatment. Conversely, Siskind et al. (1977, cited in Yates, 1991) report that only 12% of the chiropractic patients sampled had favorable opinions of orthodox practitioners. Fifty-two percent reported neutral opinions, and 36% reported unfavorable opinions of orthodox practitioners. The most commonly reported reason for this dissatisfaction of orthodox medicine included the doctor’s attitude, and the treatment prescribed by the doctor. A study by Parker and Tupling (1976, cited in Yates, 1991), also utilizing a sample of chiropractic patients, judged their chiropractor to possess equal technical competency and superior interpersonal skills to those of a general practitioner.

While the findings in these three studies may suggest that satisfaction with the physician-patient relationship may influence the decision to use CTs, they are inconclusive. Further, none of these studies sampled patients with cancer. Additional patient satisfaction studies regarding orthodox and CT practitioners, utilizing samples of cancer patients need to be done.

In a study specific to patients with advanced breast and ovarian cancer, Payne (1991) implemented a grounded theory study to investigate patients’ perceptions of their interactions and level of satisfaction with orthodox health professionals. Thirty-seven percent of 53 women in the study described their oncologist as unapproachable, abrupt, and lacking empathy. General practitioners, on the other hand, were perceived by 79% of women to provide
emotional, tangible, and informational support. These GPs were seen as accessible, willing to talk, empathetic, provided information, and used understandable terms. Although patients in this study did not use CTs, findings of this study are valuable as they highlight attributes of desirable relationships between women with breast (and ovarian) cancer and their health care practitioners, whether these practitioners are medical doctors or CT practitioners. If CT use is indeed related to the degree of satisfaction with the physician-patient relationship, then these findings may eventually be helpful in predicting patient’s CT use based on their level of satisfaction with their orthodox health practitioner.

The degree to which orthodox physicians actively discuss and support CT use by their patients (and subsequently rate more highly on patient satisfaction scales) is a direct result of that physician’s attitudes toward CTs (LaValley & Verhoef, 1995). Four Canadian surveys involving GPs in Quebec, Ontario, and Alberta have evaluated GP’s views and practices regarding CTs (Bourgeault, 1996; Goldszmidt, Levitt, Duarte-Franco, & Kaczorowski, 1995; Gray et al., 1997; Verhoef & Sutherland, 1995). Findings from Verhoef and Sutherland’s (1995) random sample of 200 physicians in Alberta and Ontario revealed 56% of general practitioners believed that “alternative medicine” has ideas and methods from which orthodox medicine could benefit, 54% referred to CT practitioners, and 16% practiced some form of CT. These physicians considered acupuncture, chiropractic, and hypnosis as the most helpful CTs.

A similar survey by Goldszmidt et al. (1995) randomly sampled 121 GPs from Quebec. Findings from this survey indicate that 59% of GPs made referrals to physicians who practice CTs, and 68% referred to non physicians who practiced CTs practitioners. Thirteen percent of GPs practiced at least one CT. These findings are similar to Verhoef and Sutherland’s (1995) survey findings, and suggest that GP attitudes toward CTs and CT practitioners in many Canadian provinces are positive. Further, in addition to the surprising percentage of GPs practicing CTs in addition to orthodox medicine, 63% of GPs in Ontario, 43% of GPs in Alberta, and 48% of GPs in Quebec indicated that they would like training in one or more CTs (Goldszmidt et al., 1995; Verhoef & Sutherland, 1995). These survey findings indicate a rising
level of acceptance and interest in CT use by orthodox practitioners, suggesting a positive influence on the physician-patient relationship.

A pilot study using open-ended telephone interviews to survey 19 GPs and oncologists in Ontario regarding their perspectives on CT use challenges the above findings (Gray et al., 1997). While the physicians indicated that they wanted more information about CTs, and expressed a desire to be supportive of patient choices of CTs, they also expressed little interest in initiating communication about CTs. Further, they indicated that discussions about CT use were a waste of their time. A study using in-depth interviews by Bourgeault (1995) also found similar negative opinions regarding CT use in a sample of 30 oncologist and GPs. These attitudes by physicians do little to encourage the safe integration of CT use into one’s orthodox treatment plan, and continues to perpetuate the code of secrecy surrounding CT use by patients with cancer. More research is necessary to identify the factors affecting physician’s attitudes toward CT use.

**Comparison Studies: Effectiveness of Complementary Versus Orthodox Therapies**

Surprisingly, only one study could be located which has compared the effectiveness of orthodox treatments alone to CTs in addition to orthodox treatments on survival rates and quality of life (Cassileth et al., 1991). Seventy-eight matched control patients with extensive metastatic disease were chosen from an orthodox cancer treatment center and a prominent “unorthodox” cancer center. No differences between groups were found regarding length of survival. Although it was hypothesized that the CT group would score higher on quality of life measures due to the self-care components and absence of toxicity associated with chemotherapy, findings did not support this. Despite repeated measures of quality of life, patients in the orthodox treatment group scored consistently higher than those patients in the CT group.

Cassileth et al. (1991) identify a number of methodological flaws inherent in this research project. These include the use of convenience samples which consisted of all Caucasian subjects, inability to blind the interviewers so that bias cannot be ruled out, and the sampling of
patients with extensive disease that may not have allowed the CTs to succeed. Further, the baseline quality of life measures were different between the groups. Additionally, the potential for patients in the orthodox treatment group to practice CTs such as imagery and relaxation should not be overlooked. Due to these limitations, the findings of this study must be interpreted carefully. More research is needed to evaluate the effect of CTs versus orthodox treatment on variables such as quality of life.

Summary

Non research literature was reviewed to provide a context in which CTs are currently being practiced within our traditional health care system. Support for the use of both orthodox and complementary systems of health care was derived through examination of theoretical and opinion based perspectives. Further, numerous variables suspected to influence an individual’s decision to use CTs were identified.

A review of the research literature has revealed a small yet growing body of knowledge related to the use of CTs by individuals with cancer. Variables such as health and illness beliefs, knowledge and attitudes about cancer and CTs, preferred degree of decision-making control, and the physician-patient relationship have begun to be studied in depth to determine their relationship to individuals’ decisions to use CTs. However, small sample sizes, the use of convenience samples, and differing definitions of CTs limit many of these research studies. Further, many of these studies did not include cancer patients, or more specifically women with breast cancer as subjects.

Although numerous variables have been identified in the literature which may influence an individual’s decision to use CTs, no research has been done to examine process of decision making to use CTs by women with breast cancer. Further, there has been no research which links the CT decision-making process with the cancer trajectory and orthodox treatment process. Much of the current research has taken a static view of CT use, largely from the perspective of health care providers, rather than examining how CT use evolves as patients move through the cancer experience, from the patient’s perspective. The current research study
addresses these issues by employing grounded theory methodology to examine decision-making process used by women with breast cancer to determine whether to use CTs in addition to orthodox treatments for breast cancer. In this way, the dynamic nature of the CT decision-making process is captured as it relates to the cancer trajectory, from the patient's perspective.
CHAPTER THREE
METHODOLOGY

Grounded theory technique was utilized in this study to inductively develop a beginning theory that explains the processes by which women with breast cancer make decisions to use CTs. According to Stern (1980), the aim of grounded theory research is to understand how a group of people define their reality via social interactions. Based on the assumption that reality is a subjective phenomenon, and that patients communicate their reality via psychological processes (Hutchison, 1986), grounded theory methodology is consistent with the purpose of the study which aims to discover the processes by which women with breast cancer make decisions to use CTs.

The grounded theory approach to generating and analyzing qualitative data is vastly different from quantitative approaches in that its aim is to develop rather than test a theory (Hutchison, 1986). This difference manifests itself in a methodological framework giving general direction to the grounded theory study, rather than a recipe stating explicit instructions to guide the conduct of the study. The grounded theory research design for this study served to chart an initial direction and identify an outer boundary for inquiry. This design allowed room for the expression of the process by which women with breast cancer make decisions whether to use CTs.

The goal of this grounded theory study was to develop knowledge through accurately perceiving and presenting the world of women with breast cancer as they made decisions about CT use. To achieve this goal, the investigator was involved in (a) ongoing and concurrent data collection, categorization, and interpretation, (b) intentional sampling of subjects who could illuminate the process of decision making to use CTs, and c) the use of strategies to ensure the validity of the study (Chenitz & Swanson, 1986). The grounded theory research process was driven by the nature of the data generated by the subjects. The process of making decisions to use CTs was therefore created from the ground up, from the women’s rather than the investigator’s perspective.
Sample Selection and Criteria

Purposive sampling was employed to recruit subjects who could thoroughly articulate the experience of making decisions to use CTs. A non-probability sampling technique, purposive sampling is commonly utilized in grounded theory research to gain access to the “experts” who can describe the topic well (Morse, 1986). Based on the assumption that all actors in the setting are not equally informed about the knowledge sought by the researcher, the informants were deliberately selected according to the theoretical needs and direction of the research (Strauss & Corbin, 1990).

The target population for this study consisted of women with breast cancer who were receiving or have received traditional treatment for their breast cancer and who have used or have considered using CTs for their cancer. Eligible subjects were 18 years of age and older, able to speak English and communicate their experiences of making decisions to use CTs. Subjects were selected from various support groups and agencies around the Lower Mainland and from communities within Northern BC. Sampling of subjects from areas outside of the Lower Mainland added variation and richness to the description of the phenomenon and ensured that all areas of the phenomenon were addressed (Morse, 1986).

Within the Lower Mainland, subjects were sampled from groups such as Treasure Chests, the British Columbia Cancer Agency (BCCA) Breast Cancer Support and Relaxation Groups, the BCCA Ambulatory Chemotherapy Unit, and the Tzu Chi Institute for Complementary and Alternative Medicine at Vancouver Hospital. A contact person was established within each of these groups to act as a liaison between the investigator and potential subjects. The contact person identified and approached potential subjects regarding participation in this research study. Subjects agreeing to explore the possibility of participating in the research study were then telephoned by the investigator to gain informed verbal consent.

In Kitimat, Terrace, and Prince Rupert, BC, subjects were sampled from the Communities Oncology Program, operated collaboratively by the BCCA and the local community hospitals. The clinic nurse booking patient appointments for the oncology clinic identified potential
subjects and obtained verbal consent to discuss the possibility of participating in the study. This phone call by the clinic nurse took place well in advance of the patient’s clinic visit, at the same time she called that patient to book his or her clinic appointment. Informed verbal and written consent were obtained by the investigator immediately prior to the interview.

In addition to recruitment of volunteers from various agencies, an advertisement to recruit volunteers for this study was placed in Abreast in the Nineties, a quarterly newsletter aimed at breast cancer survivors around the Province. Interested individuals telephoned the investigator for further information, and informed verbal consent was obtained at that time, if appropriate.

A total of 16 women were interviewed for this study, using purposive sampling for maximal variation to guide sampling decisions and to determine the number and type of women to be interviewed. As the quality of the data gathered from the subjects, rather than the number of subject responses is more important (Hutchison, 1986; Chenitz & Swanson, 1986), sampling continued until data saturation was achieved. Morse (1986) suggests evaluating the adequacy of the sample to determine when sampling is complete. Adequacy refers to the quality, completeness, and amount of information provided by informants, rather than the number of subjects. In this way, adequacy of the sample was ensured when no new themes or patterns emerge from the data, indicating that the information given by the sample was complete (Morse, 1986).

Efforts were made to include women in the study from all phases of the breast cancer trajectory, from a variety of cultural backgrounds, and from most of the seven categories of CTs identified by the Office of Alternative Medicine (OAM) at the National Institute of Health (NIH) in the United States (US). A broad variety of subjects added variety and richness to the description of the phenomenon and ensured that all areas of the phenomenon are addressed (Morse, 1986). This method of sampling is especially important with grounded theory research, as the investigator does not know in advance all the kinds of groups to be sampled (Sandelowski, Davis, & Harris, 1989).
Data Collection Procedure

In keeping with the purpose of the study and grounded theory techniques, multiple approaches to data collection were employed to uncover the process of making decisions to use CTs from the women’s perspective. Interviews, field notes, and theoretical memoing comprised the data collection methods in this study, where the women were the source of the information, and the investigator was the instrument through which the data was collected, interpreted, and analyzed.

Procedures

A total of 18 interviews were completed, with two women being interviewed twice. Interview settings within the Lower Mainland included the women’s homes, the investigator’s home, an office at the University of BC, and conference rooms at the BCCA. Within Northern BC, interviews were conducted in conference rooms in the local community hospital. All but one interview were audio-taped; in this instance detailed notes were taken during the interview.

After written informed consent for participation in the study (Appendices A and B) and demographic and medical information were obtained (Appendix C), the interviewer reviewed the purpose of the study and answered any questions. The interviews began with one open ended question such as “Tell me how you came to use complementary therapies for your breast cancer.” The investigator ensured that the interviews remained open-ended, where the informant determined the general content and pace of the interview. Trigger questions were utilized to stimulate discussion throughout the initial interviews (Appendix D).

In later interviews, as data collection proceeded, questions arising from the review of the transcripts were included. In this way, emerging categories and themes from the earlier interviews were expanded, contrasted, and validated. In the final three interviews, written visual representations of the investigator’s interpretation of the CT decision-making process was presented for validation.

The interviews were completed over a period of 16 months, in three clusters; five interviews in the beginning, eight interviews at midpoint, and three interviews (including two repeat
interviews) toward the end of data collection. Each audio-taped interview lasted between 40 and 120 minutes.

Recording of the Data

Each of the 16 audio tapes were transcribed verbatim to provide an accurate record of the dialogue. Each transcript was then reviewed with the tape to ensure accuracy. Following each interview, field notes were recorded. They included a brief description of the woman and the setting as well as observations made about the subject during the interview (e.g., patient’s obvious physical responses to breast cancer and the patient’s emotional responses to topics disclosed in the interview). Immediately after each interview, the investigator recorded these observations in a journal, which then became data to be coded in the analysis. The investigator’s thoughts, ideas, and reactions to the interview were also recorded.

Theoretical memoing was also included as a data collection method, where the investigator’s thinking process during data analysis was documented, elevating the descriptions of empirical events to a theoretical level (Hutchison, 1986). As insights developed during the analysis of the data, they were recorded as memos by the investigator, referencing the related data. Although memos represent the researcher’s ideas, they were grounded in the data.

Data Analysis

Data analysis occurred simultaneously with sampling and data collection in this grounded theory study. Rather than following a linear series of steps, the investigator was involved in a matrix where several research process were in operation at the same time (Stern, Allen, & Moxley, 1984). A variety of qualitative techniques were utilized to analyze and verify explanations of the data, with emphasis on the description of processes by which women with breast cancer make decisions to use CTs in addition to orthodox treatments for cancer.

After the completion of the first five interviews, each transcript was coded line by line, searching for words that describe action in the setting. Using exact words or phrases, these data were labeled level I or substantive codes, and were written in wide margins next to the line in which it appeared on the transcript (Hutchison, 1986). These substantive codes were based
only on the data, thereby preventing the investigator from influencing the analysis with preconceived impressions of the phenomenon. In addition to transcripts from interviews, field note journals were handled in the same manner.

In these first five interviews, common codes which began to recur included, for example, control/loss of control, uncertainty, information overload, balancing, aims of CT use, sources of CT information, types of CTs used, health and illness beliefs, and hope. The transcripts were then literally cut and pasted and reorganized into folders according to the above codes. Next, a draft diagram of the potential associations among the codes was created. Further questions were raised upon examination of these associations, such as, for example, What do these women have in common and how are they different?, What is the effect of phase of the breast cancer trajectory on decisions to use CTs?, What are some strategies for maintaining/regaining control over their cancer?, Is hope a process or an outcome?, and What is the relationship between health and illness beliefs and actual CTs used? These questions, among others, were explored in subsequent interviews with women.

After the completion of 10 interviews, analysis of transcripts revealed the emergence of a number of new codes, including relationships with health care providers, fatigue, searching for CT information, changes in CT use over time, covering all the bases, and making sense. At this time, substantive codes which seemed to pertain to similar phenomena were then grouped into broader categories, which were generally more abstract in nature than substantive codes (Strauss & Corbin, 1990). Axial coding was used to define categories and make connections among categories and sub-categories. Strauss and Corbin’s paradigm model (Strauss & Corbin, 1990) was used to guide the linking of categories, encouraging organization of the data in terms of a set of relationships including the causal conditions, strategies, and consequences. Categories which emerged after 10 interviews included a) getting something into place, b) hand-picking CTs which fit, and, c) living with the security of CTs. These data were reviewed and coded again, allowing new themes to emerge. For example, within the category of hand-picking CTs which fit, sub-categories such as patterns of searching, credibility of
information, paying attention, evaluating the fit of a CT with beliefs, perceived disease status, establishing a CT regimen, evaluating the CT regimen, and modifying the CT regimen were identified. Again, the data were reorganized into folders related to the emerging new categories and subcategories. Visual diagrams were created to depict the relationships among the data, outlining a framework for the CT decision-making process of women with breast cancer. These diagrams, as well as questions generated during the analysis of previous transcripts were discussed with women in the final six interviews. Through selective sampling, the developing conceptual framework was tested by collecting data to prove or disprove the hypotheses generated by the framework.

Once saturation of the codes, categories, and constructs was reached, and when no new data emerged, the core variable was identified. Regaining control through CT use was articulated as the core variable, or the basic psychological process, which illuminated the main theme in the data (Hutchison, 1986). This core variable occurred frequently in the data, linked various data together, and explained most of the variation in the data (Hutchison, 1986).

During the final phase of data analysis, theoretical constructs were derived which describe the relationships between the three levels of codes. At this point, the data was woven back together again, and a theory, grounded in the data, began to emerge (Hutchison, 1986; Strauss & Corbin, 1990). Once the theory was formulated, the researcher asked selected informants if the theory accurately describes the process they use when making decisions to use CTs in addition to orthodox treatments for breast cancer. Three of the women confirmed that the analysis had captured their experience of making decisions about CT use. Chapter Four describes the emerging theory of the CT decision-making process.

While abstracting the data into categories and then theoretical constructs, a record of the hypotheses generated and tested concerning the interrelationships among the categories of data was kept (theoretical memoing). In addition to providing an audit trail, theoretical memoing allowed the investigator to conceptualize ideas and continually test them out as more data was collected and analyzed (Hutchison, 1986).
The constant comparison method of data analysis was used throughout all phases of data analysis to discover a core variable in the processes of making a decision to use CTs. By comparing the developing codes, categories, and constructs within and among each level of analysis, the investigator began to determine the presence, variation, or absence of patterns. Hutchison (1986) also suggests comparing behavior patterns of different groups sampled. For example, data collected from women who disclose their CT use to their orthodox physician was compared with those who do not, and women with recurrent breast cancer were compared to those newly diagnosed with breast cancer. Examination and comparison of these groups maximized differences and variation, contributing to the richness of the theory.

As the theory began to emerge, selective literature was incorporated to support and aid in its development. In grounded theory, the literature is used to illuminate or extend the theory which has developed out of observed patterns in the field, establishing a vital connection between theory and reality (Hutchison, 1986). Chapter Five outlines a discussion of the findings, which incorporates the literature.

**Ethics and Human Rights**

Ethical approval to conduct the study was obtained from two sources. These sources included the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects, and the BC Cancer Agency Clinical Investigations Committee.

Prior to each initial interview with subjects, the investigator explained the study and procedures to the subject, provided an information letter to take home, and obtained written consent to participate in the study (see Appendix B). An opportunity for the subject to ask questions concerning the study was ensured prior to obtaining written consent.

Subjects were informed both verbally and in writing that their participation was entirely voluntary and that they may withdraw from the study at any time without any effect on the health care that they receive. Further, subjects were informed that they were under no
obligation to answer any specific questions, or to discuss any particular topics. None of the women chose to exercise this right.

Throughout the recruitment and/or interview process, it was anticipated that the investigator may encounter women with physical, emotional, or spiritual problems. On two different occasions, women identified specific health concerns and were referred to the appropriate health care services. Follow-up telephone calls by the investigator to these women ensured that they were successful in accessing the appropriate health care service.

Confidentiality and anonymity of subjects was ensured by using code numbers rather than subjects’ names during the collection and analysis of the data. During the study, the key which matches the subject names to code numbers was kept in a locked drawer, to which only the investigator had access. Upon completion of the study, the key was destroyed and all audio tapes were erased. Transcripts were retained for future educational and research purposes, with written consent from the subjects. Approval from appropriate university and other committees will be obtained prior to any future educational or research activities related to the information collected in this study.

Summary

A grounded theory research design was outlined in this chapter as a means to investigate the process by which women with breast cancer make decisions whether to use CTs in additional to orthodox treatments for breast cancer. The sample selection and criteria, the data collection procedure, and the processes involved in data analysis were outlined. Aspects of rigor and ethical considerations were also discussed.
CHAPTER FOUR
FINDINGS

In this study, the experiences of making decisions about complementary therapies (CTs) were explored in a group of women with breast cancer. The findings provide a glimpse into the process that women engage in to make decisions about CT use while concurrently making decisions about orthodox treatment for their breast cancer.

The findings presented in this grounded theory study are to be applied, rather than generalized because they are tied closely to a specific time, place and persons. However, the understanding of these findings may have transferability in similar settings. Transferability depends on the degree of similarity between the actual setting and the study population, and the readers (Guba, 1981). Although the findings cannot be wholly applied to another setting, they may be used to generate insights and understanding, and then applied to a new setting. The consumer who reviews the findings and knows his or her setting and practice is the best judge of how these findings may be applied (Johnson, 1997).

The findings are organized in the following manner. To understand the context from which these findings are generated, a description of the women, including their choice of CTs is provided. In the next section, the study's core category and a general overview of the phases of the CT decision-making process are described. Finally, the specifics of each of the three phases of the CT decision-making process are outlined.

CONTEXT OF THE WOMEN'S DESCRIPTIONS

Sixteen volunteers were interviewed for this study, ranging in age from 39 to 71 years of age. Eleven of the women reside in the Lower Mainland, while five of the women live in Northern BC, in the communities of Prince Rupert, Terrace, New Hazelton, and Kitimat. A variety of cultural backgrounds were represented by this group of women, including two First Nations, one Spanish, one South American, one Italian, one Jamaican, one Chinese, and nine women of European descent. A range of educational levels were represented, from grade eight to university degrees, and the women reported a variety of occupations, including
homemakers, a bank teller, an administrator, a fish plant worker, teachers, a school principle, nurses, a mortgage specialist, and a book keeper.

The entire breast cancer disease trajectory was represented by this group of women, from early diagnosis to palliative care. At the time of interviewing, one woman had been diagnosed for three months, three women had been diagnosed within one year, seven were diagnosed for one to seven years, two were experiencing their first recurrence, and three were in the palliative phase of their breast cancer. For all of the women, the diagnosis of breast cancer was their first primary cancer diagnosis. None of the women were considered at genetic risk for breast cancer prior to their diagnosis, and none had undergone genetic screening for the BRCA1 and BRCA2 genes. Four women were aware of metastatic disease at the time of interviewing; one woman facing her first recurrence and three in the palliative phase of their illness.

All of the women had completed surgery by the time they were interviewed, 14 opting for lumpectomy and two receiving modified radical mastectomies. Of the 13 women who were offered radiotherapy after their lumpectomy, two declined this treatment. While chemotherapy was an option for 12 of the women, only nine chose to receive this treatment. Nine women were offered tamoxifen for hormonal treatment of their breast cancer; three declined this treatment. Three women declined both chemotherapy and radiotherapy, opting instead for complementary treatments only post surgery. All of the women in this study therefore received at least one orthodox treatment for their breast cancer, with most women utilizing two or more orthodox treatments.

Six out of the seven categories of CTs identified by the Office of Alternative Medicine (OAM) at the National Institute of Health (NIH) in the United States (US) were represented by the CTs used by this group of women. Women in this study reported using: a) herbal medicines such as essiac, selenium, ginseng, primrose oil, ginko biloba, taheebo tea, Devil's claw, yew tree bark, echinacea, and green tea; b) mind-body techniques such as visualization and imagery, relaxation therapy, supportive-expressive group therapy, meditation, prayer, and yoga; c) diet and nutritional changes such as high dose vitamins.
(A, B, C, and E), dried mushrooms, soy products, high fibre low fat diets, flaxseed oil and cottage cheese, apple seeds and almonds, increased vegetable intake (especially cruciferous vegetables), garlic, the Hoxsey diet, antioxidant supplements, calcium supplements, and natural progesterone from yams; 
d) **manual healing** such as massage, therapeutic touch, reiki, reflexology, and acupuncture; 
e) **biologic and pharmaceutical preparations** such as Co-enzyme Q10, melatonin, Mixed Immune Vaccine, sharks cartilage, and 714X; and, 
f) **alternative systems of medical practice** such as Ayervedic medicine, traditional Chinese medicine, homeopathy and naturopathy. The use of bioelectromagnetic CTs, the seventh category of CTs identified by the OAM at the NIH, was not reported by any of the women in the study. Other CT studies involving women with breast cancer have also found that the use of bioelectromagnetics was not represented in their samples (Balneaves, 1996; Gray et al., 1996). The emerging literature on the use of bioelectromagnetics suggests that this type of therapy is intended to relieve inflammatory joint pain and promote wound healing, which may not be priorities for women with breast cancer.

All of the women utilized a combination of CTs, usually from a variety of CT categories. The most commonly utilized CTs were: 
a) essiac; 
b) relaxation, meditation and imagery; and, 
c) vitamin therapy.

**REGAINING CONTROL THROUGH COMPLEMENTARY THERAPY USE**

The process of CT decision making by women with breast cancer began at the time of diagnosis and involved a struggle to regain control. The core category in this study, **regaining control**, was found to involve three phases; **taking action**, **taking back control**, and **maintaining an illusion of control**. (see Figure 2).
These three phases were closely intertwined with the tasks involved in breast cancer trajectory, where women slowly took back control from their cancer and the orthodox health care system in order to live their lives fully in spite of their cancer. The use of CTs by women in this study was reflected as a means through which an illusion of control over a disease full of uncertainty could be achieved and maintained. As one woman explained:

*It is essential to have hope in order to beat this thing... There are no guarantees, even with traditional cancer treatment, that I will be cured of my cancer. But you've got to believe that you can beat it, or you're sunk... The complementary therapies give you a sense of control, a sense of security that you're doing something for yourself. I don't really know if the essiac and other complementary therapies are really helping, you know, physically, but I feel in my mind and my heart like they are working. That's the main point to it all, to feel like something is helping you to heal. And when you believe that something is helping you, then you have hope.... Even if taking complimentary therapies only creates an illusion of control, you still have hope. Without hope, you're sunk.*

THE COMPLEMENTARY THERAPIES

DECISION-MAKING PROCESS

The CT decision making process was found to be comprised of three major interconnected phases: a) Getting Something in Place: Covering all the Bases; b) Hand-picking CTs Which Fit: Getting a Personalized Regimen in Place; and, c) Living With the Security of CTs: Fine
Tuning a CT Regimen to Live With. All of these phases occurred within the context of the breast cancer trajectory and correlated with the three phases involved in regaining control (see Figure 3). The first phase, Getting Something in Place, was often initiated at the time of diagnosis, and usually ended just before surgery. Phase II, Hand-picking CTs Which Fit, did not usually begin until after surgery and lasted through orthodox treatment and beyond. The third phase, Living With the Security of CTs, had a more individually determined start and finish with respect to the breast cancer trajectory. Generally, this phase began sometime after orthodox treatment was completed, and extended perhaps for the remainder of one's lifetime. However, should a recurrence of breast cancer occur, women usually returned to the second phase of the decision-making process, modifying their existing CT regimen (Phase II). Similarly, when the focus of orthodox treatment for breast cancer changed from curative to palliative, a return to the second phase of the decision-making process also occurred.

Figure 3. Overview of the CT Decision-Making Process

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Surgery</th>
<th>*XRT / Chemo</th>
<th>Recurrence</th>
<th>Palliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting something in place: “Covering all the bases”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand-picking CTs which “fit”: “Getting a personal regimen in place”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with the security of CTs: “Fine tuning a regimen to live with”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Taking Action  Taking Back control  Maintaining Illusion of Control

*XRT = Radiation Therapy
Chemo = Chemotherapy
For a small subgroup of the women interviewed, CT use did not begin until the time of recurrence. These women also proceeded through the three phases of the CT decision-making process. The first Phase, Getting Something in Place, occurred at the time of diagnosis with cancer recurrence. The second phase, Hand-picking CTs Which Fit, usually began after orthodox treatment decisions were made and lasted until orthodox treatments, with the exception of hormone therapy, were completed. Phase III, Living with the Security of CTs, often began sometime after radiation and/or chemotherapy for recurrence was completed.

Similar to the first group of women, when the focus of orthodox treatment for breast cancer changed from curative to palliative, women beginning CT use at the time of recurrence returned to the second Phase of the decision-making process. This second group of women differed from those who began CT use at the time of initial diagnosis in that they had never used CTs prior to their diagnosis with cancer, and believed that orthodox cancer treatments would cure their cancer. Further, once the orthodox treatments were completed, this second group of women believed that their cancer would never recur. As such, these women did not allow themselves to experience a high degree of uncertainty surrounding the efficacy of orthodox cancer treatments and their expectations of cure. They reported feeling in control of their health care decisions and their health prior to experiencing a recurrence. However, the diagnosis of a breast cancer recurrence heightened their feelings of uncertainty about the efficacy of orthodox treatments and reduced their feelings of control over their health and their future.

**Phase I: Getting Something in Place**

Phase I, Getting Something in Place: Covering all the Bases, usually began with a diagnosis of breast cancer, and for most women, ended at the time of surgery (see Figure 4). For some women, however, this phase lasted until orthodox treatment was well established, or even until after orthodox treatment was completed. During this phase women began using one or more CTs with the aim of quickly reducing feelings of loss of control.
The diagnostic and early treatment phase of the breast cancer trajectory is associated with high stress levels and a great deal of uncertainty (Northhouse, 1992; Rowland & Holland, 1991). During this phase, women may spend long periods waiting for test results and contemplating the possibility of a malignant diagnosis and eventual death. Once the diagnosis of breast cancer is confirmed, women are plunged into a new and uncertain world of specialized care, where they are expected to make sense out of complex treatment regimens and make decisions which will affect the rest of their lives, while simultaneously dealing with the anxiety inherent in a life threatening illness (Carnevali & Reimer, 1990).

Most of the women interviewed reported feeling a sense of information overload at this time and described feeling overwhelmed with the tasks of making decisions about orthodox treatment. As such, decisions about CTs often took a secondary place in this phase of the breast cancer trajectory. Women spent very little time researching information about CTs, if at all. In addition, some women were bombarded by advice from well meaning friends, family and coworkers at this time, adding to feelings of information overload and difficulties sorting through and making sense of the information in any meaningful way. One woman recalls her
feelings during the time between diagnosis and surgery, and how this impacted her CT
decision making at that time:

   I was spinning my wheels alot.... It was almost impossible for me to read at that point,
my brain wouldn't work. I guess I was in shock and you're so freaked out and
frightened that nothing, nothing functions anymore. I just basically relied on people to
tell me things and if it sounded good and I could afford it, I would go for it.

Another woman described the impact of unsolicited advice:

   The minute I was diagnosed it was just instantaneous. Everybody was coming at me
with all this advice. I couldn't process it. It just made me more tense.

A sense of loss of control over one's body, day-to-day life, and one's future was also a
common feature of this phase of the breast cancer trajectory, adding to the difficulty of making
decisions about both orthodox and CTs. A pre menopausal woman described her feelings:

   I went through a really difficult stage after the diagnosis and before the mastectomy
when I felt that my life had been taken over for me. The doctors were telling me that
they would be putting me into an artificial menopause, and that I would be getting
chemo. They were going to take my 40-60 years away from me and turn me into an old
woman. I had no control over it.... They'd taken over. They were in control.

Despite feelings of anxiety, loss of control, and information overload in this early phase of
the breast cancer trajectory, many women felt compelled to "do something" with regard to CTs,
especially in the waiting period between diagnosis and surgery. For most women, there was a
sense of urgency associated with doing something at this time. One woman described how she
could visualize the cancer cells taking over within her body, during this waiting period:

   I guess it was about three and a half weeks from my diagnosis to my actual surgery, but
from when I found my lump to my actual surgery was six or seven weeks. So I was
starting to feel like this is going on and nothing is happening.... I remember having
nightmares about having all these little cells running around in my body, breaking off
and spreading the cancer.... I needed to do something immediately to decrease my anxiety
and make me feel like I had some control over the situation while the medical profession
were figuring out what they were going to do with me.

This feeling of loss of control over the cancer and resultant anxiety was common among
women throughout the breast cancer trajectory, during periods when orthodox treatment is not
occurring (i.e., pre surgery, between surgery and chemotherapy and/or radiation therapy, after
orthodox treatment is completed). However, women described the period between diagnosis
and surgery as the time when these feelings are the strongest, compelling the woman to take action, to "do something."

Given the lack of guarantees of cure associated with the orthodox treatment of breast cancer, women were motivated to take action to put "something" quickly into place that would potentially increase the odds of achieving a cure for their cancer. Although women understood that most CTs lack scientific evidence of efficacy, this was not a deterrent. A young woman who has just been diagnosed with breast cancer stated:

Sure, people still die after orthodox treatment...but obviously complementary medicines don't work either because there's still people that die after getting all of them. So why wouldn't anyone try everything they could? You know, cover all the bases, just in case?

Covering all the bases was a major theme in the first phase of the CT decision-making process which was seen to add "extra protection" against the uncertain outcomes associated with both orthodox and complementary treatments for breast cancer. Attempts to cover all the bases was initiated early in the breast cancer trajectory as a method to increase a sense of control during a period of great uncertainty and loss of control, as well as to enhance the odds of a cure as a result of both orthodox and complementary treatments. However, decisions regarding which CTs to utilize to cover all the bases was generally made very quickly. Anxiety, shock, information overload, feelings of loss of control, and a sense of urgency to get a CT into place precluded any well researched, reflective decisions about CT use at this time. At this point, women appeared to react to the shock of the cancer diagnosis, rather than proactively making decisions about CT use.

Mind-body CTs, such as meditation or therapeutic touch, and herbs such as essiac were the most commonly utilized CTs during the first phase of the CT decision-making process. Generally, women put into place a CT that they had used successfully in the past for other health related crises, or relied on advice from trusted others. Minimal analysis of this advice from trusted others was carried out beyond determining whether the advice "sounds reasonable" and whether the therapy was affordable.
Outcomes of Phase I

Getting Something into Place resulted in enhanced feelings of control over the spread of the cancer cells during the waiting period and/or during surgery and treatment. This in turn, increased women's' sense of hope that breast cancer could be cured. One woman, reflecting on the impact of using imagery during the first phase of the CT decision-making process stated:

*I felt like I was finally doing something for myself. I was influencing what was happening to me, you know, making a difference. I was controlling the cancer cells, limiting their spread. I felt stronger, more hopeful. Maybe I could beat this thing.*

Phase II: Hand-picking CTs Which Fit

Phase II, Hand-picking CTs Which Fit: Getting a personalized regimen in place, constituted the major portion of the CT decision-making process (see Figure 5). During this phase, women researched, tried out, evaluated, and modified various CTs to create a regimen that suited their own personal beliefs and needs. Generally, this phase began after the woman had undergone surgery to remove the cancer, and lasted through orthodox treatment (chemotherapy and/or radiotherapy), and for many months or perhaps years post orthodox treatment. For some women, this phase did not begin until orthodox treatment was completed and lasted for many months or years.

Figure 5. Phase II: Hand-picking CTs which Fit: “Getting a Personalized Regimen in Place”
Immediately post surgery, women reported feeling less time pressure to make important decisions about their complementary and orthodox treatments to manage their cancer. They described an increased sense of relaxation and reduced anxiety knowing that the cancer was removed from their body. Further, they felt that the CT put in place during the first phase of the CT decision-making process may have contributed to the control of the spread of their cancer cells. However, at this point, women still felt a great deal of uncertainty regarding the degree to which the CT they had selected was actually helping. Compared to the sense of urgency experienced pre surgery to get a CT in place, women felt they had more time immediately post surgery to review their pre surgery CT choice(s) and explore other CT alternatives to include in their treatment regimen. Similarly, this increased sense of time provided women an opportunity to make and revise decisions about orthodox treatment. However, the women were also aware of the potential for "stray" cancer cells to be still "circulating", even after the surgical removal of the tumor and/or breast, and the inclusion of one or more CTs during Phase I. Further, if radiotherapy and/or chemotherapy were indicated, oncologists often suggested that women start these treatments as soon as possible post surgery. Therefore, although women felt that they had more time post surgery to make decisions regarding both orthodox and complementary therapies, this time period had definite limits.

The aims of CT use during the second phase of the CT decision-making process were broader than those of the first phase. In addition to attempting to control the spread of stray cancer cells, women reported using CTs in the second phase for the purposes of managing the side effects of orthodox treatments, promoting feelings of well being, boosting the immune system, and for the prevention or delaying of a recurrence. None of the women interviewed thought that CT use would cure their cancer. Rather, CT use was seen as a supportive action to enhance the beneficial effects and/or manage the unwanted side effects of orthodox treatments.

Searching for Information

Phase II of the CT decision-making process generally began with active searching for information about various CTs, including the CT put in place in Phase I. Rather than merely
reacting to the shock of a breast cancer diagnosis and relying on the advice of trusted others to make decisions about CTs as evidenced in Phase I, women in the second phase took a more proactive and systematic approach to seeking out and evaluating CT information. The degree to which women searched for information, the type and number of CTs they sought out, and the sources of information they utilized varied widely.

**Sources of Information**

A common problem associated with the task of searching for information about CTs is the lack of objective, evidence-based scientific information available to both the lay public and health care professionals alike. Few written sources of information exist in lay language which critically evaluate a wide range of CTs with respect to efficacy and side effects, according to Western scientific principles. Women were forced to search among bits and pieces of information, making their own evaluations of whether or not a particular CT is “proven”. Further, this piecemeal approach to searching for information did not assist women in focusing their search for information in a way that assisted them to make quick and easy decisions about which of the hundreds of CTs to use.

In addition to written information about CTs, those individuals seen as having some expertise regarding CT use were accessed for advice and information. These individuals included cancer survivors, friends, co-workers, health food store workers, CT practitioners, and, less frequently, orthodox health care practitioners (OHCPs).

Orthodox health care practitioners were chosen less frequently than other individuals as sources of information about CTs because women recognized the varied levels of knowledge and negative attitudes about CT use by many OHCPs. Prior to discussing CT use with an OHCP, women made an assessment of whether their OHCP would be a good source of information about CTs and whether he or she would support and endorse CT use. Only then would she decide to potentially discuss CT use with that OHCP.

Most women identified her oncologist and, occasionally, her general practitioner (GP) as the main OHCP with whom she felt it was important to discuss her current or potential CT use.
However, this occurred only if these OHCPs were "paying attention." Nurses and other medical specialists were not seen as having any major influence or input into one's decisions about CT use, nor in the ongoing support of their use of CTs. These particular OHCPs were seen as having little control or input into decisions about a woman's orthodox cancer treatment plan and were therefore viewed as having little to contribute to discussions about how various CTs would fit in with orthodox treatment. Clearly, if anyone in the orthodox health care system was seen by women as an "expert" or authority on CT use, it was the oncologist or GP.

**Paying Attention.** Deliberate and active listening to the patient were described as critical behaviors of an OHCP who paid attention. The OHCP who paid attention was concerned about how the patient viewed her situation, and wanted to know the patient as a whole person, rather than merely as a tumor attached to a breast. These individuals approached situations with an open mind, acknowledged and validated women's beliefs about health and illness, and supported women's decisions to include or exclude orthodox and/or complementary treatments. Other hallmarks of an OHCP who paid attention were identified as trusting that a woman knows what is best for her, and viewing her as a true partner in the treatment decision making process, both for orthodox and complementary treatments. The women interviewed wanted to be seen as individuals rather than as breast cancer statistics, and wanted their OHCP to know how their breast cancer diagnosis affected them as individuals.

Unfortunately, the majority of women interviewed described their oncologists and/or GPs as *not* paying attention. These oncologists and/or GPs clearly did not convey an attitude of acceptance and validation of the women's concerns, and many made no attempt to know the women beyond the pathology of their breast tumor. This behavior of not paying attention was described in situations involving decisions about both orthodox and complementary treatments.

*Almost anything I raised, be it about traditional or complementary therapies, was dismissed. I was really worried about some things, but he just dismissed me as a neurotic woman. He didn't validate the very real issue about heart disease associated with chemo that I had raised. I felt totally unlistened to. I didn't feel that he even looked at me as a person. He didn't even want to know me. I felt like telling him, "You don't know me, my power, my energy. You don't know who I am. I am more than a person with breast cancer."*
When women did not accept the recommended orthodox treatments, they recognized that some physicians had a difficult time accepting their decisions. Women reported feeling that the physicians thought they were being foolish, essentially signing their own death certificates by not accepting the recommended orthodox treatment. A number of women described feeling as though the physician was in charge, and that their own beliefs and needs were not important. The relationship with the physician was therefore commonly characterized by a sense of loss of control, powerlessness, and dissatisfaction.

_There was never any acknowledgment of the validity of my belief that chemo was not the right thing for me. I knew in my heart and soul that chemo was bad for me, but they weren’t listening. They just said, “You’re supposed to be on Protocol II or whatever....” They don’t [sic] say that, but I knew that’s what went through their minds. I just got the message, “We’re the experts. You just do what you’re told”.... Once I decided I wasn’t having chemo, they really treated me like I had signed my own death warrant. And they paid me lip service, like, “Well of course that’s your decision.” They were saying the words but their body language and facial expressions were, they were shaking their heads in disapproval at me._

When an oncologist or GP did not pay attention, a number of outcomes were described. Women reported feelings of being unsafe and frightened in his or her care and were therefore unable to develop any level of trust in this physician. Without this trust, women did not feel they were able to openly discuss CT use with them, due to the highly controversial nature of CT use within the orthodox health care system. Many of the women interviewed deliberately withheld information about current and potential CT use, due in part to the physician's lack of paying attention.

_The cancer doctor at the Cancer Clinic was totally unreceptive to anything I had to say. He was totally closed to anything. He couldn't hear me because of his attitude. I didn't feel in any way that I would be safe. I felt like I was just another research article and they were going to pump drugs into me just because that is what the protocol says.... He wouldn't see me as a person and I didn't feel safe. In fact I felt really frightened._

_How could I talk with him about using various herbs and visiting a naturopath? He couldn't even talk to me as an equal about the chemo and radiation. I just couldn't see him being open minded or fair about alternative therapies. There was no point in even bringing it up._

A common strategy considered by women when they felt their oncologist or GP were not paying attention was to search for a new physician who does pay attention. However, few
women actually ever carried out this strategy during this phase of the breast cancer trajectory. Generally, women were still learning how the orthodox health care system works during the early phases of the breast cancer trajectory, and were still overwhelmed by the complexity of it. To find a new physician meant the woman must search for even more information, compounding any feelings of fatigue or information overload. Further, women feared that they may develop a reputation of being "uncooperative" or "a problem" among the tightly knit group of physicians, thereby jeopardizing future medical care. The majority of the women interviewed chose not to find a new physician, instead opting for other strategies that would enable her to maintain control over her situation and become informed about CTs.

Information Overload and Fatigue. In addition to whether or not the OHCP was paying attention, a woman's level of information overload and/or fatigue also played a role in whether she discussed CT use with her OHCP. Often, at the point in the breast cancer trajectory where women were searching for information about CT use, they were also trying to make sense out of complex orthodox treatment information at the same time. As such, many women frequently reported feeling overwhelmed or overloaded with information. Additionally, these women were usually recovering from surgery and the shock of being diagnosed with a potentially life threatening illness. Varying levels of fatigue were reported at this time, from mild to severe. In their search for information about CTs, these factors, in addition to whether the physician was paying attention or not, influenced a woman's decision to access her physician as a source of information.

Figure 6 depicts ways of maintaining control during the search process for CT information as women decided whether or not to discuss CT use with her physician.
Figure 6. Ways of Maintaining Control During the Search Process

**OHCP Interaction Pattern**

<table>
<thead>
<tr>
<th>Women's Level of Fatigue/Information Overload</th>
<th>OHCP Paying Attention</th>
<th>OHCP Not Paying Attention</th>
</tr>
</thead>
<tbody>
<tr>
<td>*OHCP Paying Attention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintains control through a high</td>
<td>Maintains control</td>
<td></td>
</tr>
<tr>
<td>attention to discussion and/or witholding</td>
<td>through deliberate</td>
<td></td>
</tr>
<tr>
<td>CT use information to maintain beliefs</td>
<td>avoidance of</td>
<td></td>
</tr>
<tr>
<td>Avoids risk of receiving advice or</td>
<td>discussion and/or</td>
<td></td>
</tr>
<tr>
<td>information that may undermine</td>
<td>withholding of CT</td>
<td></td>
</tr>
<tr>
<td>&quot;tentative&quot; decision re: CT use</td>
<td>use information</td>
<td></td>
</tr>
<tr>
<td>Does not discuss CT use with OHCP</td>
<td>Avoids negative</td>
<td></td>
</tr>
<tr>
<td></td>
<td>confrontation re: CT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>use</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintains control by selectively</td>
<td>Maintains control by</td>
<td></td>
</tr>
<tr>
<td>introducing CT topics and questions in</td>
<td>deliberately witholding</td>
<td></td>
</tr>
<tr>
<td>discussion with OHCP</td>
<td>information re: CT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>use</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Seeks reinforcement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>and information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>re: CT use</td>
<td></td>
</tr>
<tr>
<td>Discusses CT use with OHCP</td>
<td>Does not discuss CT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>use with OHCP</td>
<td></td>
</tr>
</tbody>
</table>

* OHCP = Orthodox health care professional

Cell a (Figure 6) represents those women who did not feel overwhelmed with information, had minimal fatigue, and were fortunate to have a physician who paid attention. These women were likely to have the physical and emotional resources to engage in discussions about the pros and cons of CT use and had the opportunity to discuss controversial issues such as CT use in an accepting and supportive environment. Women represented by this cell were most likely to discuss CT use with their physician(s). Physicians were utilized by women both as a source of CT information and as a means of monitoring their ongoing CT use for safety. The women maintained a sense of control through selectively introducing CT topics and questions for discussion with their physician(s), who, in turn, conveyed respect to the women in this situation.
She [the oncologist] was very accommodating. She bent over backwards to make it okay for me.... She’s completely supportive of anything I take and I can check it out with her because I don’t want a weird reaction with the Tamoxifen.... I talk to my doctor about anything I like regarding complementary therapies and I don’t feel silly or foolish.... I expect her to monitor what I’m taking and tell me if there’s a possibility of it having an adverse effect on something else I’m taking. I expect her to catch that.

Cell b (Figure 6) represents those women who, although they had a physician who was paying attention, chose to not discuss their CT use with them. While information overload and/or fatigue are cited as main reasons for withholding CT information in this situation, the major benefit to the woman was a maintained sense of control. Accessing information from the physician served only to increase the sense of information overload and possibly fatigue for these women, thereby reducing feelings of control. Further, in accessing CT information from their physician(s), these women feared the possibility of receiving information which would challenge their foundational ideas about CT use. These women trusted their physician(s) and found it impossible to ignore their advice, even if it involved re-examining the CT information she had already sought out and assimilated. Given that these women were already fatigued, the notion of re-examining information perpetuated their sense of information overload, and in turn, their fatigue. Avoiding discussing CT use with their physician(s) was therefore a positive strategy that these women employed to maintain a sense of control.

Even though I consider my oncologist a credible source of information about CTs and I trust him completely, I’ve deliberately withheld information about my various alternative therapies. I don’t want to have a discussion around it.... I don’t want to hear that he doesn’t think that I should be doing it. Then I’d have to go back and sort through that all again.... I’d have to decide how that additional piece of information fits in...and I just don’t have the energy. I can’t put anymore information in my head and have it make sense anymore; it’s too full.

Many of the women interviewed were represented by cell c (Figure 6). These women unfortunately did not have a physician whom they felt was paying attention, and they reported moderate to severe levels of information overload and fatigue. Therefore, these women did not discuss CT use with their physician. They felt that initiating a discussion about CT use with their physician(s) would prove to be confrontative and judgmental, which would only add to
feelings of fatigue and being overwhelmed. Control over the situation was therefore maintained by deliberately avoiding discussing current and potential CT use.

_They're [orthodox physicians] totally close minded and very negative about my complementary therapy use. It's almost like it's a big threat to them. I just didn't have the energy to try to convince them that I believe in both forms of treatment [orthodox and complementary]. I think I get good advice about traditional medical treatment for my breast cancer from my oncologist, but I think he feels threatened because traditional medicine doesn't have all the answers and complementary medicine might fill in some of the gaps. I can't spend my energy trying to change his beliefs. It's just better to keep my mouth shut._

Although the women represented by cell d (Figure 6) did not experience a great deal of fatigue and information overload, they did not have access to a physician who paid attention. These women sought out CT information elsewhere, primarily outside of the orthodox health care system. In this way, these women maintained control over their CT decision making and avoided any negative confrontation regarding CT use by deliberately withholding CT information from their physician(s).

_I tried once to ask my oncologist about co-enzyme Q10, but his eyes just glazed over. I knew he wasn't listening. I don't bother asking him anymore.... I just talk to my naturopath, another woman who uses co-enzyme Q10, and the librarian at the BCCA. They know me really well and I trust their advice._

Figure 6 explains why the majority of women with breast cancer may not access their oncologist and/or GP as a source of CT information or discuss ongoing CT use. The decision to discuss CT use with a primary physician is complex, and is affected by the physician's attitude and behavior and the woman's level of fatigue and information overload. In an effort to maintain control over her situation, the woman either chooses to discuss or withhold information about CT use. If a woman is unable to utilize her OHCP as a source of information about CTs, she must search elsewhere. The majority of women interviewed did not have access to a physician whom they felt paid attention, and, as a result, largely relied on sources of information outside the orthodox health care system to make decisions about CT use. These outside sources included the lay literature, the internet, word of mouth, advice from health food store employees, television programs, and less frequently, discussions with alternative health care practitioners.
Patterns of Searching

All women searched for information about CTs in the second phase of the decision-making process. However, the patterns of searching for CT information varied among women. Generally, the patterns of searching for information about CTs in Phase II of the CT decision-making process were related to a woman’s level of information overload and subsequent fatigue as a result of her orthodox treatment, and her level of clarity of beliefs about health and illness. Figure 7 provides a schematic representation of the patterns of information searching about CTs.

Figure 7. Patterns of Information Searching About CTs

<table>
<thead>
<tr>
<th>Beliefs About Health and Illness</th>
<th>Known / Clear</th>
<th>Unknown / Unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Limited</td>
<td>Limited</td>
</tr>
<tr>
<td></td>
<td>Focused</td>
<td>Diffuse</td>
</tr>
<tr>
<td></td>
<td>Searching</td>
<td>Searching</td>
</tr>
<tr>
<td>a</td>
<td>b</td>
<td>c</td>
</tr>
<tr>
<td>Low</td>
<td>Limited</td>
<td>Limited</td>
</tr>
<tr>
<td></td>
<td>Focused</td>
<td>Diffuse</td>
</tr>
<tr>
<td></td>
<td>Searching</td>
<td>Searching</td>
</tr>
<tr>
<td>d</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women’s Level of Fatigue/Information Overload</td>
<td>Extensive</td>
<td>Extensive</td>
</tr>
<tr>
<td></td>
<td>Focused</td>
<td>Diffuse</td>
</tr>
<tr>
<td></td>
<td>Searching</td>
<td>Searching</td>
</tr>
<tr>
<td>a</td>
<td>b</td>
<td>c</td>
</tr>
</tbody>
</table>

Cell a (Figure 7) represents those women who focused their searching to a limited number of CTs, but extensively searched out those specific CTs. These women were aware of their beliefs about health and illness, such as ideas about what caused their cancer and how orthodox cancer treatments affect their physical and mental well being. In turn, these women had clear
ideas about which CTs fit with these beliefs. They were not limited by a sense of information overload and/or fatigue and were therefore able to exhaustively search various sources for information regarding the specific CTs that they were interested in.

For me, I think my cancer was stress related. I've had alot of stresses in my life in the last two years, and I believe it's the straw that broke the camel's back. I'm convinced I don't handle stress well, so therefore I must learn to handle it to be well again. That's why I focused on reading about meditation and took a meditation course.... I talked to the librarian at the Cancer Agency about it and did a literature search, I talked with the woman there [at the Cancer Agency] who does the relaxation group, and I talked with various cancer patients who use meditation.... I feel like I explored every source of information about meditation available.

Cell b (Figure 7) represents those women who also focused their searching to a limited number of CTs, but due to a sense of information overload and fatigue, these women also limited the scope of information they searched out related to those CTs. Similar to those women in cell a, this group of women also had a clear idea of what their beliefs were regarding the cause(s) of their cancer and the effects of orthodox treatment on their physical and mental self and were therefore able to limit the number of CTs about which they search for information.

I decided to use therapeutic touch without doing too much researching on the subject. I believe in the idea of a human energy field, and I had the idea that radiation was messing with that energy field. So I needed the therapeutic touch to stay well during the radiation treatment.... I didn't go and do the research study thing. I didn't do a literature search.... I didn't read everything that I could find that had been written about it.... By the time I got to the end of my [orthodox] treatment I was so totally exhausted that I didn't want to research any more. I felt like I should go and read the studies and find out more for myself, but I didn't have the energy. I just talked with the Clinical Nurse Specialist and a nursing friend about it.

Cell c (Figure 7) represents women who did not have clarity regarding their health and illness beliefs. As such, they could not easily determine which of the hundreds of potential CTs upon which to focus their search for information. Women represented by this cell also were overwhelmed by information about their orthodox treatment and, as a result, limited the scope of their information searching about CTs due to fatigue and information overload. A diffuse approach utilizing limited sources of information typified the process of searching for information about CTs by women represented by cell c.
An extensive, diffuse approach to searching for information is represented in cell d (Figure 7). Women represented in this cell had yet to clarify their beliefs about health and illness, and subsequently which CTs fit with those beliefs. Further, these women were not limited in their scope of information seeking by information overload or fatigue. As such, they searched extensively about a wide number of CTs.

I sort of believed that everything would sort of help. I didn't really know at that point what I specifically believed in. I was just going to try everything. I was searching to try anything I could. I was all over the map.

I started picking up the Alive magazine in the health food store and going to the library and reading books.... I kept going to the library and talking to the librarian and doing literature searches...people gave me books and I poured over them.... I talked with other cancer patients and watched videos on lots of different topics. At first it was like too much information overload. I thought, "How can anyone sort through this stuff and know where to start with taking any of these complementary treatments? How can I know whether to start with meditation or taking herbs?" There's just way too many complementary therapies out there and too much information, both good and bad, to know where to start.

While a small number of women were able to articulate their beliefs about health and illness during the early phases of the breast cancer trajectory, the majority of women interviewed had not clarified their beliefs at this point and had difficulty narrowing the scope of potential CTs they might use. These women therefore took a more diffuse, less focused approach to searching for information about CTs. In an attempt to compensate for this lack of focus, these women also relied upon other strategies to assist them in sifting through information in order to make decisions about which CTs to use. Women who were clear about their health and illness beliefs and were able to focus their searching for information about these CTs also reported using these strategies to support and strengthen their CT decision-making. These strategies included: a) evaluating the credibility of the source of information; and, b) determining whether the information "makes sense."

Credibility of the Source of Information

Given the lack of evidenced-based information about CTs available to the lay public and the absence of professional regulations associated with many groups of CT practitioners in British Columbia, women were left to evaluate the credibility of the source of CT information on their
own. This strategy was mainly used to evaluate a CT practitioner (e.g., naturopath, homeopath) or promoter of a CT (e.g., health food store employee, friend, cancer survivor), rather than a written source of information (e.g., lay literature, the internet), or an OHCP.

A variety of criteria to evaluate the source of CT information were used by the women interviewed including repetition of the same information across multiple sources, the reputation and length of experience of the CT practitioner, women's intuition, and the amount of trust in the person promoting the CT. This trust was established by determining whether the promoter of the CT had humanitarian versus commercial aims, whether the promoter of the CT was able to produce either research-based or anecdotal evidence of the efficacy of the CT, the cost of the CT, and whether the promoter was able to answer questions about the CT. Most women reported using all of these criteria to varying degrees; intuition was reported as the major force in evaluating sources of CT information.

All this information about complementary and traditional treatments...it's just very confusing. I really start to question if any body really knows what the hell they're talking about. Maybe my own inner guidance is the best thing.

Making Sense

Along with criteria to evaluate sources of CT information, women also used another strategy to determine whether the information presented by a promoter of a CT or in written sources of information "makes sense." In the absence of evidenced based information to support the use of a particular CT, women relied on their common sense to evaluate whether that CT has the potential to be effective.

I try to see things from a scientific point of view, like when I read about the 714X injections, I investigated a little bit. And although it is not proven, its something that makes sense to me....With alternative therapies it is very difficult because its not proven so I try to use my common sense and use those things that make sense to me.

Determining whether information makes sense involved three processes, including evaluating the fit of the potential CT with beliefs about health and illness, determining one's perceived disease status, and balancing risk versus harm.
Evaluating Fit of CT with Beliefs. Evaluation of the fit of a particular CT with one's health and illness beliefs was employed only when women were clear about their beliefs. In this way, the number of CTs that a woman might consider trying could be reduced from the potential number of CTs available. For example, a number of women firmly believed that their breast cancer was caused by stress. Therefore, their repertoire of potential CTs was limited to those CTs which aim to reduce stress, such as meditation. In keeping with this belief, one woman avoided situations which she believed would greatly increase her stress, including orthodox treatments such as chemotherapy.

As I understand it, chemotherapy damages the body and is very violent. I just would have been so stressed out going for chemo. I just couldn't see how adding to my stress would cure my cancer, especially when I believe that stress is what caused it [the cancer] in the first place. It just doesn't make sense to me... but if the chemo was 100% guaranteed to work, if there was no risk of it coming back, well, then it makes sense... I think that meditation will help me to reduce my stress, rather than assaulting my body. Meditation makes sense to me.

As stated earlier, many women in this phase of the breast cancer trajectory had not yet clarified beliefs about health and illness. These women therefore relied on the remaining two processes, determining one's perceived disease status and balancing risk versus harm, to sort through and narrow down the overwhelming amount of CT information. Beliefs about health and illness, however, did not play a strong role in decision making for women in the palliative phase of their illness. Although these women had spent a long time examining their beliefs about health and illness, they were more likely to engage in CTs that may not fit with their belief systems. For these women, making sense of the CT information was largely influenced by her perceived disease status.

When the doctor tells us there's almost nothing they can do for you, then you reach for something else. Whether or not you believe in these things, we try. So you try it.

Perceived Disease Status. Making sense of CT information was also described in the context of the woman's perceived disease status. Although the breast cancer trajectory is a useful framework for health professionals to gauge a woman's disease status, women made their own evaluations of whether their cancer had been cured, and the likelihood of it coming
back. The women interviewed used many cues to determine their current disease status and perceived risk of recurrence (or the risk of death in the case of women in the palliative phases of their illness) from breast cancer. These cues included the integration of:

a) intuitive based cues, elicited from within the woman herself; b) statistical information from an OHCP, such as numerically based estimations of disease recurrence; and, c) anecdotal stories of other women's experiences with breast cancer.

Intuitive based cues regarding disease status and perceived risk of recurrence were commonly used by all women when making sense of CT information. Women described this intuition as "inner guidance" and "gut instinct," and had difficulty articulating where these feelings originated from. However, these instinctual feelings were strongly relied upon when determining which CTs made sense. For example, immediately post surgery some women intuitively felt that their cancer was completely gone; others felt that stray cancer cells were still circulating. Therefore, which CTs "made sense" were different for each woman. The woman who believed that her cancer was gone post surgery felt that preventive CTs such as relaxation and a modified diet made sense given her perceived disease status. Conversely, the woman who felt that stray cells still circulated in her body post surgery reported that CTs that directly attacked the stray cells, such as 714X, made sense to her. Clearly, making sense is a very personalized and individual process; what makes sense to one woman may not make sense to another.

Many of the women also relied on statistically based estimations of disease recurrence presented by OHCPs to make sense of CTs. Women were commonly given an estimation of the risk of recurrence by their oncologist(s) when making decisions about orthodox treatment. Although women reported utilizing these statistical estimations, these cues were not used in isolation; women also incorporated instinctual cues to make sense of CT information. For example, one woman identified how her estimation of her disease status, both now and in the future, was influenced by both instinct and statistical data.

_I didn't want to have any part of those [mixed bacterial vaccines to stimulate the_
immune system], and the biggest reason was that I felt healthy enough at that point. I didn’t think I needed them. I felt that my cancer was gone at that point.... But I know there are no guarantees. There’s a chance it might come back.... If I were sitting here in an office with metastatic disease, I know I’d feel really different about this and I might be willing to try this on the off chance that it might help me. But right now I’m sitting here and I know that statistically I’m in a good risk prognosis group, and I feel really healthy. In my gut I feel I don’t need it right now. It just doesn’t make sense at the present time.

This quote also demonstrates the fluidity of CT decisions, and how they may change over time as a woman’s position along the breast cancer trajectory changes. This woman had definite ideas about which CTs, if any, she would and would not utilize presently, in her current situation. However, she allowed for the fact that despite recurrence statistics which were in her favor and gut instincts that told her that her cancer was gone, there were no guarantees that she would be cured forever. Therefore, she acknowledged that what CTs made sense to her now may not make sense later in her life.

Anecdotal stories of other women’s breast cancer experiences were used less frequently than intuition and statistics as cues to make sense of CT information. Although women frequently talked about other women’s breast cancer stories related to CT use, many identified how these women were different than themselves. As such, women were less confident in using what they had learned from these stories when initially determining whether a CT made sense. However, upon trying out and evaluating a particular CT to be an effective component of their CT regimen, women often cited anecdotal stories of other women’s CT use as support for ongoing use of that particular CT.

Balancing. Balancing was the third strategy utilized by women when determining whether a particular CT makes sense. Balancing involved at least two steps, balancing risk versus harm, and harm versus good.

Balancing the risk of recurrence versus the potential harmful effects of CTs necessitated an estimation of the potential outcomes which could occur if a woman either did or did not practice a particular CT. If she did not practice a particular CT, the woman evaluated the potential risk of her cancer recurring. This was weighed against an evaluation of the potential harm incurred if the woman chose to practice CTs. Essentially, the women at this stage asked themselves, "Is
my risk of recurrence and/or death without using CTs greater than the risk of harming myself by using CTs, given the lack of scientific information about harmful side effects of many CTs?"

_I remember asking myself, "What will happen if I don't use these herbs? If I choose NOT to take them and my cancer comes back, will I spend the rest of my life agonizing over whether I made the right decision or not? And if I do take the herbs, can I feel confident that I'm not hurting myself?" There's just not enough known about these things. It's really hard to know what to do. For me I think I felt that my cancer had been eliminated by the chemotherapy and surgery. But I wasn't sure that it wouldn't come back. I knew I couldn't live my life each day fully and be at peace with myself, knowing that my cancer could be growing again. So I took the herbs.... It just made sense to me. My need to feel that I was doing everything to prevent my cancer from coming back was stronger than my fear of side effects from the herbs. Besides, I was fairly certain from the stuff that I've read that the herbs wouldn't kill me. I wasn't so sure about using things like sharks cartilage or injecting 714X, though.... I guess in retrospect I was taking a calculated risk with the herbs._

For some women, balancing risk versus harm included an evaluation of orthodox treatments such as radiation and chemotherapy against a particular CT. In this way, these women were able to determine which treatments made sense to them by utilizing a balancing strategy.

_They told me I had a 30 percent chance of recurrence. Well, that's a 70 percent chance that it won't come back. The chemo would only give me a 10 percent improvement, so that's a 20 percent chance that if I had chemo, it would come back anyway. So they're asking me to take something that could make me very ill, it could have alot of side effects that might kill me, and there's a 90 percent chance that it won't do me any good. That's silly, it's not good thinking. It doesn't make sense to ask someone to take the treatment based on those odds.... Reflexology makes way more sense in my situation.... I know the risks of not taking the chemo, but I feel I can achieve the same or better outcome from reflexology without the serious side effects from the chemo._

In the second step of the balancing strategy to make sense about CTs, women evaluated the potential benefits of using a particular CT against the potential harmful side effects incurred in practicing such a CT. This step was more focused than the first balancing strategy, in that it dealt with an evaluation of a particular CT's risk of doing more harm than good as reflected in one woman's statement:

_Apparently it [essiac]will do you no harm, so why not give it a try? Even if it doesn't end up doing anything positive for me, at least it won't hurt me._

All of the women interviewed were very attentive to this second balancing strategy, aiming to maximize benefits and avoid or minimize harm from a particular CT. The women were
concerned about harm from taking: the wrong combination of therapies, including orthodox treatments, thereby risking harmful drug interactions; a therapy that was "too weird", "too way out", "too far out on the edge;" or too much of a therapy, thereby risking an overdose.

*I don't want to do more harm than good, you know. You can be gung ho in one way with a complementary therapy, and then you end up getting sick. It's important not to go too overboard...you need to balance it out.*

*I try to stick to a happy medium, you know. I didn't want to go too overboard because you can intoxify your body by taking too much or the wrong complementary therapy. I figure I know some, but I don't know enough to avoid doing harm to myself. In reading more and more you find that if you don't do it right, you can do more damage than good. The risk just doesn't make sense.*

Women articulated their understanding of the need to avoid harm by taking CTs, especially given the lack of information about side effects and the uncertainty surrounding the benefits of many CTs. As a result, many women reported seeking a "happy medium" when determining which CTs made sense to them.

*The dosages that I picked are sort of in the mid range. I'm not taking as much as what some people might say, but I'm taking more than what other people do, so I'm pretty much sticking to the mean. The complementary therapies that I've chose are fairly mainstream, you know, I didn't want to get too far out on the edge. I read about shark cartilage and exotic mushrooms; there's just so much stuff out there. I just thought no, they're too weird. And I think I balanced the risk of harming myself against the potential to give myself some benefit.*

Although all of the women spoke of the importance of avoiding or minimizing harm related to CT use, the degree of harm tolerated by an individual was dependent on her perceived disease status. For example, one woman in the palliative phase of her illness was more willing to risk unpleasant side effects and uncertain benefits from her CT than those women who considered themselves cured or in remission from the disease.

*I worry about the risks involved with taking 714X all the time, because it's not proven. It's very scary. But there's no guarantees that the chemotherapy will help me, especially now that I have metastatic disease... So I'm willing to take the risks, even though there are no guarantees with the 714X either. I worry about how much is too much. Is it going to harm me? No one has the answer to that. So for now, I will help myself and hope for the best. Hope is sometimes all I have at this stage. Hope is my lifeline.*

Clearly, making sense of CT information through evaluating the fit of the potential CT with beliefs about health and illness, determining one's perceived disease status, and balancing risk
versus harm resulted in highly individualized notions of which CTs might be useful. Through these processes, each of the women hand-picked CTs to constitute a potential CT regimen to be tried out, evaluated, and modified.

**Trying Out Complementary Therapies**

Once the women had determined which CTs made sense to them, these CTs were then tried out to determine the degree to which expected benefits could be realized (see Figure 5). Most of the women initiated one or more CT while undergoing orthodox treatments such as chemotherapy and/or radiation; only two women waited to start their CTs until after the orthodox treatment was completed due to concerns regarding drug interactions.

During this trying out period, the CT initiated during the first phase of the CT decision-making process was either continued or discontinued. As the women did not have the time nor the energy to do an in-depth search for information about the initial CT in the first phase of the CT decision-making process, this task was carried out in the second phase. Most of the women continued practicing their initial CT(s) while initiating one or more new CTs with the aim of getting a CT regimen in place. Only one woman discontinued her initial CT due to the high cost of the herbal preparation.

The length of the trying out period varied among the women and was dependent on the type of CT utilized, and the woman's experiences with orthodox treatments, including her level of fatigue. Most CTs which are ingested/injected, such as herbal or biologic preparations, require a prescribed length of time (i.e., months) for benefits to be achieved. Similarly, other CTs, such as meditation and relaxation techniques require time for adequate skill to be acquired in order for benefits to be realized. The length of the trying out period for most CTs then, generally lasted a few months.

Women's experiences with orthodox treatments also affected the length of the CT trying out period. For example, women who experienced moderate to severe fatigue from their orthodox treatments may have had less reserves to stick with a CT until it became effective, particularly when that CT required the acquisition of new skills or experiencing unpleasant side effects.
Evaluating the Complementary Therapies

After a period of trying out or testing one or more CTs, women evaluated these CTs to determine whether that CT was effective or had the potential to be effective (see Figure 5). Criteria to determine whether a CT was effective was highly individualized, and was in part, dependent on the reasons for or aims of the CT use. Further, not all women needed evidence of efficacy of the CT in order to deem that CT effective or beneficial. Some women were comfortable relying on intuition or faith that the CTs were being effective. Other women required evidence of efficacy in order to continue with a CT. For example, one woman used a regimen of herbs, imagery, and therapeutic touch to manage the side effects of her chemotherapy, with the aim of improving her overall health and well being:

*I feel better.... I can feel that the complementary therapies are helping me to keep healthier. I know without it I would be worse. I just have this sense. You just have to have faith that its doing what you think it will do...you have faith that its helped other people for hundreds of years...its more like a faith thing than needing to really see that they're working.*

The majority of women interviewed held similar views and, accordingly, did not look for any physical changes that would provide evidence of efficacy of the CT. All of these women were in the early phases of their illness, from the time of diagnosis to completion of their first round of chemotherapy and/or radiotherapy. These women also felt that the subjective experience of CT use was at least as beneficial as any positive objective changes in physical status.

*I think part of it is not just what it [CT use] does, but how you feel about what it might do for you. In my mind, it must be doing me some good. It just makes me feel that I'm doing something. I trust that it is helping me.*

In contrast, two of the women interviewed reported the importance of seeing objective changes in their physical self which they could attribute to CT use. Both of these women were in the latter phases of their disease; one woman was living with metastatic disease and the other was in the palliative phases of her breast cancer. A sense of a time pressure was cited by these women as their reason for needing objective evidence of efficacy of their CT use.

*After I started taking the 714X, I noticed that cancer slowed down. I noticed it helped me to have more energy and to cope with everything. I wouldn't keep up the injections if it didn't help me.*
I keep taking a complementary therapy when I'm seeing changes. Like I saw changes when I changed my diet and added the Devil's Club. I felt better and less nauseated. If I didn't see any changes, I would quit. I might go on blind faith for a little while, but eventually I start questioning. And if I'm not noticing a huge difference, then I will stop.

Upon determining whether a CT regimen was effective, women chose to either modify that regimen, or continue taking the CTs which they had carefully hand-picked and put in place. All of the women interviewed felt it was necessary to modify the regimen to some degree, for a variety of reasons.

Modifying the CT Regimen

After an initial evaluation of one's CT regimen, most of the women interviewed made modifications to this regimen (see Figure 5). Modifications were made according to a number of criteria, including the degree of effort required to use the CT, the cost of the CT, the severity of side effects, and for only two of the women, whether they felt the CT was influencing objective changes in their illness experience.

Cost of the CT over a prolonged period was cited by the women as the most frequent reason for either stopping a CT or modifying the dose to fit with their budget. Many of the women reported feeling frustrated and angry at the fact that they were not able to afford certain CTs which they felt might help them. As a result of this cost factor, women were careful to hand-pick those CTs which they felt would be the most beneficial to them.

Definitely cost is a huge factor. And even at a discount I can't afford it.... I wasn't taking any vitamins for well over two months simply because I didn't have the money to buy them, even at cost.... It really depresses me, and I feel angry sometimes.

It's [herbs] very expensive. I have to consider the cost involved, so I really hand-pick the stuff that I feel is really good stuff.

Disease status also played a role in whether women (who were financially able) chose to pay for expensive CTs. The further the women were along the cancer disease trajectory, the more likely they were to pay for expensive CTs. However, those women were still careful to hand-pick those CTs which they felt would be most beneficial. One woman in the early phases of the breast cancer trajectory, upon completion of her orthodox treatment reported:
I really wasn't interested in dropping any more money on stuff [CTs] that I wasn't quite sure if it was actually going to do anything for me. Again, that's a risk driven thing...if I had metastatic disease then I probably wouldn't hesitate to put money out for that kind of stuff, that might do me some good. I'd be picky and choose the ones I felt would help me the most, though. I wouldn't just be all gung ho and blindly try anything. I don't think I could afford to do that anyway.

Cost and access to CTs and was cited by both First Nations women interviewed as reasons for modifying their CT regimen during the trying out period. Both of these women began using herbal preparations (Devil's club and yew bark) either in the store-bought form, or hand-made by themselves and/or relatives. The First Nations women using the store-bought herbal preparations either stopped using the herbs due to cost, or began using herbs prepared by relatives. Neither of the First Nations women were willing to prepare the herbs themselves; they saw this as interfering too much with their daily activities of living.

I stopped taking the store-bought herbs. They were too expensive. We have Indian medicine similar to this that we make...we just boil strips from trees or what ever...its the same thing you know. My Auntie volunteered to go out to the woods and gather the herbs and she boils it up for me.... I wouldn't take it if I had to prepare it myself. Too much hassle.

The degree of effort required to use the CT and the severity of side effects from the CT were also important factors influencing women to modify and or stop certain CTs. Modifications to the CT regimen based on these factors were implemented in an attempt to conserve energy and to normalize or re-establish previous routines in their lives.

I bought the fluorescence. But when I read the directions about having to mix it all up, it seemed too overwhelming to me. I just don't have that kind of energy at this point. I thought this is too big a thing and I'll never do this.... If it comes ready made, then that's perfect.

I should be taking my Vitamin C in divided doses throughout the day, but that's too much for me to deal with. I don't want to have to take the vitamins to work with me and have to remember to take them at lunch and then at night. All I can do is just to take the damn things and get them done in the morning.... This past year has forced so many adjustments.... I'm just not interested in bending much on stuff if I don't really have to. I just want to be normal again. I don't need so many reminders that I've had cancer.

Most of the women interviewed were not willing to tolerate unpleasant side effects as a result of taking a CT. The effect that a given CT had on one's daily life was therefore as important as the benefits of that CT. Almost all of the women felt that a CT which is considered
effective must also not cause discomfort in the process of achieving some benefit for their cancer.

_Some of the Chinese remedies, I couldn't handle very well. The smell and taste made me sick, more sick. At the same time, I was having chemotherapy, so I just tried it one week and gave up._

_I took it [Huxley's Formula] for a while, but my stomach was so bad from the chemotherapy, I decided to stop taking it._

Only the woman in the palliative phases of her illness felt she could tolerate some discomfort in order to gain some eventual benefit from the CT. However, she was quick to point out that if the CT did not allow her to engage in things in her life which were important to her, she would probably stop that CT.

_Although, 714X injections hurt a lot and I don't look forward to them, but it is worth it if it will help to slow my cancer spread. They don't interfere with my life too much, though._

Making modifications to one's CT regimen often also required returning to the _Searching for Information_ stage, at the beginning of Phase II of the CT decision-making process (see Figure 5). Women often needed to return to sources of information regarding CT use to either seek out new CTs to add to the initial regimen, or direction to modify CTs already in place. These women then proceeded through the subsequent stages of Phase II, making sense of the information, trying the CTs out, and eventually evaluating and possibly modifying the CTs. Once modifications had been made to their CT regimen, women re-evaluated this regimen to determine whether it was effective/beneficial. This process of modifying and evaluating their CT regimen was continued until the women were comfortable that their CT regimen was being effective or had the potential to be effective.

**Outcomes of Phase II**

Three outcomes of the second phase of the CT decision-making process were identified from the interviews with the women. These outcomes included increasing a sense of personal control over one's life, maintaining hope, and promoting healing (see Figure 5). By hand-picking CTs which "fit," women effectively put a personalized regimen in place allowing them to begin to take back control of their lives at a time when everything seemed to be out of
control. After the initial shock of the cancer diagnosis and the trauma of initiating and undergoing orthodox treatments for their cancer had decreased, the women in the second phase of the CT decision-making process were able to mobilize enough energy to search for, try out, evaluate, and modify a CT regimen. Through this process, women began to feel a sense of increasing personal control over their cancer and their lives.

My healing with cancer was going to be much more than going through surgery, chemo, and radiation. It was also going to be about what I could do for myself. It's very tied to my sense of control about it. I had to believe that I could heal myself in some way, that I had some control over what was happening at all. I needed to believe that I could influence what was happening to me, and the complementary therapies helped my to feel in control. I was going to do what they [orthodox health care professionals] wanted me to do, but I was also going to do what I wanted to do.

Hope was another important outcome of the second phase of the CT decision-making process, resulting from an increase in the women's sense of control over her situation. As with the first phase of the decision-making process, the presence of hope allowed the women to continue to believe their cancer could be controlled. Complementary therapy use was the vehicle for that hope.

Lastly, at the completion of the second phase of the CT decision-making process, women began to talk about healing from facing a chronic life threatening illness such as breast cancer. Instituting a CT regimen helped to facilitate this healing process, which entailed coming to terms with and finding meaning within the cancer experience. In addition to physically recovering from the treatments for cancer, the women identified the importance of emotional and spiritual healing, and how this process required taking back control of one's life.

The reflexologist helped me to get in control and be able to heal myself. The reflexologist didn't heal me; she just helped me to be able to do it myself. I realized that healing wasn't what people did to me, like the oncologist giving me the chemotherapy. Healing is from within yourself, and the people helping were generally the alternative practitioners. I came to realize that I needed to heal emotionally and spiritually with whatever help that I could get and that it would be my way.... I had to find some meaning in all of this pain and overwhelming stress and I did it by taking back the control.
Phase III: Living with the Security of Complementary Therapies

Phase III, Living with the Security of CTs: "Fine-Tuning a Regimen to Live With", constituted the final phase of the CT decision-making process (see Figure 8). This phase generally began after one's orthodox treatment was completed, and could extend for the remainder of one's lifetime. Generally, women entering this phase had stable disease; that is, they believed that their cancer was under control as a result of both orthodox and complementary treatments. Diagnostic tests and physical status did not indicate that the cancer was actively progressing in the early stages of this decision-making phase.

During this phase, women monitored sources for new CT information, slowly decreased the number and/or dosage of CTs in their regimens, and managed periods of stress by altering the content of their individuals CT regimens. The aim of this third phase was to maintain hope, decrease uncertainty, and create a long term illusion of control.

Figure 8. Phase III: Living with the Security of CTs: “Fine-tuning a Regimen to Live With”.

Monitoring for New Information

At the beginning of this phase, women were comfortable with their CT regimen and felt that it was effective according to their own individually defined criteria. However, most women reported needing to continually monitor the CT literature to varying degrees. As most CTs are
in their infancy in terms of western scientific validation of efficacy, women felt it important to keep abreast of new developments. This approach to monitoring sources of information was less intensive than in the second phase of the CT decision-making process.

*I'm doing a bit of reading all the time.... I like to know if anything new comes up. Mostly I just keep my eyes and ears open to anything new. I don't aggressively search out information like when I was first diagnosed.... I'm not all gung ho like in the beginning, but I like to keep my finger on new developments.*

**Increasing Control**

As time progressed after the completion of orthodox treatments for their breast cancer, most women began to feel an increased sense of control over their cancer. Trust in one's body to prevent a cancer recurrence or metastasis was voiced as the major reason for this increased sense of control. Women felt that the combination of orthodox treatments and CTs had virtually eradicated their cancer, their immune system was regaining strength, and their bodies were learning to manage the few stray cancer cells that may still circulate. Slowly, the need to actively "fight" the cancer faded.

*It's almost as though I get a little bit more comfortable in myself about the idea of having had cancer. I don't need to feel like I'm working at it all the time.... It's more like I trust that my body in general is taking care of itself. I've learned how to achieve some degree of wellness through alternative therapy use and lots of hard work. Now I think my body instinctively knows how to manage any deviations like cancer.*

**Decreasing Vigilance**

As a result of this increased trust in one's body to manage any potential cancer cells, women began to be less vigilant about new symptoms which may or may not be related to their breast cancer. This vigilance regarding new symptoms was reduced in this third phase of the CT decision-making process, when compared to the second phase. In the second phase, women were still receiving orthodox treatment or had completed treatment only for a short time. At that point, most women were still highly uncertain about whether their cancer had been cured and whether it would recur. As such, new or unfamiliar symptoms, such as pain or cough, may have been associated with a return or spread of their cancer. Women in the third phase, however, had completed their orthodox treatment for some time and had learned that new or
unfamiliar symptoms did not necessarily indicate a return or spread of their cancer. Further, they did not feel the need to continually monitor all their symptoms, due to the developing trust in their body to manage those underlying conditions which may cause those symptoms.

As time progressed away from the completion of their orthodox treatment and women became less vigilant about their symptoms, most women reported that their breast cancer was no longer the central all-consuming force in their lives. Slowly, women were able to allow their cancer to become secondary in their lives. One woman who was cancer free at three years post completion of her orthodox treatment stated:

*I like not having to worry about having cancer. It's great to be a normal person again. I still have my relaxation group and I take my herbs daily, which are reminders that I had cancer, but it's not like an "in your face you have cancer" kind of a feeling. I can relax now.*

**Modifying the CT Regimen**

Along with an increasing sense of confidence in their body's ability to control stray cancer cells and the subsequent feeling that cancer was secondary in their lives, women reported at this stage of the CT decision-making process that they altered their CT regimen by reducing the frequency and/or dose of many CTs. They no longer felt it was necessary to "work so hard" at healing from their cancer or achieving wellness.

*I don't feel that I need as much now [CTs]. I still need the reflexology; that's my time when I pull it all together and think about healing. As time goes by, I don't think about it [CTs] much. In the first year I found the healing part that I was doing most exhaustive because I was really working on that feeling and it was taking every ounce of my energy. I knew I had to keep at it at that point. It was really important because I knew that healing was still needed. Now I don't feel I need to work at it so hard because I feel healed. I feel more relaxed about it. It's not such an urgent feeling anymore.*

**Maintaining a Core CT Regimen: "The Security Blanket"**

Despite a paring down of their CT regimen, most women felt it was important to maintain a core regimen of CTs as a "security blanket." Women felt the need to continue to "do something" to ensure a level of control over the potential for a recurrence, thereby reducing uncertainty about the future. Clearly, women did not definitively trust their own bodies to manage stray cells or prevent recurrence. The need to "do something" to manage their cancer or
the potential for cancer was still necessary in this third phase of the CT decision-making process.

*There are three or four complementary therapies that I won't quit...because they're like a security blanket. They make me feel okay. They make sure that I stay well. It helps me feel more confident that my cancer won't come back.... Who knows if they're really helping or not, but they make me feel better, which is the main thing.*

Uncertainty regarding the efficacy of both orthodox and complementary therapies for breast cancer motivated women to feel the need to continue using a core regimen of CTs during this third phase of the CT decision-making process. Fear of not using CTs, which was essentially generated from uncertainties regarding efficacy of treatments, was also cited as a motivating factor for CT use. Some women who were ambivalent about whether or not using CTs actually made a difference were afraid *not* to use CTs. They feared that by not using them, their cancer *might* recur. Therefore, these women continued with a core regimen of CTs. One woman who maintained a security blanket of high dose vitamins at one year post completion of her orthodox treatment stated:

*I hope they're doing some good. I'm not convinced of this, but I hope they are.... I think my ongoing use is really quite motivated by fear probably more than hope. I feel like I have to take them just in case it's going to make a difference. I'm afraid not to take them.*

**Managing Stressors**

Women continued to maintain this core regimen of CTs until they experienced stressors in their lives. These stressors were inevitable in all the women's lives and included, for example, a cold or virus, or increased fatigue. Periods of increased emotional stress such as a divorce, or death of another family member were also revealed as stressors by the women interviewed. At these times in the women's lives, they reported increasing vigilance for changes in their bodies and emotions, for fear that their cancer might recur. Most of the women believed that the potential for their breast cancer to recur was high at times of stress on their bodies and/or minds. Unusual or marked symptoms, such as bone pain, a persistent cough, or severe headaches were also identified as stressors and were often feared by women as early warning
signs, indicative of cancer spread. Cancer once again became the central focus in their lives, whether or not the stressors were truly indicators of a return of the cancer.

Modifying the CT Regimen

In response to these stressors, women again made changes to their CT regimen, usually by increasing dosages and/or frequency of CTs already in place, or by bringing back CTs which were used successfully earlier in Phase II of the CT decision-making process. The aim of this modification to one's CT regimen was to manage increased demands on one's body for short periods in order to remain healthy and to prevent a cancer recurrence.

I take the high dose vitamin C, Devil's club, and essiac regularly. I stick to a regime [sic]. But when I feel a cold coming on or something, I tend to take more.... Also, if I feel really stressed out or not quite myself, then I'll take a little more [CTs] then too.... I keep the higher doses up until a few days after I feel back to normal.... Sometimes I'll get some therapeutic touch at this point as well, to help put my body back into balance. This is really important to me, because I feel that I need more [CTs] when my body is taxed in some way. My body needs a little help to stay healthy now and again.

Immediately following a modification to one's CT regimen in response to stressors, women were more vigilant for a period of time regarding the presence, absence or changes in symptoms. If no new symptoms occurred and/or current symptoms subsided, and the emotional stressor was removed, women returned to the beginning of the third phase of the CT decision-making process, where they began to monitor for new CT information (see Figure 8). With the passage of time, women once again began to develop trust in their bodies to manage stray cancer cells, reducing the need to be highly vigilant about changes in their bodies. Slowly, their cancer once again became secondary in their lives, allowing the women to return to their core regimen of CTs. Women continued to use their core CT regimen until a new stressor presented itself, whereby the entire process was repeated.

If symptoms persisted and/or new symptoms presented themselves after modifying one's CT regimen in response to stressors, women returned to a higher state of vigilance regarding those symptoms (see Figure 8). As time progressed without a decrease or disappearance in symptoms, women again modified their CT regimens, usually by increasing dosages and/or increasing the frequency of CTs within the core regimen, or by adding CTs used previously
with success. This cyclic process of modifying one's CT regimen and being highly vigilant for symptoms was continued until the symptoms decreased and/or subsided, or the stressor was removed. Some women spent long periods of time (e.g., months or years) in this cycle, altering their CT regimen and maintaining a highly vigilant state. The length of time spent in this cycle was dependent on the number of stressors encountered, and the number and severity of symptoms experienced.

About six months after my chemo was finished, I pared down my regime [sic] to just relaxation group once a week and a couple of herbs. But a few months later, I started to get all these problems, like lots of colds and I was always tired. I thought I should go back to using the acupuncture and seeing the naturopath then.... I needed the extra protection in case my cancer had started to act up again. But after a couple of months of this my mother died, which was a real emotional blow. I know about the relationship of stress to your immune system, so I thought I'd better dial up the doses of my herbs, do relaxation exercises every day, and I added some vitamins as well. My doctor said my cancer was still in remission, but I was all stressed out, so I kept taking all those things, just in case.... I slowly stopped seeing the naturopath, getting acupuncture, and the vitamins. This was about six months after my mom had died.... I had to make sure my body and my stress levels had returned to normal before I could go back to just the relaxation group and the herbs.

Once the women felt comfortable that their symptoms had subsided and the stressor was removed, they returned to the initial stages of the third phase of the CT decision-making process, where they began to monitor for new information (see Figure 8). These women continued to regain a sense of control over their bodies and their cancer, eventually returning to their core CT regimen.

A diagnosed cancer recurrence or shift to a palliative focus of care was also described as a major stressor which lead to the alteration of one's CT regimen in the third phase of the CT decision-making process. Generally, women facing a diagnosed cancer recurrence or shift to a palliative focus of care returned to the second phase of the CT decision-making process (see Figure 3, p. 57). Rather than simply modifying their core CT regimen in the third phase by increasing the dosage and/or frequency of CTs already in use, these women felt it was necessary to engage in a complete re-evaluation of one's CT regimen, hand-picking those CTs which fit the woman's new situation. Women facing a recurrence with the possibility of cure or control of their cancer from orthodox treatments usually continued with most of their core CT
regimen, adding new CTs which were not tried out in the second phase of the CT decision-making process. These women progressed rapidly through the second phase, the second time around, due to their familiarity with the searching for information process.

Women shifting to a palliative focus of care either completely overhauled their core CT regimen, or made slight modifications and new additions to that regimen. These women also progressed rapidly through the second phase of the CT decision-making process, the second time around, due to their familiarity with the process. Whether or not these women in the palliative stage completely overhauled their core CT regimen, or modified it slightly depended on their need for evidence of efficacy of the CT. Those women who relied on objective evidence to know that their CTs were effective tended to totally abandon their core CT regimen for a new regimen, citing that if the old CT regimen were maximally effective, they wouldn't be facing a recurrence.

When I found out that my cancer had come back, I was totally devastated. I went back to that state of shock, like I felt when I was initially diagnosed... I thought that obviously, the alternative therapies that I was doing weren't helping. I felt like I needed to try something different, something new...but I kept doing the daily meditation, because that helped me to deal with all the stress of suddenly no longer having a long and healthy future.... The meditation was the only alternative therapy that I kept after I found out that I was palliative. The rest I scrapped.

In contrast, those women who relied on faith that their CT regimen was effective (i.e., rather than needing evidence of efficacy) usually simply added a new CT to their existing core regimen. These women believed that their CT regimen was indeed effective, despite knowing that their cancer now could not be cured. They rationalized that their beliefs about whether the CTs were helping were more important than objective evidence of the CT's efficacy. Further, these women tended to believe that their CT regimen had kept them well for a longer time period than without that same regimen. However, they did acknowledge that it was time to add another CT to the regimen, now that their disease status had progressed. Adding one or more CTs to the original regimen was thought to increase the effectiveness of that regimen.

I've kept doing the reflexology, high dose vitamins, and essiac right from the time that I started my chemotherapy for the first time, until now. I kept up those three things throughout my first recurrence and then the chemo and radiation. They [the CTs] helped
me to deal with everything that was happening... and I think that I might have recurred sooner if I hadn't kept up with these three things... Just because my cancer came back doesn't mean that the alternative therapies aren't working. I'll keep doing these three alternative therapies, even now that traditional cancer medicines can't cure me. I think it's more important than ever now to keep doing those things that I believe are helping me.... I'll also probably add the 714X injections. There's no reason not to try it now.

Women facing a shift to a palliative focus of care were more willing to use those CTs which may pose more risks with less benefits than those woman in earlier phases of the breast cancer trajectory. These women felt that their risk of dying had been elevated with their disease progression, which allowed for an escalation in risk related to CT use. They essentially felt that they had nothing to lose by using these more risky CTs, and had everything to gain in the slim chance that it might be of some benefit. Examples of these more "risky" CTs included 714X and a variety of potent herbs.

When the doctor tells us there's nothing they can do for you, then you reach for something else, something stronger.... I kept taking my high dose vitamins, calcium, Chinese remedies, and I kept up my macrobiotic diet, but I had to try something else too. I had to make my immune system stronger than ever.

Once women facing a recurrence and/or shift to a palliative focus of care had modified their existing or recreated a new CT regimen in the second phase, they again entered the third phase of the CT decision-making process. If their disease continued on a fairly stable course, they were able to re-establish a core regimen of CTs, occasionally modifying that regimen in response to stressors (see figure 8). However, if women experienced frequent exacerbations of their disease, re-establishing a core CT regimen was difficult as they could not develop a degree of trust in their body to manage their cancer nor a sense of control over their cancer. These women bypassed the process of re-establishing a core CT regimen, focusing on maintaining a highly vigilant state regarding symptoms which might indicate further disease progression, as well as making modifications to their CT regimen in response to those stressors. Women with unstable disease after a recurrence or shift to a palliative focus, then, were constantly fine-tuning their CT regimen in response to symptoms and/or stressors.
Outcomes of Phase III

Outcomes of engaging in the third phase of the CT decision-making process, Living With the Security of CTs; "Fine-Tuning a Regimen to Live With," included maintaining hope, decreasing uncertainty, and maintaining an illusion of control over one's cancer. As identified in the first and second phases, maintaining hope was also an important outcome in the third phase. Women continued to need a reason to continue on with their lives and to believe that their cancer can be beaten. A woman facing her first recurrence of breast cancer stated:

*If I had no hope, I wouldn't bother taking anything [CTs]. So I guess you have to have a little hope to begin, and then taking the complementary therapies builds that hope. I think it is essential to have hope.... You might as well shrivel up and die without it.... The complementary therapies help me to have hope and believe that I can beat this thing.*

Closely tied to the maintenance of hope, decreasing uncertainty about the future was also reported as an outcome of this third phase of the CT decision-making process. From the time of diagnosis, women identified that the lack of guarantees for cure associated with both orthodox and CTs contributed to high levels of uncertainty about the future. In describing the maintenance of hope, women also reported decreased uncertainty about their future as a result of ongoing CT use. Further, a security blanket of core CTs helped to decrease uncertainty, allowing the women to focus on their lives once again, rather than on their cancer.

Maintaining an illusion of control was identified as the last outcome of the third phase of the CT decision-making process. In the two earlier phases, women established and slowly began taking back control from their cancer. The third phase ensured that women maintained this regained control. However, women recognized that in this third phase, the perception of control over one's cancer was more important than whether or not that control actually existed.

*Taking the complementary therapies gives you a sense of control, a bit more sense of security that you're doing something. I had to keep doing something, even after I was fairly certain that the cancer was gone. The herbs and meditation helped me to live my life normally again.... I didn't have to worry all the time about my cancer, because the complementary therapies were taking care of that.... Even if they weren't really helping me, I thought that they were, which is more important. I guess you could say that taking complementary therapies really creates an illusion that you are in control of your cancer.*
CHAPTER FIVE
DISCUSSION

To date, there has been no research which links the CT decision-making process with the cancer trajectory and orthodox treatment process. Further, much of the current research literature has taken a static view of CT use, largely from the perspective of health care providers, rather than examining how CT use evolves as patients move through the cancer experience, from the patients' perspective. The purpose of this study was to capture the dynamic nature of the CT decision-making process as it relates to the breast cancer disease trajectory, from the patient's perspective, for those who also subscribe to some form of orthodox treatment.

In this chapter, a number of the most significant aspects of the findings are discussed in light of relevant research. In turn, implications for nursing practice, education, and research are identified. Strengths and weakness of the method of this study are analyzed, and the significance of the study is articulated. Finally, this chapter concludes with a summary of the study.

Discussion of the Findings

A number of themes emerged during analysis of the data which merit in-depth discussion as they relate to the CT decision-making process. Four major themes are explored here, including regaining control, maintaining hope and health care relationships. Each of these three themes are discussed separately. The fourth major theme, treatment decision making, is discussed in relation to the three aforementioned themes. An exploration of these four areas will help to put the findings of this study in context, in light of the current state of knowledge about the CT decision-making process of women with breast cancer.

Regaining Control

The core category in this study, regaining control through CT use, provided the framework for explaining the dynamic nature of the CT decision-making process throughout the breast
cancer disease trajectory. Decisions regarding CT use empowered the women through a sense of being in control of their treatment, their cancer, and their health.

The desire to regain control after diagnosis with a chronic life-threatening illness such as breast cancer has been well documented in the literature (Cull, 1990; Fryback & Reinert, 1993; Fryback & Reinert, 1997; Loveys & Klaich, 1990; Slaby & Glicksman, 1985; Taylor, Lichtman, & Wood, 1984). A diagnosis of breast cancer changes one's life forever, imposing multiple losses, unrelenting uncertainty, and high levels of stress (Fredette, 1995; Goodman & Chapman, 1993; Pelusi, 1997). In turn, many women report a sense of loss of control over their life and health, which, if prolonged, may lead to poor adjustment, including hopelessness, helplessness, anxiety, and depression (Krouse & Krouse, 1982; Mishel, 1988; Slaby & Glicksman, 1985). Actions to enhance feelings of control, therefore, such as using CTs, may be viewed as positive coping strategies for women with breast cancer.

Complementary therapy use for the purpose of regaining a sense of control is beginning to be discussed in the research literature, particularly for individuals with cancer and other populations such as AIDS (Fryback & Reinert, 1997; Montbriand, 1995a; Montbriand & Laing, 1991; Pawluch, Cain, & Gillett, 1994). These studies, however, do not explain the dynamic nature of control as it relates to the disease trajectory. In the current study of women with breast cancer, regaining control was found to be comprised of three interconnected phases: taking action, taking back control, and maintaining an illusion of control. These phases of control were linked to the phases of the breast cancer disease trajectory, where *taking action* generally occurred during the early diagnosis period, *taking back control* began at or around the time of orthodox treatment, and *maintaining an illusion of control* began sometime after orthodox treatment was completed, lasting perhaps for the reminder of one's lifetime. This study therefore extends current knowledge regarding the concept of control as it relates to CT use across the breast cancer disease trajectory. The following section discusses each of the three phases of the CT decision-making process in relation to the changing nature of control over the breast cancer disease trajectory.
Phase 1: Taking Action

Immediately after diagnosis, women in the current study reported a very strong need to take action in an attempt to exert some control over their cancer, despite feeling overwhelmed with the complexity of their new situation. While waiting for surgery, most women took action by beginning to use one or more CTs with the aim of quickly reducing feelings of loss of control.

Women in this phase of the breast cancer trajectory experienced a sense of urgency with regard to putting a CT into place, therefore spending little time, if any, researching that CT. Without information regarding the CT’s efficacy, women really did not “know” whether the selected CT was indeed “controlling” their cancer. Rather, the effect of CT use in this early phase of the trajectory was one of perceived control. The women felt that by doing something (rather than nothing), they were exerting some control over their cancer. Taking action by using CT(s) to increase control in this early phase is supported by Dennis (1990) who found that perceptions of control over one’s experiences may help individuals to interpret their situation as less threatening, and in turn, less stressful. Taking action to enhance perceptions of control by using CTs may be particularly helpful then, especially in this early phase of the breast cancer trajectory where stress levels are high.

Seeking information about one’s diagnosis and treatments has been described as an important way to take action in the early phases of the cancer trajectory (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Derdiarian, 1987). However, in the current study, women in the early phase of the breast cancer trajectory did not extensively seek out information about CTs as a treatment option. Rather, they felt overwhelmed with the tasks of assimilating complex information about orthodox treatment and dealing with the realities of living with a life-threatening illness. Seeking information, or receiving gratuitous information from well meaning friends about CTs was therefore seen as adding to one’s stress and anxiety in this early trajectory phase, rather than promoting feelings of enhanced control.

Most of the women interviewed felt that assimilating information about orthodox and complementary treatments were separate processes in the early phase of their illnesses.
Information about orthodox treatment and the disease itself took priority in the women's minds at this time; once this information was sorted and preliminary decisions about orthodox treatments were made, only then could women begin to seek out and absorb information about CTs. The act of compartmentalizing information into smaller, more manageable parts is a common coping strategy utilized during times of stress or crisis (Strauss et al., 1984; Sutherland et al., 1989). In this way, compartmentalizing information about both orthodox and complementary treatments in the early trajectory phase was used by the women in this study as an action strategy to enhance feelings of control.

It is not clear as to why orthodox treatment decisions initially took precedence over CT decisions. Reasons for this prioritization could be related to the study sample characteristics, or the effect of using an orthodox physician as their primary health care provider. Only those women who use, have used, or have considered using CTs in addition to orthodox treatments for their cancer were eligible to be interviewed for this study. As such, women in this study believed that using orthodox treatments for their cancer were important, and began their cancer journey from within the orthodox health care system. These women received information about their cancer, including options for orthodox treatment, from their primary health provider (e.g., oncologist or general practitioner). In all cases but one, no mention of CT use was made by the primary physician during the early diagnostic phase of the breast cancer disease trajectory. Women therefore were presented with only the biomedical perspective of curing cancer with orthodox treatments, without mention of physical, emotional, and spiritual healing from one's cancer. It is not surprising then, considering the extreme stress that women are under during the early diagnostic and treatment phases of their illness, that women felt orthodox treatment decisions took priority.

Phase 2: Taking Back Control

Once women had put one or more CTs into place, and had recovered from their surgery, the nature of the control they desired over their health and their lives began to change. Taking back control from the health-care system, increasing control over their cancer and regaining their
health were major tasks accomplished during this phase of the breast cancer disease trajectory. At this point, women felt less anxious and less pressured to make decisions about orthodox treatments. While uncertainty regarding the future remained high, they felt they had more time to explore CTs, hand-picking those CTs which fit with their personal beliefs and lifestyle. Most felt they had a very basic understanding of their orthodox treatment choices, and could now begin to explore how CT options might fit with orthodox treatment.

All women in the current study opted for surgery as an orthodox treatment option without much deliberation. However, it is interesting to note that while all of the women took time to deliberate the pros and cons of chemotherapy, radiation, and hormone therapy as viable treatment options, three women chose not to have any further orthodox treatment after surgery. These three women, after having their tumors surgically removed, were able to move directly into the process of hand-picking CTs while they made decisions about adjuvant orthodox treatment (i.e., chemotherapy, radiation therapy, and hormone therapy). The remaining 13 women made decisions about adjuvant orthodox treatments first; only then were they able to consider CT decisions. These two groups of women differed in a number of ways. The women in the surgery-only group were younger (39-42 years), had smaller tumors with minimal nodal involvement, and, most importantly, were very clear about their beliefs regarding health and illness. Complementary therapies had also been a part of their lives prior to receiving a cancer diagnosis. These three women therefore had less information to process to make treatment decisions. Due to their premenopausal status and small tumor size, they were presented with a limited range of orthodox treatment options to consider. Previous CT use and clarity regarding health beliefs also may have functioned to narrow their scope of CT information they needed to process in order to make CT decisions.

Women who opted for surgery plus adjuvant orthodox treatments generally were older (i.e., postmenopausal), and had larger tumors with more nodal involvement. One woman had metastases at the time of diagnosis. While two women in the surgery plus adjuvant treatment group had smaller tumors, the size was such that it made the women eligible for a number of
adjuvant treatment options, rather than just one or two options. Most of the women in this group had not used CTs to any great extent prior to being diagnosed with cancer, and had not spent a concentrated amount of time clarifying their beliefs about health. Clearly, women in this group had more treatment options to consider, and more work to do regarding becoming familiar with CTs and their beliefs about health. As such, it is not surprising that they were not able to make decisions about orthodox and complementary treatments at the same time. While the current study suggests that factors such as amount of information to process, previous CT use, and clarity of health and illness beliefs might have an effect on how CT and orthodox treatments are made, further research is necessary to identify the relationship among these factors as well as additional factors affecting whether CT and orthodox treatment decisions are made separately or in tandem. Identification and clarification of these factors will assist health care providers in understanding how best to assist women in different situations in making CT and orthodox decisions about their cancer treatment plan.

Complementary therapies were used as a control mechanism in various ways during this phase of the breast cancer disease trajectory. For example, many women reported feeling that orthodox health care professionals (OHCPs) were in control of their cancer treatment up to this point. While many women took a more passive role in treatment decision making prior to surgery when anxiety was high and knowledge about breast cancer treatment was limited, after surgery their desire to take back some control from OHCPs increased. A British study supports this finding, where newly diagnosed women with breast cancer preferred to leave initial treatment decision making to their doctor (Beaver et al., 1996). However, the women in Beaver et al.’s study were generally older, and their findings are consistent with those of Degner and Sloan (1992), who reported women’s age to be associated with preferred decisional role, with older women preferring a more passive role in treatment decisions. In the current study, the majority of women were 50 years of age and older, which may explain the predominance of passive role taking with regard to orthodox treatment decision making prior to
surgery. In the future, replication studies need to include younger women to explore the effect of age on preferred decisional roles.

After surgery, women in the current study felt ready to make more of their own decisions about their health care, based on enhanced knowledge and reduced anxiety. Initiating CT use therefore was a means by which women began to take some control back from the OHCPs. One woman clearly expressed this sentiment, stating, “I was going to do what they wanted me to do, but I was also going to do what I wanted to do”.

Findings from a number of research studies support the positive benefits of individuals using CTs as a mechanism to regain control from OHCPs (Fryback & Reinert, 1997; Montbriand & Laing, 1991). However, more recent work by Montbriand (1995a, 1995b, 1997, 1998) explicates some of the drawbacks associated with being in control of one’s health care. For example, she states that, “...taking control involves responsibility, and responsibility of a personal health care therapy for cancer is stressful” (Montbriand, 1997, p. 7). To avoid this stress, most informants in Montbriand’s study took control back from OHCPs, and then gave the responsibility of being in control away to an alternative healer. An important distinction between the action of choosing a CT and assuming responsibility for the outcomes of that CT on one’s cancer is made by Montbriand (1995a). Women in the current study, however, were able to take some control, without being completely responsible for the outcomes of using that CT on their cancer. All of the women remained within the orthodox health-care system, completing at least one of the recommended orthodox treatments for their breast cancer. Further, none of the women in the current study believed that their CT use cured their cancer. Rather, they felt that CT use may produce synergistic effects in combination with orthodox treatments or address the unwanted side effects of orthodox treatments. In this way, women were not completely responsible for the outcomes of their cancer therapies, because these outcomes were a shared responsibility between OHCPs and themselves through CT use. In contrast, in many of Montbriand’s studies (Montbriand, 1995a, 1995b; Montbriand & Laing, 1991), where patients gave control away to alternative practitioners, it is not clear what
the patient’s expectations were with regard to cure as a result of CT use. One might hypothesize that if an individual used a CT to regain control from the orthodox health care system, with the intention of curing his or her cancer, the responsibility associated with assuming control would be much greater than if that individual used that CT without the expectation of cure. In at least one of Montbriand’s (1997) studies, patients left biomedicine to pursue a cure through alternative therapy use. These individuals therefore assumed sole responsibility for their cancer treatment outcomes, which, as Montbriand reports, was too much responsibility. In response, they gave control over to alternative healers.

The notion of taking and giving away control as it relates to the concept of responsibility for health care outcomes is important to the current study, and for CT use in general. The discussion points to patients’ desire to have at least partial control over their cancer treatment, with the responsibility associated with that control being shared with a health professional, whether orthodox or complementary. Shared responsibility, according to Montbriand (1995a, 1995b, 1997) allows patients to experience less stress while reaping the benefits of achieving a sense of control over a portion of their cancer treatment. Women in the current study took some control back from the orthodox health care system by choosing to use CTs, but shared some of the responsibility for the outcomes of their cancer treatment with OHCPs.

Information seeking regarding CT use was another avenue for taking back control in the second phase of the CT decision-making process. At this point in the breast cancer trajectory, information seeking functioned as a means to enhance feelings of control, rather than increasing feelings of being overwhelmed, as was experienced in the first CT decision-making phase. Increasing knowledge about CTs in this phase of the CT decision-making process allowed women to begin to actively participate in decisions about their health, which in turn, enhanced feelings of control.

The role of information in enhancing control during treatment decision making has been well documented in the literature (Bilodeau & Degner, 1996; Blanchard, Labrecque, Ruckdeschel, & Blanshard, 1988; Brockopp, Hayko, Davenport & Winscott, 1989; Cassileth
et al., 1980; Degner & Russell, 1988; Degner & Sloan, 1992). No research could be located, however, that incorporates information about CTs into treatment decisions. While much of the literature specific to breast cancer treatment decision making includes only orthodox treatment options (Beaver et al., 1996; Bilodeau & Degner, 1996; Hack, Degner, & Dyck, 1994; Hughes, 1993; Pierce, 1993; Porter, 1993), aspects of this research may be extrapolated to explain and support CT decision-making practices as a control measure used by women with breast cancer.

In the current study, the act of searching for information about CTs was one strategy to enhance perceptions of autonomy. A number of authors have pointed out, however, that the desire for information is quite separate from the degree of willingness to use such information in making decisions (Averill, 1973; Degner & Beaton, 1987; Degner, Sloan & Venkatesh, 1997). While many individuals want maximal information about their disease and treatment options, they may not necessarily want to play an active part in making choices about their medical care. This was found to be the case with a small number (n=3) of the women in the current study where they took a more passive role with respect to orthodox treatment decision making throughout the entire breast cancer disease trajectory. These three women were older and had more extensive disease at the time of diagnosis than did the other women in the study, which is consistent with other studies identifying advancing age and extensive disease as variables correlated with preferences for more passive decisional roles (Beaver et al., 1996; Bilodeau & Degner, 1996). The women in the current study, while taking passive roles in all orthodox treatment decisions, however, took very active roles in making decisions about their complementary treatments. This apparent contradiction suggests that preferences for decisional control may not be static, nor encompassing of all types of health-care decisions. It is not clear from the findings of this study why women would take both active and passive roles regarding orthodox and complementary treatment decisions. One might hypothesize that the culture of the orthodox health-care system encourages a more passive approach to treatment decisions, whereas complementary medicine is based on the individual being an active participant in his or
her care. More research is necessary to understand this phenomenon of multiple decisional roles.

Complementary therapies were used in a number of other ways to enhance feelings of control in the second phase of the CT decision-making process. After recovering from surgery, women reported using CTs for the purposes of managing the side effects of orthodox treatment, boosting one’s immune system, promoting feelings of well being, and for the prevention or delaying of a recurrence. These findings are consistent with other research, where CTs were used by patients to reframe their cancer diagnosis and improve their ability to cope with conventional medical treatments (Balneaves, 1996), and improve their physical and emotional well being (Balneaves, 1996; Cassileth et al., 1991; McGinnis, 1991). The use of CTs as adjuvants to orthodox treatments, rather than as cures, dispels a common belief among critics of CT use that CT users are seeking a “cure” for their cancer (Brown, 1987; Danielson et al., 1988; Lerner & Kennedy, 1992). This finding must be interpreted, however, in light of the fact that only women who used CTs in addition to orthodox treatments for their cancer were included in the current study. These women represent a subset of all CT users who believe the best chance for a cure remains within orthodox treatments. According to McGinnis (1990), only 5% of all CT users leave biomedicine to seek a cure from alternative treatments.

While women in the current study believed that their best chance for a cure remained within orthodox treatments, many believed that orthodox treatment did not offer a holistic approach to managing a life-threatening illness, nor did it assist in regaining health. Orthodox treatments were viewed as necessary “evils” which assaulted the cancer and stressed one’s body, mind, and spirit with minimal regenerative or healing effects. Most believed it was very important to take control of the “missing pieces” necessary to aid healing and regain health. As such, women reported using CTs before, during, and after orthodox treatments to buffer the negative effects of orthodox treatments and to rebuild one’s health. Further, a number of women felt that CT use may have a synergistic effect when combined with orthodox treatments; others felt that many CTs, when used concurrently with orthodox treatments, would have a detrimental
effect. Both sets of women viewed themselves as taking back control; the nature of the control was dependent on their beliefs about health and illness and their understanding of the mechanisms of both orthodox and complementary therapies.

In all cases, women reported using a variety of CTs during the second phase of the CT decision-making process to address multiple aspects of health. For example, one woman receiving chemotherapy reported that she was using a number of herbs and relaxation/imagery to boost her immune system in response to the damaging effects of chemotherapy. She also practiced yoga and meditation to balance her emotional state, and prayer to address her spiritual distress related to her cancer diagnosis. This woman began to take back control from the orthodox health-care system by choosing her treatment based on her own, more broadly defined notion of health. The holistic health movement helps to explain the phenomenon, that emphasizes personal responsibility for one’s health (Cassileth, 1989). This responsibility has enhanced the desire of many individuals for more control over their health care, tailoring their treatments to fit with their belief systems (Fryback & Reinert, 1997; Furnham & Bagrath, 1993; Furnham & Beard, 1995; Furnham & Smith, 1988; Yates et al., 1993).

In Phase II of the CT decision-making process (Hand-picking CTs Which fit: Getting a Personalized Regimen in Place) women focused on tailoring a CT regimen to “fit” with their belief systems about health and illness, as well as their lifestyle. Women drew upon their beliefs about health and illness to make initial decisions about which CTs to research and try out. These CTs were then evaluated and modified according to a number of criteria, including the degree of effort required to use the CT, the cost of the CT, and the severity of side effects. For example, some women chose to stop using Essiac because it required too much planning (e.g., Essiac should be taken twice daily on an empty stomach). Other women chose not to take 714X injections, because of the pain associated with an intralymphatic injection. The majority of women believed that CTs should disrupt one’s day-to-day life only minimally. As the severity of disease progressed, however, women were more willing to accept greater disruptions to their day-to-day life, but within limits, caused by their CT use. The process of
tailoring a CT regimen to fit with one's beliefs and lifestyle functioned to maintain a sense of normalcy about one's day-to-day life. In this way, a degree of control over one's daily life was maintained. Kelly-Powell (1997) also reported a process of tailoring treatment decisions in a population of individuals facing a life-threatening illness. She referred to this process as personalizing choices. While these treatment decisions included only orthodox options, this study emphasized that treatment decisions involve more than evaluations of the statistical effectiveness of various treatment options.

**Phase 3: Maintaining an Illusion of Control**

Once orthodox treatment had been completed for some time, the nature of control created through CT use changed once again. In the previous phase, women had worked hard at taking back control over their health and from the orthodox health care system. In the third phase of the CT decision-making process, women began to regain their sense of "normality" in their lives, where cancer no longer occupied a central and all consuming focus. As women moved further away from the completion of their orthodox treatment and began to feel well, they also began to feel an increased sense of control over their health and their cancer. They felt that they no longer had to work so hard at healing from their cancer or achieving wellness. Therefore, the women felt that their CT regimen could be pared down to a bare minimum or core regimen of CTs at this point in the disease trajectory. In this way, women could actively maintain control over their health through implementing their core CT regimen in order to prevent or delay a recurrence without much interference in their day-to-day lives.

Pelusi (1997) referred to orthodox breast cancer treatment as a "sanctuary", where the treatment itself offered women feelings of security that they were actively doing something to fight the cancer. In this way, women felt they had some control over their illness while they were receiving orthodox treatment. Similarly, in the current study, women in the third phase of the CT decision-making process referred to their CT regimen as a security blanket, which also provided feelings of security and comfort that they were actively doing something for their cancer. Once these women had completed orthodox treatment, they no longer felt the security
that accompanied actively doing something to fight their cancer. Maintaining a core regimen of CTs helped the women to continue to feel that they were actively influencing their health, thereby preventing or delaying a recurrence. Pelusi’s (1997) study may help to explain why women use CTs, particularly at times along the breast cancer disease trajectory when orthodox treatment has not yet begun, or when it has been completed.

Maintaining an illusion of control was described by a number of the women interviewed as a major and positive outcome of their CT use in the middle to latter parts of the breast cancer trajectory. A number of authors define an illusion of control in a negative light, using it synonymously with false hope (Hickey, 1986) or the product of unrealistic goals (McGee, 1984). The women in the current study, however, defined an illusion of control in a more positive manner, referring to it as perceived control, or the belief that one may exert some control over one’s destiny. The majority of the women were quick to add that they were uncertain as to whether their CT regimen was actually helping them in this third phase; they believed that they could never really know to what extent, if any, that their CT regimen was keeping them well or preventing a recurrence. One’s perception of control over one’s health through maintaining a core CT regimen was identified as more important than actual control. Actual control over the recurrence of breast cancer was seen as an unrealistic goal due to the uncertainties inherent in the disease. Therefore, perceived control over their health through CT use allowed women to continue to live their day-to-day lives once orthodox treatment had been completed.

Research indicates that having a perception of control, or the illusion that one can exercise a personal choice, is as effective in sustaining life as having actual control (Lefcourt, 1973). Taylor (1983) found that women who maintained illusions adapted better to their diagnosis of breast cancer and believed they had more control over their disease. In the current study then, the use of a core CT regimen to maintain an illusion of control over their cancer and their health continued to be an adaptive coping strategy for women in the latter phases of the breast cancer disease trajectory.
A belief that one can alter one's destiny was found to be an important characteristic among all of the women in the current study related to CT use. In this way, women felt they could exert some control over their cancer and their health by using CTs. Without this belief, the use of CTs as a control mechanism becomes a moot point, where one believes she can do nothing to alter the course and outcomes of one's life. Certain cultural groups, such as women of South Asian descent, commonly believe in the power of fate or destiny, where they feel they are unable to influence their future to any significant degree (Johnson et al., 1998). At the same time, many of these women access orthodox medical treatments, and it is likely that many also utilize CTs, given the popularity of complementary/alternative approaches to health care such as Ayurvedic Medicine, which is based on South Asian beliefs about health and illness. The use of CTs as a control mechanism then is not likely to be the core variable underlying the CT decision-making process for these women, as was identified in the current study. More study is therefore necessary to include women of cultural groups which commonly hold beliefs about fate or destiny to determine the role of CT use for these women.

Throughout all three phases of the CT decision-making process, women made decisions about whether or not to discuss their CT use with an OHCP. Choosing to either disclose or withhold information about CT use from OHCPs, particularly physicians, was a way of maintaining control. Almost all the women in the study chose to withhold information about their CT use, for a variety of reasons. These reasons included poor communication skills on the part of the physician, negative attitudes regarding CT use on the part of the physician, lack of knowledge about CTs by the physician, the need to be in control of at least a part of one's cancer treatment plan, fear of being viewed as foolish for using CTs, and fear of receiving information from the physician which might threaten the woman's hope. Non-disclosure of CT use therefore protected women's hope, conserved precious energy that might otherwise be used to deal with the negative fallout of telling her physician about her CT use, and promoted women's sense of autonomy within her cancer treatment experience. Montbriand (1995a) reported similar findings, where 62% of patients in her sample were secretive about their CT
use as a means to maintain control within the orthodox health care system. Further discussion regarding the effects of health care relationships on disclosure of CT information, and its effect on hope are included in the following sections.

**Maintaining Hope**

Hope was a theme which surfaced frequently during women’s descriptions of the CT decision making process. Throughout all three phases of the CT decision-making process, women reported hope as a positive outcome of CT use. The act of “doing something” for themselves, such as using CTs, enhanced women’s sense of control, which has been identified in the literature as an important hope inspiring strategy (Erseck, 1992; Miller, 1989; Raleigh, 1992). Actions to regain control, such as through CT use, therefore, contributed to the maintenance of the women’s hope.

Hope has been identified as playing a therapeutic role in adjustment to a chronic life threatening illness (Christman, 1990; Erseck, 1992; Hall, 1990; Herth, 1989; Hickey, 1986; Stotland, 1969; Taylor, Lichtman, & Wood, 1984). Positive outcomes of being hopeful identified in the literature include improved emotional, spiritual, and existential well-being, decreased anxiety and depression, enhanced immune functioning, and prolonged survival (Erseck, 1992; Post-White et al., 1996). The women in this study articulated that being hopeful helped them to have a future life in spite of their diagnosis, and to take actions to enhance their survival. Complementary therapy use helped these women to feel stronger and more able to carry on with the day-to-day activities of their lives, to engage in activities which promoted their health despite their illness, and enhanced their will to live. Based on these findings, then, interventions to promote or maintain hope are an important and necessary part of one’s cancer treatment plan. For women in this study, the use of CTs were described as a means to maintain hope in the face of an uncertain future.

In the current study, as women moved along the breast cancer trajectory, they hoped for different things in relation to their CT use. In the early phases of the trajectory, women used one or more CTs to control the spread of their cancer while they waited for surgery with the
hope that CT use, in addition to orthodox treatment, would increase their odds for achieving a cure. After surgery and during orthodox treatment, women used CTs to control stray cancer cells, manage unwanted side effects from orthodox treatments, promote feelings of well being, and to boost the immune system, with the hope of preventing or delaying a recurrence. Once orthodox treatment was finished and the women began to re-establish their lives without cancer as their primary concern, women continued to use a core regimen of CTs with the hope of preventing or delaying a recurrence. However, when women experienced a recurrence or shift to a palliative focus of care, women’s hopes related to CT use again changed. At this point in the trajectory, women hoped for quality of life versus quantity of life. Clearly, as the women progressed through the phases of breast cancer trajectory, the aims or goals of CT use changed with the outcome of maintaining hope. Recent research exploring the concept of hope reflects these findings. Hope has been described as a dynamic process where the nature of hope changes over the disease trajectory (Dufault & Martocchio, 1985; Laskiowski & Morse, 1993; Morse & Doberneck, 1995; Owen, 1989; Penrod & Morse, 1997). According to Stotland (1969), hope involves goal setting, where expectation of achieving the goal is the focus of hope. One would expect then, if a newly diagnosed woman with breast cancer hopes for a cure, then as she progresses through the cancer trajectory towards a recurrence (where a cure is less likely to occur), her hope may be threatened. Current research, however, has indicated that this downward spiral of hope with progression along the cancer trajectory is not necessarily inevitable (Ballard, Green, McCaa, & Logsdon, 1997; Herth, 1990). Instead, to maintain hope, individuals change the nature of their goals over the course of the trajectory. The ability to reset goals contributes to one’s ability to remain hopeful in response to changing circumstance or prognosis (Owen, 1989). In the current study, goals related to CT use were constantly re-evaluated, thereby enabling women to maintain hope throughout the ups and downs of the breast cancer disease trajectory.

Discussions surrounding realistic versus unrealistic goal setting by patients frequent the hope literature, which has implications for the phenomenon of CT use (Brown, 1987; Dufault
& Martocchio, 1985; Erseck, 1992; Herth, 1991; Hickey, 1986; Miller, 1985). Implied in this literature is the notion that if an individual continues to have a strong will to live and hopes for a cure despite odds that do not favor her survival, that somehow they are not accepting of reality (Hall, 1990). Yates (1993) points out that during these discussions, it is not clear whose concept of reality is being referred to; the patient’s or the health care professional’s (HCPs). If one’s reality is constructed based on personal beliefs and life experiences, then it follows that what one person views as realistic, others may not. It is not surprising then, that HCPs have difficulty differentiating between realistic and unrealistic hope, if indeed this dichotomy exists at all (Yates, 1993). Similar debate exists in the CT literature, where critics of CTs balk at the use of many CTs, particularly in situations where cancer mortality statistics do not support long term survival. Here, the HCP’s reality of the situation is deemed more accurate than that of the individual. However, if one acknowledges that an individual’s beliefs about CT use fosters hope for that person, and that hope is a life sustaining force, then the HCP’s reality is not important in this situation (Hall, 1990; Yates, 1993). In the context of hope, then, understanding and sustaining women’s beliefs about CT use is paramount. In the current study, women’s beliefs about CT use played a major role in their decisions to use CTs, and in their maintenance of hope. Advice from HCPs regarding CT use was rarely factored into women’s CTs decisions, and in some cases, this advice dashed women’s hopes. A more in-depth discussion of HCP’s positive and negative influences on the maintenance of hope can be found in the next section on health care relationships.

While the actual use of CTs may have the effect of promoting hope, deliberate withholding of information about CT use by patients from health care professionals may also function to maintain hope in some cases (Erseck, 1992). In the current study, a number of women consciously withheld CT information from their oncologist and/or GP for fear of receiving threatening information about their CT use. They rationalized that by not discussing their CT use with the health care professional, they would not have to deal with information from a trusted individual that may threaten their ideals about certain CTs, causing them to re-examine
and/or stop using one or more CTs. Hope was therefore maintained through non-disclosure of CTs. These women reported high levels of fatigue, and felt that they did not have the energy necessary to reconfigure their CT use so as to maintain their hope. Viewing the phenomenon of CT use through the concept of hope, then, one may see how non-disclosure may in fact be a positive coping strategy to maintain hope. Research on decision-making behavior supports this finding. Janis and Mann (1977) coined the term defensive avoidance, where they described individuals who attempted to keep from being exposed to information that might reveal the shortcomings of the course of action chosen. Defensive avoidance helped these individuals to reduce feelings of distress associated with making choices, which in turn, fostered their sense of hope for the future.

Despite the possible benefits of non-disclosure of CT use to HCPs, much of the CT literature espouses the safety risks of not discussing CT use with HCPs (Danielson et al., 1988; Hopkins & Brigden, 1991). From the patient’s perspective then, it would seem that for some individuals, the act of discussing CT use with their HCP may in fact carry more risk than withholding that information. Careful consideration must be undertaken by HCPs before offering gratuitous advice or recommendations about CT use. While all patients should be made to feel that discussions about CT use are welcomed by a HCP, they should be offered the option of discussing their own current or potential CT use in detail.

Women’s beliefs about the efficacy of their CT regimen, their need to regain control, and the maintenance of hope were closely related in the current study, particularly for women in the latter phases of the breast cancer disease trajectory. These women described their CT use as a means to maintain an “illusion of control”, where they acknowledged that beliefs about whether or not their CT regimen contributed to the prolongation of their lives was more important than whether the regimen actually had an effect. Erseck (1992) believes that these illusions of control allow women to potentially dismiss the “facts” about their situation, in order to maintain hope. In this way, an environment of normality is created where women may continue to face up to their day-to-day lives, without feeling hopeless and immobilized by the uncertainties
inherent in their diagnosis (Hall, 1990). In the context of CT use then, perceptions of control over their health and illness, based on their beliefs, created a foothold for maintaining hope for the women in this study.

The uncertainty associated with the efficacy of many CTs may also allow some women to maintain hope. According to Mishel (1988), for some individuals, uncertainty allows for positive outcomes to be imagined, rather than the certainty that a situation is hopeless. The uncertainty associated with the causes of breast cancer, in addition to the uncertainty inherent in the efficacy of many “unproven” CTs allowed the women in the current study to create their own outcomes, believing that they potentially could beat their cancer. The women described the effects of this uncertainty in a positive manner, referring to the illusion of control created through CT use.

Health Care Relationships

Accessing objective, evidence-based information about CTs has been identified as one of the most difficult tasks in the CT decision-making process (Montbriand, 1993). Women in the current study voiced this difficulty, which became most apparent during the period between surgery and the initiation of adjuvant cancer therapies. During this phase of the breast cancer trajectory, women were initiating new relationships with their oncologist(s) while trying to assimilate the complexities of deciding on orthodox treatments. For most women, their oncologist became their primary physician for the remainder of their cancer treatment and beyond. For others in more remote areas of British Columbia, their GP continued as their primary physician. Although one’s primary physician is perhaps the most logical source of information when attempting to integrate CT use with orthodox cancer treatments (Herbert & Paluck, 1997), studies have shown this not to be the case, for a variety of reasons (Gray et al., 1997). Many North American orthodox physicians have been identified by patients as lacking knowledge regarding CTs, having negative and paternalistic attitudes about CT use, and possessing poor communication skills (Bourgeault, 1996; Cassileth, 1988; Goldszmidt, Levitt, Duate-Franco, & Kaczorowski, 1995). It is not surprising then, that a large US survey
reported that 72% of CT users did not discuss their CT use with their physician (Eisenberg et al., 1993). The current study mirrors these findings, where the majority of women chose not to talk to their GP and/or oncologist about their current or potential CT use. Decisions to not discuss CT use with the women's primary physician were affected in part by the relationship with that physician, and functioned to enhance a sense of control and to maintain hope.

Dissatisfaction with the physician-patient relationship is frequently cited in the literature as the primary reason for CT non-disclosure (Dunfield, 1996; Langner, Clarke, Kelly, & Bouchard, 1993). However, in the current study, reasons for non-disclosure of CT use were found to be more complex. In addition to dissatisfaction with the physician-patient relationship, important factors influencing a woman's decision whether or not to discuss CT use with her primary physician included extreme levels of fatigue and information overload, fear that one's hope may be threatened by disclosure of CT use, and the need for complete autonomy over a portion of one's cancer treatment plan.

Satisfaction with the patient-physician relationship was a common recurring theme in all of the women's interviews. While most women were satisfied with their primary physician's knowledge about up-to-date and effective orthodox treatments for breast cancer, and their ability to provide the women with these treatments, many of the women reported dissatisfaction in their relationship with their primary physicians. They believed that many physicians did not want to know them beyond the pathology of their breast cancer, and, consequently, the women were made to feel more like a cancer statistic than a human being. Further, many women felt that their primary physician had negative attitudes toward CT use. Not surprisingly then, most of these women purposefully withheld information about their personal CT use, and did not approach their physician for information or advice about CTs. What is surprising, however, is that women who were dissatisfied with their relationships with their primary physician did not seek out another physician who might approach patients in a more holistic manner, validating and supporting women in their use of CTs. Fatigue and information overload was cited as a major factor in preventing women from seeking out a more satisfactory health care provider,
particularly in the earlier phases of the breast cancer trajectory. After struggling to adapt to living with a life threatening-illness and sorting through complex information to make decisions about orthodox treatments, women simply did not have energy to seek out a new physician. Rather, to maintain some control within the unsatisfactory relationship, women purposefully avoided discussions about potential and current CT practices. Instead, these women turned to more sympathetic sources for CT information, such as CT practitioners, fellow breast cancer patients, and the lay literature.

Fatigue in cancer has gained recent attention in the literature as the most frequently reported symptom and as an important factor affecting patient’s quality of life (Winningham et al., 1994). Many of the women in the current study experienced moderate to extreme fatigue levels as a result of the disease process, side effects of orthodox cancer treatments, and information overload. This fatigue in turn interfered with the women’s CT information seeking efforts; they did not have the physical or emotional resources to engage their primary physician in discussions about CT use. Initiating discussions about CT use within the orthodox health care system requires strength, determination and courage, due to the stigma associated with CT use. Many of the women found that they did not have the energy to deal with the potential negative consequences of discussing CT use with physicians who may not be supportive of this behavior. Further, a number of women relayed fears of being abandoned by their primary physician as a result of using CTs in addition to orthodox treatments. These women felt that they might be labeled as “uncooperative” or a “problem” within the medical community, making it difficult for them to find another primary physician. Moreover, these women did not have the energy to engage in an uphill struggle to find a new, more sympathetic primary physician.

Fatigue is also mentioned in the literature as a threat to hope (Herth, 1990). Owen (1989) described hope as a process which requires energy to continue, so that when individuals experience fatigue, threats to hope are avoided to conserve energy for the hoping process. In the current study, a number of physicians’ attitudes toward CTs were viewed as threats to
hope, so that women experiencing fatigue did not discuss CT use with those physicians. These women felt that they did not have the energy to deal with convincing the physician about the merits of CT use, nor energy to assimilate information about CTs currently used which might threaten her hope.

It is not clear from the findings of the current study how the patient-physician relationship changes as women move along the breast cancer trajectory, and what impact this has on CT disclosure/non-disclosure. As women move further away from the completion of orthodox treatments, they often feel less fatigued, more in control, and have increased confidence in their ability to negotiate the intricacies of the health care system. One might hypothesize that women who initially were dissatisfied with the patient-physician relationship and did not feel they were able to discuss CT use might eventually either find a new more sympathetic physician, or feel more able to discuss CT use with her original physician without fear of reprisal. While time may improve some relationships to the point where women feel able to discuss CT use with their physician, the findings of the current study point to a critical period earlier in the breast cancer trajectory where women with breast cancer would most benefit from a positive patient-physician relationship. Women described the period after recovery from surgery as the time when CT information needs were the highest, and women were most receptive to acquiring and understanding this information. Obtaining assistance in locating a sympathetic physician/oncologist early in the breast cancer trajectory becomes an important task which may have an impact on decreasing the difficulty in accessing objective CT information, and may open up opportunities for safe integration of CTs into one’s orthodox cancer treatment plan.

The impact of the patient-physician relationship on patients’ hope has begun to receive more attention in the literature, and has implications for the current study. A number of studies have identified the physician as a symbol of hope, where a positive interpersonal relationship between the patient and physician can function to nourish and strengthen patients’ hope (Bruhn, 1984; Hall, 1990; Herth, 1990; Wong-Wylie & Jevne, 1997). Given that hope is a
necessary and life-sustaining condition (Raleigh, 1992), it is critical that physicians use strategies to nurture hope within the patient-physician relationship.

Wong-Wylie and Jevne (1997) and Herth (1990) have identified strategies which either foster or threaten patient’s hope within the context of the patient-physician relationship. Unfortunately, most women in the current study described their primary physician as using more hope-threatening than hope-fostering strategies during their interactions. Women described being devalued as a human being, where they were reduced to feeling like a cancer statistic. Many physicians made no attempt to connect with the women on a personal level or understand the women’s feelings about their situation, dismissed women’s concerns about orthodox treatment side effects, insisted on maintaining control within the orthodox decision-making process, and expressed negative or unsupportive attitudes about CT use. Women believed that discussion of CT use with this type of physician would only result in feeling further devalued as an individual, thereby threatening their hope. Therefore, in an attempt to protect her sense of hope, many women who experienced this type of patient-physician interaction chose not to discuss their CT use with their physicians.

Much of the criticism from the orthodox health care system surrounding CT use relates to the secrecy surrounding CT use. Many physicians believe that non-disclosure of CT use may pose safety threats, either through interactions with orthodox treatment, or through abandonment of curative orthodox treatments for CTs. However, in light of the above discussions, it seems that health care professionals, including physicians, must balance the patient’s need to maintain hope against any potential threat to safety related to CT use. In fact, a threat to hope, such as discussing CT use with an uncaring physician, could result in an assault on one’s sense of psychological safety.

A few women in the current study were fortunate to have primary physicians who they felt were respectful, understanding, communicative, and used mainly hope-fostering strategies in their interactions with them. However, although they felt that they could discuss CT use with their physician, these women chose not to disclose their CT use for fear of receiving hope-
threatening information. These women felt that they respected their physician’s advice on most matters concerning their health, but felt they could not risk receiving information from this professional that might challenge their ideology regarding their current and/or potential CT use. In this way, the women’s hope was maintained through non-disclosure. To complicate the situation, all of these women also experienced a great deal of fatigue and information overload, and felt that they did not have the energy to reconfigure their CT regimen to fit with the information given by the physician. Again, fatigue functioned as an influencing factor in the maintenance of the women’s hope.

It is not clear why the majority of women in the current study had primary physicians with whom they were not satisfied. This phenomenon might be explained through the sampling techniques utilized in this study, where women purposely were chosen for their ability to articulate clearly the CT decision-making process. These outspoken women may have been more likely to agree to participate in this study in order to speak out against negative patient-physician interactions without fear of reprisal. Perhaps women who did not want to participate in the study had very caring and supportive physicians and did not feel the need to speak out about CT use. Further sampling to include women in this latter category might clarify the issue.

Recent surveys of physician and medical student attitudes toward CT use in Canada brings hope to this dismal picture of strained physician-patient relationships. Physicians are becoming increasingly positive about the more established varieties of CTs, and have begun to reject many negative stereotypes of practitioners of CTs (Furnham, 1993; Goldszmidt et al., 1995; Verhoeff & Sutherland, 1995). Medical schools throughout the US and parts of Canada are including course content on alternative medicine as well as techniques to foster therapeutic relationships (Monson, 1995). National forums for patients and physicians, sponsored by the Canadian Breast Cancer Initiative, were held to develop strategies to enhance patient-physician relationships. One strategy evolving from this workshop included the creation of a partnership between a group of women with breast cancer and the University of British Columbia Faculty of Medicine to help educate upcoming physicians regarding therapeutic communication
techniques. While strategies to enhance patient-physician communication are beginning to have an effect on the new generation of physicians, many older, more established physicians may continue to expect a more paternalistic relationship with patients. Nurses may hold the key to solving this problem, acting as an advocate for women by opening up a dialogue with these physicians regarding the positive impact of CT use on women's feelings of control and maintenance of hope.

Little mention was made by the women in the current study about the role of nurses in fostering and supporting CT use. Only one women reported being asked about CT use by a nurse. In that one situation, the nurse was extremely supportive of the CT use, but was unable to provide any information on the topic due to her own lack of knowledge. For the most part, nurses were seen as having little to do with helping women to make decisions about both orthodox and complementary treatments for their cancer. As such, women did not broach the subject with nurses; nor did nurses assess women regarding CT use. This finding is reflected in the paucity of research literature pertaining to the role of nurses in relation to CT use in North America. It seems that while many nursing models give direction for nurses to assess patients from a holistic perspective, including the individual's beliefs and needs related to CT use, this area has been neglected both in the research literature and in practice. A number of factors may be responsible for nursing's hesitancy in embracing the phenomenon of CT, and in supporting patients to use CTs as a supportive action to enhance the benefits and/or buffer the side effects of orthodox treatments. These factors include nurse's lack of knowledge about CT use, fear of being ridiculed by colleagues by supporting patients in their CT use, an organizational structure that does not support nurses in assessing and supporting patients in their CT decision making, and patient's perceptions regarding the lack of clarity of nursing's role in supporting patients' decision making within the health care team (Hopkins & Brigden, 1991; Fryback & Reinert, 1997; Koopmeiners et al., 1997; Montbriand, 1993). Each of these factors must be addressed and remedied before nursing may move forward and support women with breast cancer in their CT decision making.
Implications for Nursing

The findings of this study have implications for nursing practice, nursing education, and nursing research. Major implications are discussed below, within each identified domain of nursing.

Implications for Practice

Prior to supporting women with breast cancer to integrate CT use into their orthodox cancer treatment plan, nurses must understand the purpose, the decision-making patterns, and the outcomes of CT use by these women. Further, nurses must become better informed about the most common CTs used by women with breast cancer, including the available CT resources in one's community to assist women in making informed CT decisions.

One caution must be observed when discussing the role of nurses in assisting women to make decisions about CT use. Findings of the current study did not identify nurses as playing a significant role in the CT decision-making process. While it may be hypothesized that a number of factors, including the controversial nature of CT use or lack of opportunities for discussion may have prevented women from discussing CT use with their nurse, further study must be done to explore and validate whether women would like nurses to assist them with their CT decisions. Until this research is done, however, given the theoretical role of the nurse as patient advocate, teacher and supporter, it may be assumed that most women would embrace nurse's assistance in helping women to navigate through both complementary and orthodox treatment decisions.

The findings of this study clearly indicate CT use is a means for a woman to begin to gain control over her uncertain new life as a woman living with breast cancer. Complementary therapy use was also found to be an important strategy in maintaining women's hope, which in turn, enhanced their will to live. By understanding the importance of CT use within women's lives, nurses may become better motivated to assess and offer support for this very important coping strategy. Further, understanding the process that women with breast cancer use to make
decisions about CTs will influence and give direction to the interactions that nurses have with these women.

Hope was found to be an important and life-sustaining outcome of CT use in all phases of the CT decision-making process. Nurses must therefore use strategies to foster this hope related to CT use in their relationships with women with breast cancer. The use of effective therapeutic communication skills by all health care professionals, including nurses, were described by the women in the study as a critical foundation for promoting hope related to CT use. As a part of therapeutic communication, nurses must foster interpersonal connectedness in their relationships with women using CTs, which may help them feel valued as human beings rather than a cancer statistic, or a “lunatic” who uses CTs. Development of a sense of interpersonal connectedness also allows the nurse to understand and respect each woman’s individuality, where the woman’s beliefs and values about CT use can be acknowledged and honored. A number of behaviors which have been identified as fostering interpersonal connectedness can be initiated by nurses related to CT use. These behaviors include the use of reassuring touch, a willingness to listen attentively, affirming one’s worth by showing genuine interest, and a willingness to share a part of themselves and to share in the patient’s hopes (Herth, 1990; Koopmeiners et al., 1997; Penrod & Morse, 1997; Raleigh, 1992). To achieve this connectedness with patients, nurses must first suspend their own personal biases regarding CT use, focusing on the fact that women use CTs for the purposes of maintaining control and promoting hope, both of which facilitate that woman’s adaptation to her illness. In this way, nurses may genuinely convey respect for the woman’s decision to use CTs, and are better able to support women in making these decisions.

A part of utilizing effective therapeutic communication skills includes the creation of an environment which is safe for women to discuss CT use with nurses, and potentially other health care practitioners. It must be remembered, however, that some women may purposely choose not to discuss their CT use in order to avoid receiving information which might threaten their hope. Further, the findings of this study indicate that CT use serves very important
purposes throughout the breast cancer disease trajectory, ultimately providing a sense of control and fostering hope. Attempts to undermine or challenge women’s use of CTs, particularly in the early phase of the cancer trajectory would only serve to enhance feelings of loss of control and threaten hope. Rather, offering women the option to discuss CTs in a caring and non-judgmental manner allows them to feel that their decisions to use CTs are valued, but at the same time respects the need to protect one’s hope.

Once nurses open themselves up to discussing CT use with women with breast cancer, they must also increase their own knowledge about various CTs in order to support informed decision making by these women. While this may seem like a huge undertaking given the large numbers of CTs that exist and the lack of accessible information about these CTs, nurses initially need only to become familiar with the most commonly used CTs by women with breast cancer. The Canadian Breast Cancer Research Initiative has identified the top 10 CTs used by women with breast cancer, and has published integrated literature reviews of the available scientific information on these CTs. This information may function as a starting point for nurses in their journey to become informed about CTs.

Nurses also need to be familiar with tools to assist women in becoming better informed about CTs. A number of handbooks have been published recently which may be helpful to patients. The most commonly used handbooks by the women in the current study included, a) A Guide to Unconventional Cancer Therapies, by the Ontario Breast Cancer Information Exchange Project (1994), b) Options: The Alternative Cancer Therapy Book, by Richard Walters (1993) and, c) Choices in Healing: Integrating the Best of Conventional and Complementary Approaches by Michael Lerner (1994). The first two handbooks are user-friendly, easy to read, and provide information on a wide variety of CTs. The second handbook, however, is strongly biased toward CT use and occasionally provides inaccurate information about orthodox medical treatment for cancer. The third handbook presents the most objective look at how CTs and orthodox cancer treatment may be integrated. However, information is provided in great depth about a limited number of CTs and may prove to be too
detailed for women to use in the early phases of the breast cancer disease trajectory. A major drawback of all three handbooks is that they do not assist women in choosing among the various CTs to create a personalized regimen that fits one’s beliefs and needs. Therefore, nurses may need to use portions of each handbook in assisting women to become informed and to make personalized decisions about CTs.

Knowledge of the available resources to support CT decision making within their local community is also needed by nurses caring for women with breast cancer. In some cancer centers, a Clinical Nurse Specialist may be available to assist patients in navigating through the orthodox and complementary health care systems to create a personalized CT regimen that they can live with. While this one-on-one approach with the Clinical Nurse Specialist may be desirable and effective for the individuals served, it is not cost effective and cannot possibly meet the demands of large numbers of women requiring assistance with CT decision making. Therefore, a program could be developed which assists groups of women to make informed decisions about integrating CTs into their orthodox cancer treatment plan. This program could be developed by an advanced practice oncology nurse and could include partnerships with, for example, an oncologist and a practitioner of CTs. In a group setting with support from orthodox and complementary health care professionals, women could clarify their values and beliefs about health and illness, receive the latest scientific information on a variety of CTs, use valid decision-making frameworks (e.g., O’Connor, 1993) to make informed decisions about CTs, and receive follow-up support to facilitate the integration of CTs into one’s orthodox cancer treatment plan. Creating a program which addresses women’s CT decision-making needs in an objective and welcoming manner conveys a message that the orthodox health care system validates and respects the importance of CT use by these women. While this program will likely be attended by many women with breast cancer to receive support for CT decision making, other women may purposefully not attend, in order to avoid receiving information which may threaten their hope.
In addition to developing knowledge about common CTs used by women with breast cancer, nurses may also develop practical CT skills so that they are able to administer various CTs directly to their patients. As nurses become more familiar with more commonly used CTs such as, for example, relaxation, meditation, imagery, and therapeutic touch, they will be better able to assist women to make informed decisions about the use of such CTs. This enhanced skill will allow nurses to be more helpful to women in the very early phase of the CT decision-making process, where women feel the need to quickly put one or more CTs in place without much searching for information about CTs. In this way, nurses could offer women a limited range of CT options to women in the early phase of the disease trajectory (i.e., between diagnosis and surgery), and could facilitate “getting something in place” by initially providing the woman with a chosen CT. Having the nurse provide the woman with a particular CT may also enhance the interpersonal connectedness between the woman and the nurse, which has been identified as an important strategy to foster hope (Herth, 1990). Ultimately, when the woman’s stress related to her cancer experience has decreased, nurses could then begin to teach the woman or her family members to administer that CT. This action would also support women’s desire to begin to take back control from the orthodox health care system sometime after they have recovered from their surgery.

From the nurse’s perspective, the acquisition of CT knowledge and skills fits well within nursing’s defined boundaries, and provides an area of independent practice which is complementary to medicine. Further, the practice of CTs may allow patients to view nurses as having a particular expertise different than that of physicians, thereby strengthening nursing’s image as an important member of the health care team.

Utilizing a holistic approach when determining the impact of a woman’s breast cancer diagnosis on her life is also necessary to foster women’s hope. Acknowledging the impact of the mind and the spirit on one’s body was particularly important for women using CTs in the current study, and was identified as an effective way to communicate caring and to promote hope by health care professionals. Fortunately, many nursing models direct nurses to practice
in this holistic way, encouraging the nurse to view the patient’s situation, from the patient’s perspective. In this way, the patient’s beliefs and values are identified and validated as important, laying the foundation for a respectful and hope-fostering discussion about CT use. The challenge then, is to ensure that nurses effectively utilize a holistic approach consistently.

The majority of women interviewed in the current study described their primary physician as being unsupportive of CT use and utilizing poor communication skills. While nurses cannot change these particular physicians’ attitudes and behaviors, a number of actions can be taken to lessen the negative impact on the women. Firstly, nurses may advocate for women regarding CT use, particularly during the extremely stressful period between the time of diagnosis and the start of orthodox treatment, regarding the impact of the physician’s manner of communication on the woman’s sense of control and hope. Further, nurses may begin a dialogue with physicians regarding the importance of CT use in maintaining control and fostering hope for women. Optimally, this dialogue should begin well in advance of any difficulties arising, to allow for reflection and discussion over time. However, if women do run into difficulties with their physician’s attitudes toward CT use, the nurse may need to act as a mediator to reframe CT use as a positive coping strategy which maintains control and fosters hope. In some cases, the nurse might need to assist the woman in locating a new, more sympathetic physician who utilizes effective communication skills and understands the importance of women’s use of CTs to foster a sense of control and hope. In this way, nurses may intervene to conserve women’s energy and reduce emotional fatigue. Women may better use this conserved energy to maintain the hoping process.

Fatigue and information overload were factors cited as frequently affecting the CT decision-making process. Interventions to reduce fatigue and minimize information overload will therefore enhance women’s ability to participate fully in the decision-making process. Findings from this study reveal an optimal point along the breast cancer trajectory for receiving information about CTs, thereby reducing feelings of information overload. Women reported the time between surgery and start of adjuvant orthodox treatment as optimal for being able to
assimilate CT information. Nurses may therefore aim to facilitate the acquisition of CT information for women during this time period. During the period between diagnosis and surgery, women felt overwhelmed with orthodox treatment information and could rarely integrate CT information into their orthodox treatment decisions at that time. To alleviate this sense of information overload and resultant fatigue, nurses may assist women in sorting through the orthodox information received from their physician, and to locate any missing pieces of that information. To help reduce some anxiety and information overload presurgically, the nurse may reassure women that they will receive assistance with searching for information about CTs after surgery. Facilitating a beginning awareness of beliefs and values regarding health and illness may also help women to sort through and make preliminary decisions about orthodox treatment options, prior to surgery. After surgery, nurses may continue to assist women in their journey to become aware of their health and illness beliefs and values. In this way, women may become more focused in their search for information about CTs, as they will be able to choose from among those CTs which fit with their belief and values systems. Numerous other, more general interventions to reduce fatigue for individuals with cancer are summarized in an article by Winningham et al. (1994).

Understanding the dynamic nature of the CT decision-making process also has implications for nurses working with women with breast cancer. Clearly, women in this study made multiple decisions and ultimately changed their patterns of CT use as they progressed through the breast cancer trajectory. Further, they used CTs for different purposes, depending on the phase of the trajectory. This finding suggests the importance of frequently assessing patients for CT use and offering support for CT decision making at multiple points along the breast cancer trajectory. Based on the findings of this study, optimal points might include the time between diagnosis and surgery, immediately after surgery, at some point during chemotherapy and/or radiation, and at various times of stress, including recurrence and shift to a palliative focus of care.
While the above interventions are important to facilitate women's CT decision making, the organizational structure in which the woman is cared for often does not support these interventions. For example, in many cancer care institutions, the nurse is not considered a major partner in the care of patients. Rather, the physician takes charge with occasional consultation and input from the nurse and other OHCPs. From the patient's perspective then, the nurse is not seen as an important support or source of information in making decisions about their health. Further, patients often do not feel that any OHCP is coordinating their care, helping them to navigate their way through the complex and often confusing system of cancer care. The pressure for physicians to see as many patients as possible in one day also adds to patients feeling dehumanized and rushed for precious time with their physician. A more optimal organizational structure might include one where the physician and the nurse form a partnership to ensure holistic care of the patient over their disease trajectory. At their first visit to the institution, patients are introduced to their physician and their nurse, who will consistently care for them at each subsequent visit. While both the physician and nurse address the patient's physical needs related to their cancer diagnostic and treatment procedures, the nurse also supports the patient and her family in coping with the impact of cancer on their lives. As such, the nurse functions as the coordinator of that patient's care, ensuring that all of the patient's needs, including those related to the use of CTs, are being met. Consistent care over time by one physician and nurse also helps to foster therapeutic relationships, and a sense of interpersonal connectedness which fosters hope.

Implications for Education

To develop the requisite knowledge, skills, and abilities to assist women in integrating CTs into their orthodox cancer treatment plan, a number of educational strategies for nurses must be implemented to support this behavior. These strategies must be carried out at all levels, including basic nursing education programs, graduate programs, and continuing education for practicing nurses.
Basic nursing education programs should include course content on complementary health care, and should include clinical opportunities to develop CT skills such as, for example, relaxation, imagery, relaxation, massage, and therapeutic and healing touch. Complementary therapies which have been validated via Western scientific methods, as well as those CTs which are based on non Western scientific paradigms should be explored to compare and contrast the varying tenets of many CTs and the difficulty in validating many CTs according to Western methods. In a profession such as nursing which aims to foster evidenced-based practice, however, basic education programs should focus on fostering skills related to those CTs which have at least some Western scientific validity (e.g., therapeutic touch, massage, imagery). An openness to the expanding possibilities of other CTs not yet validated must also be encouraged. A learning environment which includes students of other health care professions, such as medicine, physio and occupational therapy, social work, and nutrition, will help to clarify nursing’s unique role in relation to CTs. Further, development of strong therapeutic communication skills within this multidisciplinary environment will also strengthen beginning nurse’s ability to advocate for patients. For both basic and graduate nursing students, an exploration of how holistic nursing models direct nurses to take a patient-centered approach to care will also help to realize the importance of understanding the patient’s situation, from the patient’s perspective.

Continuing education for practicing nurses should include knowledge of the patterns of CT decision making by women with breast cancer. This knowledge will in turn enhance the interactions that nurses have with these women, where nurses may be more sensitive to the needs of women as they engage in this decision-making process, and better able to provide anticipatory guidance and support regarding that process. For nurses who did not learn about complementary health care or develop CT skills in their basic nursing program, educational sessions could be held for practicing nurses to develop this knowledge and skills. Ongoing CT skill development opportunities could also be held to support nurses in acquiring a broad range of CT skills. Further, multidisciplinary sessions which address strategies to enhance
therapeutic communication skills with patients and among other health care professionals should be held.

To address the often negative image of CT use within an orthodox health care agency, informational sessions should be held for all OHCPs to help dispel the myths associated with CT use, and to enhance OHCP's understanding of the important role the CTs play in maintaining women's sense of control, and fostering hope. In this way, a supportive environment for CT use could begin to be created within the orthodox health care agency, which in turn, would help to support nurses in facilitating CT decision making with women with breast cancer.

Implications for Research

This study represents the first qualitative exploration into the CT decision-making process of women with breast cancer and has provided a beginning point upon which to elaborate through further research. Numerous questions for further inquiry have been raised from the findings of this study. For example, is the CT decision-making process used by women with breast cancer similar for patients with other types of cancer? What is the effect of culture on the CT decision-making process? Does disease status (e.g. Tumor Node Metastases status) at time of diagnosis affect the decisions women make with respect to CT use? Why do women assume both active and passive roles with respect to CT and orthodox treatment decision making? Most importantly, how can nurses best support women with breast cancer to use CTs while encouraging them to maintain control and foster hope?

While it is likely that the women in the current study are representative of the general population of women with breast cancer, this cannot be assumed. Attempts were made while sampling for this study to include a wide variety of women with respect to diversity of culture, types of CTs used, age, occupation, and education. Further, women at differing phases of the breast cancer trajectory were included with both local and advanced disease upon diagnosis. However, a few shortcomings were noted with respect to sampling. For example, a number of cultures were not represented, such as South Asian women. Only three premenopausal women
were included, and all three of these women had local disease. Therefore, subsequent CT decision making studies need to include a larger sample of women with a greater diversity of culture, and a greater proportion of premenopausal women with both local and advanced disease at diagnosis. Further research with a larger sample will determine the applicability of the study findings to the general population of women with breast cancer, and to specific cultural groups.

The majority of women in the study described strained relationships with their primary physician, which had an effect on their search for CT information and their disclosure of CT use to that individual. Subsequent research on CT decision making should include more women who had positive relationships with their primary physician, where they felt they could openly discuss CT use without fear of reprisal. Additional studies also need to be completed which explore women’s perceptions of how health care providers can support CT use to maintain control and foster hope.

All of the women in the study began their cancer journey within the orthodox health care system. Women who primarily access the complementary health care system for their health care could be included in later studies to increase understanding of how this choice affects CT decision making.

The effect of time on memory recall of CT decisions made in the past was identified as negatively influencing the findings of this study. A prospective, longitudinal study which elicits the process of CT decision making immediately after the decisions have been made, or while they are occurring, may overcome this difficulty. However, it must be remembered that women in the early phases of their breast cancer may be overwhelmed with the tasks of assimilating information and making treatment decisions, and may be unable to recount CT decision-making patterns at that time. Sensitivity to the women’s emotional state and level of stress and anxiety in the early phases of the breast cancer trajectory must therefore be factored in when determining the feasibility of carrying out this longitudinal study.
Findings indicate that while some women preferred a more passive role in orthodox treatment decision making, all of the women took an active role in CT decision making. This finding is contrary to the current research on preferred decisional roles for orthodox treatment decision making, where it is suggested that these roles are static (Bilodeau & Degner, 1996; Sloan & Degner, 1992). More research is necessary to understand this phenomenon of multiple and potentially dynamic decisional roles related to different types of health care decisions.

The majority of women in the current study were not able to make both orthodox and CT treatment decisions at the same time. However, a small number of women were able to integrate both CT and orthodox treatment decision making in the early phase of the breast cancer trajectory. Studies to explore the characteristics of this subgroup of women would help to further explain the patterns of CT decision making by women with breast cancer.

Discussion of the Method

Grounded theory methodology was utilized in this study to inductively develop a beginning theory which describes the CT decision-making process of women with breast cancer. In the next sections, measures taken to ensure rigor of this method are described, limitations of the study are discussed, and the significance of the findings, in light of the study limitations, are reviewed.

Rigor

The design of this grounded theory research study included a number of measures to ensure rigor in the development of the theory. Reliability was established through determination of appropriateness and adequacy of the sample. Appropriateness, or the degree of “fit” between the purpose of the study and the method of sampling utilized (Morse, 1986), was ensured and was discussed in the Methodology chapter of this document. Informants were selected who could articulate the process of decision making to use CTs clearly and completely.

As the researcher identified gaps in the unfolding data, theoretical sampling was used to select informants who were able to provide information to fill these gaps. As such, the sample became representative of the phenomenon under study, rather than the population in general.
Adequacy, or the sufficiency and quality of the data, was achieved at the point of data saturation, when no new data appeared, thereby indicating that the information given by the sample was complete (Morse, 1986).

Sandelowski (1986) identifies two important criterion necessary to establish rigor in qualitative research: a) auditability, and b) credibility and fittingness. Auditability was achieved by identifying a clear decision trail from the beginning to the end of the study (Sandelowski, 1986). A field note journal was kept regarding a) how the subjects were actually sampled and approached, b) the impact the subjects and investigator had on each other, and c) specifics of each interview, such as length of time and nature of the setting. Detailed records of the process of data analysis (including all decisions made during the process of this research) and theoretical memos was also kept, allowing others to follow the logic used to develop the grounded theory. Throughout the process of sampling, data collection, and data analysis, the investigator discussed the quality of the decision trail with thesis committee members.

Credibility and fittingness was ensured through a variety of measures. Due to concern that the investigator's forestructure might influence data analysis, bracketing of assumptions, beliefs, and values by the investigator occurred prior to data collection. Hutchison (1986) argues that “only through self-awareness of mind-set can the researcher begin to search out and understand another’s world” (p. 115). A journal was kept allowing the investigator to express personal feelings and reflections related to the research study, with the aim of sustaining a heightened level of awareness.

Another important strategy to achieve credibility and fittingness involved ensuring representativeness of the data. To address the dynamic nature of the CT decision-making process across the breast cancer trajectory, efforts were made to sample women at various points along the trajectory from the time of diagnosis through to palliation, from a range of cultural groups, and from all seven of the CT categories described earlier. It was hoped that diversity within the sample could be achieved inside these parameters. Although a wide range of cultural groups were represented in the study, including First Nations, Italian, Spanish,
Jamaican, Chinese, South American, and women of Northern European descent, a number of major cultural groups were not represented, such as, for example, South Asian women. Cultural mores may prevent some groups of women from participating in this study, where they may not feel it is appropriate to openly discuss cancer or their breasts. For example, in a study by Bottorff et al. (1997), South Asian women's beliefs that cancer represents some past bad deeds in one's life prevented them from speaking openly about breast cancer, in order to preserve the honor of their family. Therefore, the presence of cancer in one's self or family was described as something to keep secret. Further, only six out of the seven categories of CTs identified earlier were represented in the study sample. The use of bioelectromagnetics may not be commonly used by women for their breast cancer and were not reported by any of the women in the sample. As such, caution is indicated when applying the findings of this study to populations differing from those within this study.

Other study limitations imposed by representativeness of the sample include the relative age of the women, and the orthodox treatment options that they were offered for their breast cancer. Only three of the 16 subjects were premenopausal, had relatively small tumors with minimal nodal involvement, and were in the early phases of the breast cancer trajectory. As such, they were given limited orthodox treatment options from which to make treatment decisions, which may have affected their CT decision-making process. It might have been helpful to have included younger women in the latter phases of the breast cancer trajectory, as it might have added to the richness of the decision-making theory. For example, younger women in the latter phases of breast cancer tend to have more aggressive disease than postmenopausal women (Olivotto et al., 1997). Younger women facing a possible death with small children might make different decisions than older women whose children are no longer dependent.

Only women who were offered adjuvant orthodox treatment after surgery were included in the study. While this order of treatment is generally the norm, some more aggressive cancers are treated with adjuvant treatment first to shrink the tumor, then surgery is completed (Olivotto et al., 1997). Women presented with this type of orthodox treatment option might make
different decisions about CTs, so that the findings of this study may not be wholly applicable to them.

The effect of recall about past events may have also affected the rigor of this study. Wagener and Taylor (1986) found that individuals remembered the decision-making process in a manner that protected the decisions they had made. Therefore, findings of this study may indicate women's perceptions of the CT decision-making process, rather than a reflection of the true events that occurred while making CT decisions.

Throughout data collection and analysis, the investigator obtained verbal validation from various participants regarding her contribution as it related to the unfolding theory. Hypotheses were continually formulated and tested, and discarded when deemed inaccurate through testing. Both typical and atypical data were sought, allowing for the development of a theory that is both broad and rich (Morse, 1986). Triangulation across data sources (i.e., transcribed interviews, field notes, and memos) was also employed to ensure congruence of findings (Sandelowski, 1986).

Sandelowski (1986) states that credibility is achieved when individuals recognize the findings of a qualitative research study as meaningful. As such, select individuals were accessed to provide insight on the degree to which they find the process of decision making explicated in the grounded theory both familiar and meaningful.

Significance of the Study

A great deal of debate exists regarding the generalizability of findings from qualitative research (Johnson, 1997). While quantitative methods produce results which may be applied across different persons, settings, and times, qualitative methods do not have the same aim. Leininger (1994) states, "Because the goal of qualitative research is not to produce generalizations, but rather depth of understandings and knowledge of particular phenomena, the transferability criterion focuses on general similarities of findings under similar environmental conditions, contexts, or circumstances" (p. 107). As such, for findings of qualitative research to be useful to consumers, researchers must provide thick descriptions of
the context in which the research was implemented. Consumers may then consider the similarities and differences between the context of the study and the context in which the findings of the study are to be applied. A shared responsibility exists then between the researcher and consumer with respect to generalizability of qualitative research findings (Johnson, 1997).

Studies utilizing grounded theory methodology aim to explain social and psychological processes that underlie a particular experience. Toward this aim, grounded theorists attempt to generate a theory which is applicable across a variety of persons and contexts through theoretical sampling and consideration of negative cases (Johnson, 1997). In the current study, the CT decision-making process of one group of women with breast cancer was described using these techniques which may enhance the potential for findings to be applicable across settings and populations. Attempts were made to include “thick description” of the context of the research, enabling consumers to judge how the findings of this study can be applied to new contexts or settings. Limitations of the study were identified, which essentially define the boundaries of the environmental conditions, context and circumstances of the study. In this way, consumers of the findings of this study may make sound judgments as to whether these findings can be applied to their own setting and population.

Summary of the Study

The current study has provided a description of the CT decision-making process of one group of women with breast cancer. It explored the dynamic nature of CT decisions across the breast cancer trajectory, and how these decisions were incorporated into orthodox treatment decision making. The concepts of control and hope, as well as the impact of health care relationships on CT use were shown to have particular significance. Several questions for further study were generated from this project.
References


Montbriand, M. J. (1993a). Decisional heuristics of patients with cancer: Alternate and biomedical choices. Unpublished doctoral dissertation, College of Medicine, University of Saskatchewan, Saskatoon, Saskatchewan, Canada.


Appendix A

Information Letter for Participants

Project Title: Complementary Therapies: The Decision Making Process of Women with Breast Cancer.

Investigator: Tracy Truant, RN, BSN Phone: xxx-xxxx

Faculty Advisors: Joan Bottorff, RN, PhD, Associate Professor Phone: xxx-xxxx
Joy Johnson, RN, PhD, Assistant Professor Phone: xxx-xxxx

Dear Participant,

I am a Registered Nurse who has worked with individuals with cancer for the past eight years. In completing my course work toward a Master of Science in Nursing degree, I am conducting a research study to investigate how women with breast cancer decide to use complementary therapies in addition to traditional breast cancer treatments. By complementary therapies I mean any treatments or methods you use or have considered using for your cancer, other than chemotherapy, radiation therapy, surgery, and hormonal therapy. Some examples of complementary therapies include meditation, herbal and vitamin preparations, acupuncture, traditional Chinese/Ayurvedic/native healing practices, and so on. I invite you to participate in this study.

Involvement in the study includes participation in a maximum of three interviews lasting approximately forty-five minutes each. These interviews will be audio tape-recorded by myself and then a secretary will type out what was said. All information will be kept confidential and your identity will be known only by myself. All audio tape-recorded interviews will be erased at the completion of this study.

Participation in this study is completely voluntary and will not in any way affect the care you receive from complementary or traditional health care practitioners. As a participant, you are free to refuse to answer any question, or to withdraw yourself or any specified data from the study at any time.

Although there is no direct benefit for you in participating in this study, the information that you provide will help nurses and other health professionals understand how women with breast cancer make decisions to use complementary therapies in addition to traditional treatments. I believe that with this information, nurses will be better prepared to help women with breast cancer safely and effectively integrate complementary therapies into traditional breast cancer care.

Thank you for considering to take part in my research study. If you are interested in learning more about the study, please inform the person who gave you this form, or call me at the above number. I can answer any questions over the phone or arrange to meet you at a time convenient to you.

Sincerely,

Tracy Truant, RN, BSN
### Appendix B

#### Participant Consent Form

**Project Title:** Complementary Therapies: The Decision Making Process of Women with Breast Cancer.

**Investigator:** Tracy Truant, RN, BSN
Phone: xxx-xxxx

**Faculty Advisors:**
- Joan Bottorff, RN, PhD, Associate Professor
  Phone: xxx-xxxx
- Joy Johnson, RN, PhD, Assistant Professor
  Phone: xxx-xxxx

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without any effect on the health care you receive.

**Purpose:**

The purpose of this study is to gain an understanding of how women with breast cancer make decisions whether to use complementary therapies in addition to their traditional treatments for breast cancer.

**Procedure:**

If you decide to take part in this study, the investigator will meet with you to talk with you about how you decided to use or not use complementary therapies. The interview will take about 45 minutes. It will be conducted at a time and place that is convenient for you. The interview will be audio tape-recorded and then a secretary will type out what was said. You are free to review the audio taped interview at the end of the interview. Up to three interviews will be required.

**Risks and Potential Benefits:**

There are no anticipated risks and you will not receive any direct benefits from participating in this study. However, it is anticipated that the information you provide may help nurses assist women with breast cancer to make decisions about using complementary therapies with their traditional treatment.

**Confidentiality:**

All information resulting from this research study will be kept strictly confidential. Confidentiality will be ensured by using code numbers rather than your name during the collection and analysis of the data. Only the investigator will hold the "key" which matches names to code numbers, and this key will be kept in a locked drawer. All identifying information will be removed from the notes, audio tapes, and interview transcripts. Your name will not be used in the research reports. At the completion of the study, the code key will be destroyed, and audio-tapes will be erased. The transcripts and field notes will be
retained for future educational and research purposes. Approval from appropriate university committees will be obtained prior to any future educational and research activities related to information collected in this study.
If you have any concerns regarding your rights as a research subject, you may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598. If you have questions concerning any other aspects of the study, you may contact the investigator, Tracy Truant at xxx-xxxx, or either faculty advisor listed above.

I have read the above information and have an opportunity to ask questions regarding my participation in this study.

I, ________________________________, freely consent to participate in the above described study. I acknowledge receipt of a copy of this consent form.

_________________________________________       ________
Signature of Participant                          Date

_________________________________________
Signature of Investigator
Appendix C
Demographic and Medical Data

Subject ID Number

The following information will assist the investigator in determining selection of further subjects for the research study. The investigator will elicit this information from the subject through the use of questioning techniques.

Demographic Data

1. Age

2. Highest level of education completed

3. Occupation

Medical Data

4. Date of initial breast cancer diagnosis (month/year):

5. Current disease status:
   ___ First time diagnosed
   ___ 1st recurrence
   ___ 2nd recurrence
   ___ Other, please specify

6. Metastatic breast cancer?
   ___ yes (sites: ___ bone, ___ lung, ___ liver, ___ brain, ___ other, specify_______)
   ___ no
   ___ unknown

7. Current orthodox treatment status:
   ___ New patient
   ___ On active treatment
   ___ Finished treatment, last treatment was______________(month/year)

8. Previous and current orthodox treatments received: (OT=on treatment, FT=finished treatment)

   ___ Surgery OT FT date of last treatment__________
   ___ Chemotherapy OT FT date of last treatment__________
   ___ Radiation Therapy OT FT date of last treatment__________
   ___ Hormone Therapy OT FT date of last treatment__________
   ___ Other OT FT date of last treatment__________
9. Previous and current complementary therapies received: (OT=on treatment, FT=finished treatment)

<table>
<thead>
<tr>
<th>Diet and nutrition</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mind-body techniques</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Bioelectromagnetics</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alternative systems of medical practice</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Biologic &amp; pharmacologic treatments</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Manual healing methods</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Herbal medicine</th>
<th>OT</th>
<th>FT</th>
<th>date of last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>describe type(s):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D
Sample Trigger Questions

The following are a sample of trigger questions that will be used in this study.

1. Tell me about how you came to use ____________________________ (complementary therapy) for your breast cancer.

2. What did you need to know in order to make decisions to use complementary therapies? Who did you talk to about this?

3. What prompted you to use ________________ (complementary therapy)?

4. How does using complementary therapies fit into your overall treatment plan for breast cancer? What has it been like for you to take ________________? (complementary therapy) along with your other treatments?

5. How has your initial decision to use ________________ (complementary therapy) changed over time?