#### AN ABSTRACT OF THE THESIS OF

<u>Jessica W. Henderson</u> for the degree of <u>Doctor of Philosophy</u> in <u>Public Health</u> presented on <u>June 26, 2001</u>. Title: <u>Complementary and Alternative Medicine Use</u> and Perceptions of Control among Women Diagnosed with Breast Cancer.

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The number of women living with a breast cancer diagnosis will continue to increase with growing breast cancer incidence rates, greater utilization of early detection, and longer length of survival times. The prevalence of complementary and alternative medicine (CAM) is likely to increase as well, making it important to determine the nature and extent of CAM use in this population. This study explored CAM use and the influence of the control constructs in the context of the theory of cognitive adaptation. Computer-assisted telephone interviews were completed with 551 women diagnosed with breast cancer in Portland, Oregon. Results indicated that two-thirds (66%) of the women used at least one CAM therapy during the past 12 months. The majority of women had high perceptions of cancer control and believed the CAM therapies were important in influencing the course of the cancer. Logistical regression analysis found that significant demographic predictors of CAM use were younger age, higher education, and private insurance. Confirmatory factor analysis was used to refine and test the construct validation of the Cancer Locus of Control scale. Results supported a

three-factor model (control over cause of cancer, control over course of cancer, and religious control of cancer) of the scale. Results of multinomial logistical regression indicated that higher perceptions of control over the course of the cancer significantly predicted CAM use in three categories. Religious control over the cancer was not a predictor of CAM use. The findings from this study will help health care professionals and policy makers identify patient needs that go beyond surgery, chemotherapy and radiation, and address patient-centered health-related goals and outcomes for optimal health and recovery from breast cancer.

# Complementary and Alternative Medicine Use and Perceptions of Control among Women Diagnosed with Breast Cancer

by

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#### A THESIS

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#### COMPLEMENTARY AND ALTERNATIVE MEDICINE USE AND PERCEPTIONS OF CONTROL AMONG WOMEN DIAGNOSED WITH BREAST CANCER

#### INTRODUCTION

This study focused on a population of women living in Portland, Oregon, who were diagnosed with breast cancer. The aims of this study were to determine the prevalence and types of complementary and alternative medicine (CAM) used by these women, and to examine cancer-related sense of control variables that are associated with CAM use.

The National Center for Complementary and Alternative Medicine (2000) defines CAM as "all practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being." It is important that health care professionals better understand what their patients are doing outside the medical model, particularly since "virtually all medical doctors see patients who routinely use unconventional therapies" (Eisenberg et al., 1993).

It is especially vital for health care professionals to be familiar with patterns of CAM use among cancer patients because of clinical implications, such as interactions and potential side effects of certain herbs combined with standard medications. Also, the understanding clinician who helps the patient make more informed choices about CAM use may also improve communication and enhance trust in the patient-provider relationship. Furthermore, given the current debate on

health care reform and the rising cost of health care, from a public policy standpoint it seems reasonable and timely to better understand CAM use.

Women diagnosed with breast cancer may also benefit from being aware of how other women are dealing with the cancer experience beyond conventional treatment. The recent proliferation of breast cancer self-help/recovery books often promote complementary and alternative practices, and the women's health and consumer rights movements have encouraged women to be more involved in medical decisions and to assume more responsibility for their own health and well-being. Research into CAM use behavior and the related control issues among women diagnosed with breast cancer may give them useful information and help keep the cancer experience in perspective.

Perceptions of control may play an important role as a psychosocial influence underlying individuals' decisions for CAM use. Riessman (1994) suggests that the rising interest in CAM use may be understood in terms of its fit with a patient's desire to feel more empowered, particularly in light of the health care consumer movement that emphasizes control over one's health care decisions and options. This is reflected in the large number of CAM practices that do not rely on professional authority or supervision, such as self-help support groups, relaxation, and non-prescription drug/herbal therapies.

Control issues may be particularly relevant to the CAM use decisions of those who are diagnosed with cancer, since popular culture and some health care professionals have promoted the idea that a "positive attitude," a "fighting spirit," or "mind control" are reasons for prolonged survival or remission from cancer.

Engaging in CAM use may represent the fighting spirit or positive attitude, and one method of gaining control. Cassileth and Chapman (1996) list "a sense of control over cancer" as one of the possible reasons given for trying complementary and alternative therapies.

The current study is part of a larger ongoing medical outcomes study funded by the Portland Medical Outcomes Consortium. The focus of this component of the study is to develop a picture of CAM use among women diagnosed with breast cancer. Further, the importance of the psychological construct of control within the context of the theory of cognitive adjustment (Taylor, 1983) to the use of CAM is explored.

#### **RESEARCH QUESTIONS**

This study focuses on the following questions:

- 1. What is the nature and extent of the use of complementary and alternative medicine among women diagnosed with breast cancer in Portland, Oregon?
- 2. Among women diagnosed with breast cancer, what is the perceived importance of complementary and alternative medicine to remaining free from cancer in the future?
- 3. To what extent do medical doctors recommend CAM therapies to their patients?

- 4. What factors are related to the use of complementary and alternative medicine by women diagnosed with breast cancer?
- 5. Is the three-factor control model of the Cancer Locus of Control Scale a reliable and valid measure among a population of women diagnosed with breast cancer?
- 6. What perceptions do women diagnosed with breast cancer have regarding control over the disease?
- 7. Among women diagnosed with breast cancer, which perceptions of cancer control are related to CAM use?

#### HYPOTHESES TO BE TESTED

- As suggested by previous research, sociodemographic variables (age, income, education level, marital status, patient dissatisfaction, patient-doctor trust, exercise, and insurance status) are predictive of CAM use among women diagnosed with breast cancer.
- Control beliefs, as measured by the Cancer Locus of Control Scale (control
  over the cause of cancer, control over the course of cancer, and religious control
  over cancer) are conceptually distinct constructs that will show evidence of
  discriminant validity.
- As suggested by the theory of cognitive adaptation, women with higher
  perceptions of control over the cause of the cancer and over the course of the
  cancer will be more likely to display CAM use as behaviors to influence the
  disease.

- 4. Perceptions of religious control over c0ancer will have no or limited influence on CAM use by women diagnosed with breast cancer.
- 5. The two control variables, control over the cause of cancer and control over the course of cancer, will explain more of the variation in predicting CAM use than the sociodemographic variables alone.

#### REVIEW OF THE LITERATURE

More than two million American women are now living with a history of breast cancer (Ries, et al., 2001). An estimated 192,000 new cases of female invasive breast cancer are expected to be diagnosed in the year 2001, an increase of five percent over the previous year (ACS, 2001). The number of women diagnosed and living with breast cancer will continue to rise as the US population ages, with increased utilization of early detection, and increased survival rates.

Many women who have been diagnosed with breast cancer utilize complementary and alternative medicine (CAM), which includes "all practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being" (National Center for Complementary and Alternative Medicine [NCCAM], 2000). A broad range of philosophies, approaches, and therapies has been used to define "complementary and alternative medicine (CAM)" and other related terms for research purposes. Several key concepts emerge from the scholarly literature. These include: (1) an emphasis on "wholeness" or "holistic health" with consideration of emotional, social, and spiritual issues as well as the specific disease or body part; (2) a base in a wellness/healing model where it is possible for a person to be "healed" without the disease being cured; and, (3) a behavior model of "self-care" or "self-healing," because people often make the therapeutic choices "on their own authority and assume a significant measure of responsibility for their own care" (Lazar &

O'Connor, 1997; Pavek, 1995; Kligler, 1996). In general, CAM approaches are considered to be enhancements, or additions to a person's repertoire in coping with disease and improving overall health rather than as a replacement of conventional medicine.

Complementary and alternative medicine therapies gained considerable attention with the landmark national study in the *New England Journal of Medicine* by Eisenberg, et al. (1993) that documented the extensive use of "unconventional" medical practices among American adults. Eisenberg et al. reported that an estimated one out of three adults—60 million Americans—used at least one unconventional medical therapy in 1990 for an estimated cost of \$13.7 billion in that year (\$10.3 billion out-of-pocket). In a follow-up study, Eisenberg et al. (1998) found CAM use had increased from 34 percent in 1990 to 42 percent (83 million people) in 1997.

The investigators' definition of "unconventional medicine" consisted of a list of the following sixteen practices: relaxation techniques, chiropractic, massage, imagery, spiritual healing, commercial weight-loss programs, lifestyle diets, herbal medicine, magavitamin therapy, self-help groups, energy healing, biofeedback, hypnosis, homeopathy, acupuncture, and folk remedies (Eisenberg et al., 1993; Eisenberg et al., 1998). In addition, survey participants were asked about their use of prayer and exercise, although this data was not included in the authors' final analyses.

A categorization scheme to define complementary and alternative medicine was developed by the National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health. Seven categories representing a variety of concepts, treatments, and approaches were developed for the purpose of discussion and research: (1) diet, nutrition, and lifestyle changes; (2) mind-body techniques; (3) bioelectromagnetics; (4) pharmacological and biological treatments; (5) alternative systems of medical practices; (6) manual healing methods; and (7) herbal medicines.

Each of these categories defined by the NCCAM contains therapies ostensibly used to treat cancer or its symptoms. Examples of cancer-related studies funded by the NCCAM include: macrobiotic diet for cancer (University of Minnesota); melanoma and antioxidant vitamins (University of Colorado); hypnotic imagery and breast cancer (Good Samaritan Hospital, Portland, OR); imagery, relaxation, and breast cancer (University of Texas); acupuncture and herbs for cancer (American Health Foundation); massage and bone marrow transplant (Dartmouth); and electrochemical treatment of tumors (City of Hope Medical Center) (Cassileth & Chapman, 1996). In addition, NCCAM works with the National Cancer Institute to oversee larger clinical trials of CAM cancer therapies.

Other national organizations have recognized the study and use of CAM therapies. For example, the American Public Health Association (APHA) added a special primary interest group (SPIG) on complementary and alternative health practices. The American Cancer Society (ACS) established the Behavioral

Research Center in 1995, which included in its research priorities "the study of the use of complementary therapies by cancer patients" (ACS, 2001). The National Cancer Institute (NCI) created an Office of Cancer Survivorship in 1996, and called for descriptive research to examine "mutable factors" such as self-care behavior and illness-related skills, and the behavioral and quality of life outcomes in patients receiving services in alternative health care delivery systems (Lewis, 1997).

Another national CAM trend with enormous policy implications is the coverage of certain CAM therapies by third-party payers and HMOs. For example, the American Western Life Insurance Company adopted a "wellness plan" that uses naturopathic physicians as gatekeepers, and the Oxford Health Plan began a program including chiropractic, acupuncture, and naturopathy as paid benefits (Cassileth & Chapman, 1996; Lagnado, 1996). The state of Washington has passed a law that requires health insurers to pay for all visits to health care providers who are either licensed or certified in some way by the state, including acupuncturists, massage therapists, and naturopaths (Crabtree, 1996). Other states are considering similar legislation. If this trend continues, alternative medical care providers will be mainstreamed into the health care system along with allopathic medical care providers.

Naturopathic doctors (NDs) have biomedical training similar to that of allopathic doctors and are licensed to practice in about one-fourth of the states.

Naturopathic physicians focus on health maintenance with "natural" healing such as nutrition, herbs, and manual manipulation. Naturopathic medicine plays a

particularly important role in breast cancer survival in Portland, Oregon, partly because two renowned naturopathic physicians practice in that area: Hudson, who developed "Vitanica," the leading U.S. manufacturer of naturopathic supplements for women, and Austin, who together with his wife (a breast cancer survivor), authored a nationally popular book on recovery from breast cancer (1994).

Naturopathic doctors also value their role as "teachers," and educate their patients about nutrition and the use of herbal remedies. Although the majority of herbs have not been scientifically proven, Americans spent \$1.6 billion on them in 1994 (Cassileth & Chapman, 1996). Sometimes there is a blurred line between herbal remedies and nutritional supplements. Alfalfa, green barley, garlic, flax seed oil, vegetable concentrations, and soy isolates, for example, are available in capsule form.

One of the most popular nutritional therapies is macrobiotics, which shuns meats and promotes whole grains, vegetables, seaweed, and beans, including soy. It is believed that soy and other plant foods contain the "good" estrogen that inhibits tumor growth.

The "mind-body" category of complementary and alternative medicine, including relaxation, meditation, hypnosis, imagery, biofeedback, and support groups, may be the most practiced and the most controversial. The mind-body approach to cancer gained worldwide attention through *Lancet* when Spiegel, et al. (1989) published the results of their prospective, randomized study with breast cancer survivors. Women in the advanced stages of breast cancer who participated

in a support group lived twice as long (36 months) as the control group (18 months). Furthermore, Fawzy, et al. (1993) found in their experimental study that group counseling and support prolonged the survival of patients with malignant melanoma. One line of reasoning is that support groups, relaxation, and the other mind-body approaches may reduce anxiety and stress, thereby improving the immune response, and possibly slowing cancer progression. A recent study by Andersen et al. (1998) at Ohio State University supported the hypothesis that stress is associated with immune responses that "are relevant to cancer prognosis." They measured stress in 116 breast cancer patients by the number of intrusive and avoidant thoughts and behaviors about cancer. Andersen and colleagues found that psychological stress levels significantly predicted levels of natural killer cell activity, T-cell responses, and other cellular responses that are related to cancer progression. Whether or not these measured cellular responses directly affect survival rates will not be known for several more years, however, indicators from these studies appear to support a need for further research assessing the effects of stress reduction techniques such as those considered CAM therapies, on cancer progression and survival.

Although no central registry of statistics on CAM cancer therapies exists, there have been studies that describe CAM use among cancer patients. In the Eisenberg et al. (1993) national survey, 24 percent of the adults who had cancer reported using at least one CAM therapy. By comparison, more recent studies suggest that CAM use among cancer patients is increasing at a rapid rate. Current

estimates of CAM use prevalence among adults who have been diagnosed with cancer are 30 percent (Ernst, 2000), to 40 percent (Metz, 2000), to 50 percent (Greene, 2000). The literature indicates that prevalence of CAM use among women diagnosed with breast cancer is higher than among adults diagnosed with other types of cancer (Morris, Johnson, Homer & Walts, 2000).

Reasons for the increasing popularity of CAM have been summarized as a reflection of the "changing needs and values in modern society in general," including "a rise in the prevalence of chronic disease, an increase in public access to worldwide health information, reduced tolerance for paternalism, an increased sense of entitlement to a quality life, declining faith that scientific breakthroughs will have relevance for personal treatment of disease, and an increased interest in spiritualism" (Jonas, 1998). Among cancer patients, suggested reasons for CAM use are: patients taking an active role in the treatment of cancer and its symptoms, maintaining general health and well-being, improving immune function, and improving quality of life (Morris et al., 2000; Astin, 1998; Ernst, 2000).

A study published in Australia reported the patterns of alternative medicine use by 319 cancer patients (Begbie, Kerestes, & Bell, 1996). Twenty two percent of the sample were CAM users, and relaxation/meditation and diet therapy were the two most common therapies. The two most frequent reasons given for CAM use were preference for natural therapy and seeing the CAM therapy as another source of hope. This is in agreement with Murray and Rubel's (1992) report that alternative medicine often renews hope in patients with chronic illness.

Thirty-seven percent of breast cancer survivors in Canada reported using at least one CAM therapy, and the most commonly used were visualization, vitamin therapy, and dietary modification (Gentile, 1997). However, in Nelson's (1991) study of women with breast cancer, 15 percent of the sample reported changes in diet, exercise habits, and stress reduction activities.

In Taylor's (1983) study of 78 breast cancer survivors, the majority of the women made changes, and they believed the changes would keep the cancer from recurring and gave them something to control. Almost half of the women reported that they had changed their diet since the breast cancer diagnosis.

A qualitative study of 20 breast cancer patients and their use of alternative medicine found that the women equated recovery from cancer with a healthy diet and lifestyle (Brown & Carney, 1996). Many of the women interviewed believed that stress was a contributor to the cause of their breast cancer, and most had a goal of "using all available resources to effect a cure."

Although dissatisfaction with conventional medical care has been associated with CAM use in some studies (Astin, Pelletier, Marie & Haskell, 2000), it appears that, in general, cancer patients who are CAM users do not abandon conventional medical care. None of the cancer patients identified in Eisenberg, et al.'s (1993) study used CAM without also using allopathic medicine for cancer treatment; and only 4.4 percent of participants in Astin's (1998) study used CAM exclusively. According to Burstein (2000), "there is no data to suggest that people who use CAM eschew conventional medicine." This is an indication that cancer

patients want all that modern medicine can offer, plus other possible modalities to achieve the best potential all-around treatment for health and well-being.

This recent trend of combining CAM modalities with mainstream medicine is being termed "integrative medicine" (Jonas, 1998). The majority of US medical schools now offer courses in CAM, and more than 70% of insurance companies offer coverage or discounts for at least one CAM therapy (Wetzel, Eisenberg & Kaptchuk, 1998; Greene, 2000). In fact, according to Straus, NCCAM director, "Things that are CAM today will be conventional medicine tomorrow. They will have been integrated" (Marwick, 2000).

#### PERCEIVED CONTROL

Perceived control, locus of control, self-efficacy, and mastery are controlrelated concepts that have been widely discussed in the literature for their roles in
both mental and physical health, including chronic illnesses such as cancer.

Studies of men and women diagnosed with cancer generally suggest that higher
perceptions of control are associated with better coping skills, emotional wellbeing, physical health, immune function, and quality of life (Dow, Ferrell,
Haberman & Eaton, 1999; Gerits & DeBrabander, 1999; Tjemsland, Soreide, Matre
& Malt, 1997; Ell, Nishimoto, Morvay, Mantell & Hamovitch, 1989), while low
perceptions of control are associated with psychiatric morbidity, cancer recurrence
and even death (Watson, Haviland, Greer, Davidson & Bliss, 1999; Akech.

Okuyama, Imoto, Yamawaki & Uchitomi, 2001; De Boer, et al., 1998; Greer, Morris & Pettingale, 1979; Pettingale, Morris, Greer & Haybittle, 1985). Hence, the potential value of perceived control as a means of restoring health after a cancer diagnosis is significant.

#### LOCUS OF CONTROL

The concept of perceived control over life was first pioneered by Julian Rotter in his social learning theory (1966), and has since been widely explored in the literature. According to Rotter, the term "locus of control" refers to a generalized expectancy that events or outcomes are contingent upon one's own actions (i.e., internal locus of control), or contingent upon others or chance (i.e., external locus of control); and, the likelihood of a behavior occurring can be predicted from knowledge of one's "internal" or "external" orientation. For example, it is hypothesized that "externals" may not be able to respond as well to an uncontrollable event such as chronic illness, whereas "internals" may be more likely to respond to chronic illness with healthy and adaptive behavior.

Rotter (1966) developed a self-report inventory called the Internal-External Control Scale (I-E Scale) to measure locus of control beliefs. The I-E Scale has been the most widely used and cited measure in the locus of control literature (Lefcourt, 1991). Recently, Grassi, et al. (1997) surveyed 113 cancer patients and found that clinical depression was associated with higher external scores on the I-E Scale.

Although Rotter's (1966) I-E Scale and locus of control concept have been extensively utilized in psychosocial and behavioral research, they have also been criticized extensively. Specifically, the criticisms are directed towards: the assumption that locus of control beliefs are unidimensional; the measurement problems created by the I-E Scale's forced-choice format; and the low variance accounted for in many studies (Lefcourt, 1991; Dickson, et al., 1985; Thompson & Collins, 1995). In fact, in their article overview of theory and measurement of perceived control to cancer, Thompson and Collins stated, "Use of this more general measure of locus of control [I-E Scale] is not recommended."

# CONTROL IN THE CONTEXT OF THE THEORY OF COGNITIVE ADAPTATION

Taylor (1983) developed a theory of cognitive adaptation that illustrates how control fits into the response to a life-changing event such as a diagnosis of breast cancer. The strength of the theory is its ability to explain psychological processes as well as behavioral efforts. The two important control constructs in the theory of cognitive adaptation are (1) control over the cause of the cancer, and (2) control over the course of the cancer. These control constructs are differentiated from Rotter's (1966) categories of "internal" and "external" control in that a person's sense of control over the cause and course of cancer integrates "personal" control and an "other" control such as a physician or treatment, and that "both together are even better" (Taylor).

The three major themes from the theory of cognitive adaptation are (1) a search for meaning of the experience; (2) mastery over the disease in particular and over one's life in general; and, (3) restoration of one's self-esteem. Each theme has an element of control explained below:

Search for meaning. For women diagnosed with breast cancer, cognitively resolving the issues of meaning (what caused the cancer?) can result in feelings of control if the cause is attributed to something in the past or something that can be controlled. For example, in Taylor's (1983) study, 95 percent of the women diagnosed with breast cancer had a personal theory as to what caused the cancer, and most of the causes were things that had changed or that could be controlled: stress, exposure to hormones or other carcinogens, hereditary factors, diet, and breast trauma. More recently, a study of 378 breast cancer survivors found very similar results—the cause of the cancer was most commonly attributed to stress—followed by genetics, environment, hormones, diet, and breast trauma (Stewart et al., 2001). Furthermore, these causal beliefs affected health behaviors such as making efforts to have a positive attitude, change in diet, maintaining a more healthy lifestyle, exercise, stress reduction, prayer, and the use of complementary and alternative medicine.

Sense of mastery. Feelings of control over the course of the cancer (what can be done to keep the cancer from coming back; or, what can be done to keep the cancer from growing) are capable of influencing much health-related behavior according to the theory of cognitive adaptation. Perceptions of control of the cancer were

"quite strong" among the women in Taylor's (1983) study, and influenced many health-related behaviors that were believed to control the cancer, such as self-care, diet, stopping hormone replacement therapy, meditation and imagery. In other studies, perceptions of control over the course of the cancer were also related to health-related behavior and a positive "fighting spirit" attitude (Pruyn et al., 1988; Watson, Greer, Pruyn & van den Borne, 1990).

Restoration of one's self-esteem. A diagnosis of cancer may initially cause a person to feel victimized and out of control, and recovery efforts involve regaining self-esteem and feelings of control. Sometimes the perceptions of control over the cause and course of the cancer are overly-optimistic or even "illusional," but the theory of cognitive adaptation maintains that optimistic cancer control perceptions may be valuable to mental health and enhanced coping (Taylor, 1983). Optimism as described in the theory of cognitive adaptation predicted a reduced likelihood of new cardiac events over six months among patients with heart disease (Helgeson & Fritz, 1999). In a review article on surviving cancer, both control and optimism were identified as important psychological variables (Andersen, 1994).

#### MEASUREMENT OF CONTROL PERCEPTIONS

Rotter's (1966) original locus of control concept referred to a broad, generalized orientation measured by the I-E Scale as one dimension with a single score (the higher the score, the more external the control expectancy). Later, Rotter

(1975) discussed the multidimensional nature of control, and made a distinction between global, or general locus of control beliefs and specific locus of control beliefs. The idea was that a person may hold multiple sets of specific beliefs in specific situations or contexts, and that these may overlap. That is, a person may feel internally in control in one area of life, but external in another area of life, and these may change over time. For example, a cancer patient could feel in control over health-related behaviors such as exercise and diet, but little control over the outcome of her personal relationships. Rotter recommended those more accurate predictions of behaviors or outcomes in specific situations may be obtained with more specifically designed scales. Researchers responded to Rotter's recommendation by modifying the I-E Scale to their targeted population or by developing new problem-specific control scales.

Wallston, Wallston and DeVellis (1978) developed a Multidimensional Health Locus of Control (MHLC) scale much like Rotter's (1966) I-E Scale, but the MHLC scale assessed control beliefs specific to health and split external control into two distinct dimensions. Wallston, et al. created the MHLC scale in an effort to increase the level of prediction of health-related behaviors. The 18 item instrument has three subscales: internal health locus of control, powerful others external health locus of control, and chance health locus of control. Dahnke, Garlick, and Kazoleas (1994) explained how physicians might relate to patients with the three health control beliefs: to a strong internal: "Healthy people follow their physician's guidelines," to a high powerful others external: "Listen to me, I'm

your doctor," and to a strong chance external: "Even though you don't think this will do much good, do it for me anyway."

In a review of the literature, Wallston and Wallston (1981) concluded that the health locus of control construct using the MHLC scale is relevant to the prediction of health behaviors, and that, in general, persons with an internal health locus of control are more likely to take responsibility for their actions in health matters. Although the MHLC scale has been widely used and its reliability and validity data are acceptable, research findings have differed in the direction or specific nature of control. Even the Wallstons have stated that the MHLC measure "is not a panacea in explaining health-related behavior (in Lefcourt, 1991).

Inconsistent findings using the MHLC scale may be due to the lack of sensitivity of the measure of specific medical conditions. Perceptions of one's own control over a chronic disease such as cancer may be more important to behavior and adjustment than how one feels about control over general health. For example, it is reported that cancer patients had difficulty in knowing how to respond to MHLC items which referred to their "health" when, in reality, what was most salient to them was their disease (Dickson, et al., 1985). In another study of 69 patients with cancer given the MHLOC scale, there was no simple "main effect" relationship between HLOC beliefs and psychological adjustment to cancer (Andrykowski and Brady, 1994). In addition, a person with a chronic illness may have differing control expectations of the specific disease and of health in general.

One could have a high internal control belief over her health in general, but perceive very little control over the effectiveness of chemotherapy to cancer.

In a critique of over 50 locus of control scales, Furnham and Steele (1993) concluded that the MHLC scale is most appropriate for people who are healthy, and less appropriate for people who are chronically ill. The multidimensional nature of control argues for measurements germane to the specific problem area (Lefcourt, 1991). In an overview of theory and measurement as it applies to control and cancer, Thompson and Collins (1995) recommended, "As a rule of thumb, the more problem-specific the measure, the better its predictive validity regarding psychological and health outcomes."

It is this approach to control specificity that prompted researchers to write their own measures of health-specific and disease-specific locus of control measures, such as: Heart Disease Locus of Control (O'Connell & Price, 1985); Diabetes Locus of Control (Ferraro, et al., 1987); Weight Locus of Control (Saltzer, 1982); Hypertension Locus of Control (Stanton, 1987); Control of Recovery from Physical Disability (Partridge & Johnson, 1989); Children's Recovery from Illness (DeVellis, et al., 1985); Smoking Locus of Control (Georgiou & Bradly (1992); and several Cancer Locus of Control Scales (Dickson, et al., 1985; Pruyn, et al., 1988; Watson, et al., 1990; and Wallston, et al., 1994).

The first Cancer Health Locus of Control (CHLC) scale to be published was developed by Dickson, Dodd, Carrieri, and Levenson (1985). Dickson and colleagues reworded the items from the MHLC scale to be cancer specific, in

anticipation that it would be more useful in predicting health behavior in the cancer population and in understanding the diversity among cancer patients' control beliefs. An internal cancer locus of control is the belief that health in the context of cancer is determined by one's own behavior. The researchers used a sample of 29 cancer patients to compare their CHLC scale to the MHLC scale for reliability and validity determinations. Dickson, et al. concluded that their scale was a "marginal success" in providing a more sensitive measurement among cancer patients.

Wallston, Stein and Smith (1994) also reworded the items from the MHLC scale to be disease-specific, calling the modification "Form C of the MHLC."

Form C provides a template survey containing the word "condition" in each item, which can be changed to any specific disease term. Wallston, Stein and Smith tested both the MHLC scale and Form C in samples of four diseases: rheumatoid arthritis, chronic pain, diabetes, and cancer. They found that the "powerful others" external control dimension had two separate factors, "doctors" and "other people." The conclusion was that the reliability of Form C was "adequate" for research purposes.

Form C of the MHLC was utilized in a study of 65 cancer patients, with results indicating that perceptions of control may be different in a cancer-specific context than in a more general context (Dahnke, Garlick, and Kazoleas, (1994). They found that the respondents had coexisting high levels of internal and external (powerful others) perceptions of control over cancer.

It is not uncommon for persons with a chronic illness to simultaneously hold both strong external and strong internal control beliefs (Helgeson, 1992). For example, a person diagnosed with cancer may strongly believe she can influence the course of the cancer with her own actions and behaviors (internal), and also believe strongly that her doctors and the treatments can influence the course of the cancer (external)—the "team effort" approach to controlling the disease.

Although the bias in Western culture is toward internal control, the literature suggests that identifying with external control (doctors and treatment) and/or oneself may separately or in combination, achieve a perception of control over the course of a chronic disease (Taylor, Helgeson, Reed, and Skokan, 1991). Towards this end, Pruyn, et al. (1988) developed a Cancer Locus of Control scale to identify three dimensions of control specifically for cancer patients: control over the course of the illness; control over the cause of the illness, and religious control. Using their scale in a study of 118 head and neck cancer patients, Pruyn, et al. found their instrument to have good reliability scores and that respondents with a high perception of control over the course of cancer were more likely to show health-related behaviors, receive more social support, have higher self-esteem, and have less anxiety and depression.

Watson, Greer, Pruyn, and Van den Borne (1990) developed an English version of the Pruyen's Dutch Cancer Locus of Control scale (1988). Watson, et al. tested the English version on 68 (mainly breast) cancer patients and found good internal consistencies (course .77, cause .80, and religious .77) and good

discriminant ability. The course of cancer subscale included items of controlling the disease both internally and externally, such as, "I can definitely influence the course of the cancer," "My doctor can definitely influence the course of the cancer," and "My spouse/partner/family can definitely influence the course of the cancer." In this sample, a high control score over the course of cancer was associated with a "fighting spirit" attitude in the early stages of cancer; a high score over the cause of cancer (cancer attributed to personal characteristics) was associated with an "anxious preoccupation" about cancer.

# ADDITIONAL STUDIES FOCUSING ON CONTROL AND/OR BEHAVIOR AMONG CANCER PATIENTS

Several studies have described control and cancer patients in general (many cancer diseases represented in the sample), and other studies have described control issues with samples consisting only of women diagnosed with breast cancer.

A study by Thompson, et al. (1993) looked at perceived control and strategies used to maintain control among 71 cancer patients. Results indicated that greater perceptions of control were beneficial to mood state and adjustment to cancer, even if the control perceptions were illusional (not based in the reality of the cancer situation). The women in the sample had significantly higher perceptions of control over the course of the disease than did the men. The types of control strategies that were most beneficial were emotional (faith, positive attitude) and physical (exercise, diet, and relaxation).

Jenkins and Burish (1995) utilized Wallston's (1978) Health Locus of Control (HLOC) scale to measure perceived control before and after several interventions. Two hundred and twenty four adults going through chemotherapy for cancer received relaxation, imagery, biofeedback, or counseling, and 89 adults going through chemotherapy for cancer were in the control group. The participants in the interventions were combined into one group and compared with the control group. Those in the intervention group increased scores in both internal and external control perceptions (control by oneself and by health care providers) after the intervention, and reported "less distress" than the control group. Higher scores on the "chance" external subscale were associated with greater distress.

Dahnke, Garlick, and Kazoleas (1994) utilized Form C of Wallston's (1994) HLOC scale to evaluate control perceptions among 65 cancer patients, and found a co-occurrence of Chance and Powerful Others external scores. The researchers noted that many of the respondents wrote in the margins of the survey that their futures were in the "hands of God," suggesting that religious control could not be clearly explained by either the chance or powerful others subscales.

The Watson, Greer, Pruyn, and Van den Borne (1990) study discussed earlier in this chapter, developed and tested the English version of Pruyn's (1988) Cancer Locus of Control scale with 68 cancer patients to measure control over cause and course of cancer, and religious control. In general, higher scores of control over the course of cancer was associated with a positive fighting spirit response, and higher scores on control over the cause of the cancer was associated

with an anxious preoccupation with cancer. In addition, higher scores on the religious control scale were significantly associated with a "fatalistic attitude to cancer." Interesting, the religious control scores were associated with "anxiety and depression" in women only. Also, religious control scores increased with age.

A more recent study used the Watson, et al. (1990) Cancer Locus of Control scale to primarily assess the religious control subscale among 80 cancer patients (Butow, et al., 1997). Butow and colleagues found that those with a high score in religious control were more likely to prefer less involvement and information, and a physician with a more paternalistic role.

Taylor's (1983) study of 78 women living with breast cancer generated the theory of cognitive adaptation, as described previously in this chapter. Taylor found that many of the breast cancer survivors adopted behavioral efforts to directly and indirectly influence the course of the cancer. Many of the women's control efforts were "mental," such as attempting to maintain a positive attitude in order to keep the cancer from coming back. In addition to positive thinking, other common "psychological control" efforts used were meditation, imagery, and self-hypnosis. In a later article using the same sample of 78 women with breast cancer, Taylor, Lichtmann, and Wood (1984) reported that a majority of the women believed they had some or a lot of control over the course of the cancer. Higher scores on the internal and external control subscales of Wallston's (1978) MHLOC instrument were both independently positively associated with psychological adjustment. Taylor, Lichtmann and Wood also reported that 26 percent of the

women in the sample increased their level of exercise after diagnosis, and that increased exercise levels were significantly related to psychological adjustment (such that "more exercise was better").

Support for the control theme of Taylor's (1983) theory of cognitive adaptation was found in Hilton's study of 227 women with breast cancer (1989). Perceived control of the cancer situation (course) had a beneficial effect in that higher levels were related to positive coping behaviors, such as "planful problem-solving," positive reappraisal, and seeking social support. The authors concluded that perceived control over the course of the cancer was an important variable in coping with a breast cancer diagnosis.

Due to the positive correlation to psychosocial adaptation over time, "good coping" was defined as seeking social and emotional support and making efforts to maintain self-control over the cancer in a study of 74 breast cancer patients (Heim, Valach, and Schaffner, 1997). Psychosocial adaptation was also studied by Schag, et al. (1993). The sample consisted of 227 breast cancer survivors who were divided into two groups according to high or low risk for distress, as determined by a personal interview. One year later the women were re-assessed, and it was found that the women in the high risk group (being overwhelmed and feeling out of control) had more physical, psychological, relationship and sexual problems than women in the low risk group, who had higher perceptions of control.

A pilot study with 13 women diagnosed with stage I breast cancer were measured for locus of control perceptions, and then given a nine-week intervention

of relaxation training, guided imagery, and EMG biofeedback (Gruber, 1996).

Post-tests revealed that the women had lower anxiety levels, and increased levels of "fighting spirit" attitude and internal locus of control after the intervention.

In a review of the literature on psychosocial issues in breast cancer, age was a variable that had a "strong influence on shaping a woman's response to the challenges of breast cancer" (Moyer and Solovey, 1996). In a study of decision-making among 179 breast cancer patients, Petrisek et al. (1997) found that younger women wanted more information and more control than their older counterparts. Hilton (1989) found that perception of control was negatively associated with age, meaning that younger women in the breast cancer sample had significantly higher levels of perceived control.

#### CAM USE AND CONTROL

One strategy to maintain or regain a sense of control after a cancer diagnosis may include the use of complementary and alternative medicine (CAM). Several studies have investigated CAM use by cancer patients. Women diagnosed with breast cancer are more likely to use CAM than the general public (Vande Creek, Rogers & Lester, 1999) or other cancer patients (Morris, Johnson, Homer & Walts, 2000).

It has been suggested that CAM use by women diagnosed with breast cancer is "about feeling better and about having greater control over one's destiny" (Burstein, 2000). In several studies, "feeling more in control" was found to be a

perceived benefit or reason to use CAM (Boon et al., 2000; Richardson, Sanders, Palmer, Greisinger & Singletary, 2000; Sparber et al., 2000).

Although these studies provided the basis for discussion, each had limitations which made conclusions questionable. First, control was conceptualized as a generalized outcome expectancy for CAM use. It may have been more appropriate to measure control constructs specific to the cancer domain—such as those pertinent to the theory of cognitive adaptation—to examine more than a single generic aspect of control and to examine the influence of each control aspect in the decision to use CAM therapies.

The second difficulty in these studies was that CAM use was conceptualized as a one-dimensional behavior (user vs. nonuser). Since CAM use includes a wide variety of "mind" therapies (i.e., relaxation, imagery, support groups, spiritual healing, hypnotherapy, and massage), and "body" therapies (herbal medicines, nutritional supplements, naturopathic, chiropractic, diet, acupuncture, immune therapy), it seems prudent to at least examine CAM use in these categories.

Specifically, more than a single aspect of control can be hypothesized to influence CAM use, and may do so in differential fashion dependent upon the type of CAM use.

In summary, perception of control may be an important variable to psychological adjustment and health-related behaviors among women diagnosed with breast cancer. According to Taylor's theory of cognitive adaptation, belief in control of the cancer situation, whether internal or external or both, is to the

woman's advantage, even if the perceptions are based on illusions. Previous control studies described in this chapter were primarily concerned with psychological outcomes and internal control. How a sense of control in the context of the theory of cognitive adaptation is related to health behaviors, such as the use of complementary and alternative medical therapies, remains in question.

## **METHODS**

## **SAMPLE**

Six health care plans in the Portland, Oregon metropolitan area provided the names, addresses and phone numbers of women diagnosed with breast cancer between January 1, 1996 and December 31, 1997. Together these organizations treated over 75% of all breast cancer patients in this region. The sampling procedure used disproportional stratified sampling to ensure each health plan was sufficiently represented; that is, sampling fractions were larger for the health plans with fewer breast cancer patients.

Interviewers called the phone numbers of all 1362 women in the sample, resulting in 605 persons declared ineligible for the study because of a disconnected/wrong phone number (351), unavailability (i.e., no answer, not home, phone blocking) (157), deceased (48), hearing problems (41), or language barrier (8). Among the remaining 757 eligible participants, 588 agreed to be interviewed, for a 78% response rate.

## PROCEDURE FOR DATA COLLECTION

The questionnaire and the data collection protocol was approved by the institutional review board at Oregon State University. Each potential participant received a letter by mail explaining the nature and purpose of the project prior to contact for the telephone interview. The questionnaire was pre-tested, revised, and

programmed for computer-assisted telephone interviewing (CATI) by a survey organization in Oregon. The interviews were conducted during July and August 2000. New and changed phone numbers were called when available unless the new number was outside the Portland metropolitan area. Telephone numbers were called up to ten times to obtain an interview. The average length of the total interview was 23.4 minutes.

## **SURVEY INSTRUMENTS**

#### CAM use

The use of complementary and alternative medicine was defined by the same set of criteria used by Eisenberg, et al. (1993), with a few modifications based on categories established by the National Center for Complementary and Alternative Medicine (2000), and based on pilot research with a sample of 13 breast cancer survivors. For example, naturopathic medicine was included as a CAM therapy in this survey because Oregon is one of the 12 states where it is licensed. Specifically, the survey participants were asked if they used any of the following 15 therapies or practices in the last 12 months: relaxation/meditation, chiropractic, massage/manipulation, imagery, spiritual healing, naturopathy, lifestyle diets, herbal medicines, megavitamins/nutrient therapy, self-help/support groups, energy healing, biofeedback, hypnosis, pharmacological/immune therapy, and acupuncture.

Women who indicated the use of a specific CAM therapy were asked if their medical doctor recommended its use, and whether or not the therapy was important (on a scale of 1 to 5) in remaining free from cancer in the future. The survey also explored overall reasons for CAM use (a close-ended list of four reasons developed from the pilot study).

#### Cancer locus of control

The 17-item Cancer Locus of Control scale developed by Watson, et al. (1990), an English version of the Dutch Locus of Control Scale for Cancer Patients (Pruyen, et al. 1988), was modified to measure control perceptions of the women in this study. The Cancer Locus of Control consists of three subscales: control over the course of cancer, control over the cause of cancer, and religious control. This scale most closely aligned with Taylor's (1983) Theory of Cognitive Adaptation, where perceptions of control over the course and cause of the disease were both important in adjustment to cancer.

Revisions to the Cancer Locus of Control scale were based on pilot research with a sample of 13 breast cancer survivors. The pilot study was conducted to identify any problems with the understanding of the directions and format of the instruments, sensitivity to items, and time required to complete the questionnaires. The participants were invited to comment about the wording and acceptability after completion of the interview. Based on the results of the pilot study, 16 items from the Cancer Locus of Control scale were selected, and four of those items were

rephrased. Furthermore, the Cancer Locus of Control scale was changed from a 4-point to a 5-point Likert-type format ranging from 1 (strongly disagree) to 5 (strongly disagree). The 4-point scale was confusing for participants because all of the phone survey questions prior to the Cancer Locus of Control questions used a 5-point Likert-type format. Thus, the 5-point response format was used to maintain consistency in the overall survey, and to "optimize reliability and validity" (Wikman & Warneryd, 1990).

Table 1 presents the final 16-item version of the Cancer Locus of Control scale used in this study. Six items measure the subscale, control over the cause of cancer, seven items measure the subscale, control over the course of cancer, and three items measure religious control.

Table 1. Cancer Locus of Control Scale used in present analysis

Control over Cause of cancer items (Scale: 1 = strongly disagree; 5 = strongly agree)

Causel Getting cancer was a matter of chance over which I had no influence.

Cause2 Getting cancer was a result of my behavior.

Cause3 It is partly my fault that I got cancer.

Cause4 Unfortunate events in my past contributed to the fact that I got cancer

Cause 5 Getting cancer had something to do with my personality.

Cause6 Getting cancer was especially due to something about me.

Control over course of cancer items (Scale: 1 = strongly disagree; 5 = strongly agree)

Coursel I can definitely influence the course of the cancer.

Course 2 My doctor can definitely influence the course of the cancer.

Course3 The key people in my life can definitely influence the course of the cancer.

Course4 By taking extra care of myself I can influence the course of the cancer.

Course 5 By living healthily I can influence the course of the cancer.

Course6 If I follow the advice of my doctor, I can definitely influence the course of the cancer.

Course 7 I can influence the course of the cancer by fighting against it.

Religious control over cancer items (Scale: 1 = strongly disagree; 5 = strongly agree)

Rell Whether or not I remain free from cancer is in God's hands.

Rel2 God can definitely influence the course of the cancer.

Rel3 My religion has an influence on the course of the cancer

The survey questions used in this study were a portion of a larger health plan comparison study sponsored by the Portland Medical Outcomes Consortium, and began with questions about patient satisfaction with treatment for breast cancer. In addition, sociodemographic data were abstracted from the tumor registries of the six health plans, which included insurance type, and location and age at diagnosis.

#### PROCEDURE FOR DATA ANALYSES

Analyses were conducted on 551 responses from participants who completed the telephone survey in its entirety. Sample size calculations (estimated CAM use prevalence in Oregon, 50 percent; Elder, Gillcrist & Minz, 1997) indicated that a minimum of 384 responses were needed to estimate CAM use with a five percent error of estimation.

#### Article 1

Prior to analysis, interview data were inspected for accuracy of data input, distribution, and missing values. Inconsistencies were checked and corrected. Missing data among variables was low, ranging from none to two percent, with the exception of the household income variable (14.5 percent missing). No missing data patterns were identified. Missing values were replaced through the Expectation-Maximization algorithm procedure.

Correlational analysis among the potential predictor variables found no problems with redundancy or extremely high correlations. There were no exceedingly high standard errors for parameter estimates. Therefore, no multicollinearity was evident among the variables to be included in the logistic regression analyses.

Participants were categorized as CAM users if they used one or more of the 15 CAM therapies. Potential predictor variables selected for correlational analysis were based on knowledge of associations with CAM use reported in the literature. In order to determine the relative importance of the factors that showed a

correlation (P < .05) with CAM use, standard logistic regression was performed with CAM use (a dichotomous measure) as the dependent variable. The variables were entered simultaneously since there was no clear theoretical rationale about the order or significance of the predictors. Three outlying cases were identified upon examination of standardized residuals of the model. They were younger women who did not use CAM; there was no reason to remove them model. SPSS Base 10.0 (for Windows, SPSS Inc., Chicago, IL) was used to perform all analyses. All p value tests were 2-sided.

## Article 2

In order to validate the Cancer Locus of Control scale, the overall analyses proceeded in two major stages: (1) exploratory factor analysis (principal components analysis with varimax rotation) and, (2) structural equation modeling (confirmatory factor analysis). Both exploratory and confirmatory factor analyses have been used to gather evidence for validity of a scale (John & Benet-Martinez, 2000). Furthermore, it has been suggested that all exploratory analyses should be completed by confirmatory factor analysis in order to produce the solution with the greatest scientific utility, consistency, and meaning (Tabachnick & Fidell, 2001).

This study used principal components analyses to investigate the factor structure, to conduct item analysis and selection, and to replicate the findings of a previous study by Watson, et al. (1990). Confirmatory factor analysis, conducted with Amos (Arbuckle, 1994), was used to test how well the hypothesized three-

factor Cancer Locus of Control measurement model fit the data (see Figure 1). In the model, ovals are used to represent the factors, or latent constructs. The double-headed arrows indicate that the three control constructs are allowed to correlate with each other. Squares represent the 16 measured variables in the Cancer Locus of Control scale. The arrow from the latent construct to the measured variable is a factor loading or regression coefficient, and represents the effect that the latent construct has on each measured variable. The other arrow pointing to the measured variable represents the measurement error, or the residual variance.

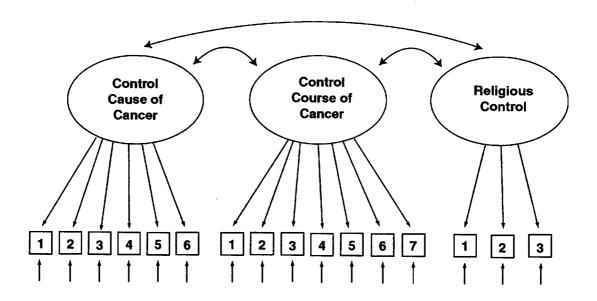


Figure 1. Hypothesized CLOC measurement model.

Several fit statistics were selected to evaluate the overall fit of the model (Figure 1) to the data: (a) the conventional chi-square statistic and the chi-square to degrees of freedom ratio, (b) goodness-of-fit index (GFI), (c) adjusted goodness-of-fit index (AGFI), (d) the comparative fit index (CFI), and (e) the root mean square error of approximation (RMSEA). Since the chi-square statistic is inflated by large sample size, it is recommended that emphasis be given to the other goodness-of-fit statistics (Dickey, 1996; Kline, 1994).

Criteria for the indices of fit used in this study are as follows: for the chisquare ratio, a value between 2 and 3 is considered acceptable, and closer to 1 is
better. The GFI, AGFI, and CFI statistics range from 0 to 1, and values greater
than .90 indicate a good model fit. For RMSEA, a value of .05 or less indicates a
good fit, a value of .08 indicates a reasonable fit, and a value of .10 and higher is a
poor fit of the model.

#### Article 3

The categorical dependent variable in this study was type of complementary and alternative medicine used. Based on individual responses to the use/nonuse of 15 CAM therapies, participants were categorized into one of four groups: (1) those who did not use any CAM therapies; (2) those who used one or more physical CAM therapies; (3) those who used one or more psychological CAM therapies; and, (4) those who used both physical and psychological CAM therapies.

Following the lead of Burstein, Gelber, Guadagnoli, and Weeks (1999), physical

CAM therapies were defined as "therapies requiring physical action on or exposure of the body" (vitamins, herbs, massage, chiropractic, diet, acupuncture, immune therapy, energy healing, and naturopathy); psychological CAM therapies were defined as those "involving primarily mental processes" (relaxation, meditation, imagery, support/self-help groups, spiritual healing, biofeedback, and hypnosis).

Demographic variables in this study were coded as dummy variables and included age (50 years and under; 51 years and over), education (high school graduate or less; some college or more), and insurance (private health insurance; other health insurance). It was important to include these variables because a previous study with this data (Article 1) showed an association with CAM use.

Three independent variables of interest were (1) Control over the Course of the Cancer, (2) Control over the Cause of the Cancer, and (3) Religious Control. Participants' cancer control beliefs were assessed by a modified version of the Cancer Locus of Control scale (Watson et al., 1990). The Cancer Locus of Control scale is a relatively new area-specific measure of perceptions of control over cancer developed for prediction of health-related behavior in cancer patients. Of all the cancer control scales reviewed for potential use in this study, Watson et al's Cancer Locus of Control scale most closely aligned with Taylor's (1983) theory of cognitive adaptation, where perceptions of control over the course and cause of the disease included both internal and external control items. Even though religious control was not germane to the theory, it was retained as a variable of interest as part of the Cancer Locus of Control scale.

The modified Cancer Locus of Control scale used in this study consisted of 14 items, each with a 5-point response scale ranging from "strongly disagree" to "strongly agree." Six items measured the subscale, "control over the course of cancer," five items measured the subscale, "control over the cause of cancer," and three items measured "religious control." Some responses were reverse-coded so that higher scores indicated increased perceived control. For each woman, item responses were totaled to create a score in each subscale. Each score was dichotomized into no/low control or medium/high control because of the low prevalence of no/low control perceptions, to allow ease in interpretation, and to avoid cells with a small number of cases in the multivariate analysis.

Evaluation of limitations included correlational analysis among the potential predictor variables, which found no correlations higher than -.26 (age and education). There were no problems with redundancy or extremely high correlations. There were no exceedingly high standard errors for parameter estimates. Therefore, no multicollinearity was evident.

Further evaluation of limitations for logistic regression with multiple outcomes includes adequacy of expected frequencies and outliers in the solution, if the fit is inadequate (Tabachnick & Fidell, 2001). Since the data had adequate model fits, there was no need to search for outliers in the solution. Evaluation of adequacy of expected frequencies did not identify any potential limitations.

The data were analyzed using bivariate correlation and multinomial logistic regression. Correlation coefficients were calculated to examine associations

between the cancer locus of control variables, the demographic variables, and each of the 15 CAM therapies.

Multinomial logistic regression was used to determine which variables were important in predicting each of four CAM use behaviors. Multinomial logistic regression is an extension of logistic regression and is used when a dependent variable has more than two categories; the log odds of three or more contrasts are estimated simultaneously. In this study, the dependent variable had four CAM use patterns, as previously explained. Adjusted odds ratios, p-values, 95% confidence intervals and goodness-of-fit statistics were computed. SPSS Base 10.0 (for Windows, SPSS Inc., Chicago, IL) was used to perform all analyses. All P value tests were 2-sided.

## **RESULTS**

ARTICLE 1: COMPLEMENTARY AND ALTERNATIVE MEDICINE USE BY WOMEN DIAGNOSED WITH BREAST CANCER IN OREGON

#### **Abstract**

As breast cancer incidence rates and survival time increase, so will the prevalence of complementary and alternative medicine (CAM) use, making it important to determine the nature and extent of CAM use in this population. Computer-assisted telephone interviews were conducted with 551 women diagnosed with breast cancer in Portland, Oregon, to determine the prevalence and patterns and reasons for CAM use. Logistic regression was performed in an attempt to predict CAM use. Two-thirds (66%) of the women used at least one CAM therapy during the past 12 months. The top four CAM therapies were relaxation/meditation (29%); herbal medicines (27%); spiritual healing (26%); and megavitamins/nutrient therapies (23%). The majority of the CAM therapies were perceived by their users to be at least "moderately important" in remaining free of cancer, and two CAM therapies were perceived by their users to be "quite important" in remaining free of cancer: diet and spiritual healing. Chiropractic medicine was perceived by the users to have the least importance in remaining free from cancer. The reasons given for using CAM were to enhance overall quality of life (41%); to feel more in control (21%); to strengthen the immune system (11%); and to reduce stress (10%). Younger age, higher education, and private insurance were found to be significant predictors of CAM use among women in this survey. It was concluded that a majority of the women diagnosed with breast cancer integrate CAM use with conventional medicine in their attempts to prevent cancer recurrence and/or improve their cancer-related outcomes. This information will help health care providers and policy makers identify patient needs that go beyond surgery, chemotherapy and radiation, and address patient-centered health-related goals and outcomes for optimal health and recovery from breast cancer.

## Introduction

More than two million American women are now living with a history of breast cancer (Ries, et al., 2001). An estimated 192,000 new cases of female invasive breast cancer are expected to be diagnosed in the year 2001, an increase of five percent over the previous year (ACS, 2001). The number of women diagnosed and living with breast cancer will continue to rise as the US population ages, with increased utilization of early detection, and increased survival rates.

The breast cancer community has received considerable attention in the research literature, primarily in relation to disease survival end-points, treatment decision-making (breast conservation versus mastectomy), and psychosocial adjustment (Fisher, et al., 2001; McVea, Minier & Johnson, 2001; Dow & Lafferty, 2000). However, the breast cancer population has been inadequately studied regarding health behaviors that are self-initiated or maintained to influence the course of the disease, reduce the likelihood or recurrence or promote overall health and well-being.

Many women who have been diagnosed with breast cancer utilize complementary and alternative medicine (CAM), which includes "all practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being" (National Center for Complementary and Alternative Medicine [NCCAM], 2000). CAM use among the breast cancer population may be different from the general population, may vary by geographical region, and may change with time (Van de Creek, Rogers & Lester, 1999; Eisenberg, et al., 1998).

Clinicians, policy makers, and patient educators need contemporary knowledge of the extent and nature of CAM practices among the breast cancer community for the common vision of improved patient care, services, research, and programming. Consequently, this study focuses on the following questions: (1) What is the extent and nature of the use of complementary and alternative medicine in women diagnosed with breast cancer in Portland, Oregon? (2) From the patient perspective, what is the perceived importance of complementary and alternative medicine to remaining free from cancer in the future? (3) From the patient perspective, to what extent do medical doctors recommend CAM use? (4) What factors predict the use of complementary and alternative medicine by women diagnosed with breast cancer?

# **Background Literature**

Complementary and alternative medicine therapies gained considerable attention with the landmark national study in the *New England Journal of Medicine* by Eisenberg, et al. (1993) that documented the extensive use of "unconventional" medical practices among American adults. Eisenberg et al. reported that an estimated one out of three adults—60 million Americans—used at least one unconventional medical therapy in 1990 for an estimated cost of \$13.7 billion in that year (\$10.3 billion out-of-pocket). In a follow-up study, Eisenberg et al. (1998) found CAM use had increased from 34 percent in 1990 to 42 percent (83 million people) in 1997.

The investigators' definition of "unconventional medicine" consisted of a list of the following sixteen practices: relaxation techniques, chiropractic, massage, imagery, spiritual healing, commercial weight-loss programs, lifestyle diets, herbal medicine, magavitamin therapy, self-help groups, energy healing, biofeedback, hypnosis, homeopathy, acupuncture, and folk remedies (Eisenberg et al., 1993; Eisenberg et al., 1998). In addition, survey participants were asked about their use of prayer and exercise, although this data was not included in the authors' final analyses.

A categorization scheme to define complementary and alternative medicine was developed by the National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health. Seven categories

representing a variety of concepts, treatments, and approaches were developed for the purpose of discussion and research: (1) diet, nutrition, and lifestyle changes; (2) mind-body techniques; (3) bioelectromagnetics; (4) pharmacological and biological treatments; (5) alternative systems of medical practices; (6) manual healing methods; and (7) herbal medicines.

Each of these categories defined by the NCCAM contains therapies ostensibly used to treat cancer or its symptoms. Examples of cancer-related studies funded by the NCCAM include: macrobiotic diet for cancer (University of Minnesota); melanoma and antioxidant vitamins (University of Colorado); hypnotic imagery and breast cancer (Good Samaritan Hospital, Portland, OR); imagery, relaxation, and breast cancer (University of Texas); acupuncture and herbs for cancer (American Health Foundation); massage and bone marrow transplant (Dartmouth); and electrochemical treatment of tumors (City of Hope Medical Center) (Cassileth & Chapman, 1996). In addition, NCCAM works with the National Cancer Institute to oversee larger clinical trials of CAM cancer therapies.

Furthermore, the American Cancer Society (ACS) established the Behavioral Research Center in 1995, which included in its research priorities "the study of the use of complementary therapies by cancer patients" (ACS, 2001). The American Public Health Association (APHA) added a special primary interest group (SPIG) on complementary and alternative health practices.

Although no central registry of statistics on CAM cancer therapies exists, there have been studies that describe CAM use among cancer patients. In the Eisenberg et al. (1993) national survey, 24 percent of the adults who had cancer reported using at least one CAM therapy. By comparison, more recent studies suggest that CAM use among cancer patients is increasing at a rapid rate. Current estimates of CAM use prevalence among adults who have been diagnosed with cancer are 30 percent (Ernst, 2000), to 40 percent (Metz, 2000), to 50 percent (Greene, 2000). The literature indicates that prevalence of CAM use among women diagnosed with breast cancer is higher than among adults diagnosed with other types of cancer (Morris, Johnson, Homer & Walts, 2000).

Reasons for the increasing popularity of CAM have been summarized as a reflection of the "changing needs and values in modern society in general," including "a rise in the prevalence of chronic disease, an increase in public access to worldwide health information, reduced tolerance for paternalism, an increased sense of entitlement to a quality life, declining faith that scientific breakthroughs will have relevance for personal treatment of disease, and an increased interest in spiritualism" (Jonas, 1998). Among cancer patients, suggested reasons for CAM use are: patients taking an active role in the treatment of cancer and its symptoms, maintaining general health and well-being, improving immune function, and improving quality of life (Morris et al., 2000; Astin, 1998; Ernst, 2000).

Although dissatisfaction with conventional medical care has been associated with CAM use in some studies (Astin, Pelletier, Marie & Haskell, 2000),

it appears that, in general, cancer patients who are CAM users do not abandon conventional medical care. None of the cancer patients identified in Eisenberg et al.'s (1993) study used CAM without also using allopathic medicine for cancer treatment; and only 4.4 percent of participants in Astin's (1998) study used CAM exclusively. According to Burstein (2000), "there is no data to suggest that people who use CAM eschew conventional medicine." This is an indication that cancer patients want all that modern medicine can offer, plus other possible modalities to achieve the best potential all-around treatment for health and well-being.

This recent trend of combining CAM modalities with mainstream medicine is being termed "integrative medicine" (Jonas, 1998). The majority of US medical schools now offer courses in CAM, and more than 70% of insurance companies offer coverage or discounts for at least one CAM therapy (Wetzel, Eisenberg & Kaptchuk, 1998; Greene, 2000). In fact, according to Straus, NCCAM director, "Things that are CAM today will be conventional medicine tomorrow. They will have been integrated" (Marwick, 2000).

In light of this forecast, CAM use takes on a special significance among those diagnosed with breast cancer, and further exploration of their CAM use will help identify what therapies and practices outside of "official" medicine are perceived to be most important to their recovery. An enhanced understanding of what women do outside the standard system of medical care can (1) shed light on the health beliefs, behaviors, and self-care goals of women diagnosed with breast cancer; (2) contribute to physicians' awareness of what CAM practices their

patients are using; (3) suggest areas of need that are not adequately addressed in the present health care system; and (4) identify research priorities involving CAM use.

The purpose of the study presented herein was to extend the current knowledge base on CAM use prevalence and patterns among women diagnosed with breast cancer. Specifically, this study conducted a survey of women diagnosed with breast cancer in Portland, Oregon, to determine the prevalence and patterns of CAM use, reasons for CAM use, physician recommendations for CAM use, and sociodemographic predictors of CAM use. Hypothesized predictors included those suggested by previous research—age, income, education level, marital status, exercise, and insurance status.

## Methods

# Sample

Six health care plans in the Portland, Oregon metropolitan area provided the names, addresses and phone numbers of women diagnosed with breast cancer between January 1, 1996 and December 31, 1997. Together these organizations treated over 75% of all breast cancer patients in this region. The sampling procedure used disproportional stratified sampling to ensure each health plan was sufficiently represented; that is, sampling fractions were larger for the health plans with fewer breast cancer patients.

Interviewers called the phone numbers of all 1362 women in the sample, resulting in 605 persons declared ineligible for the study because of a

disconnected/wrong phone number (351), unavailability (i.e., no answer, not home, phone blocking) (157), deceased (48), hearing problems (41), or language barrier (8). Among the remaining 757 eligible participants, 588 agreed to be interviewed, for a 78% response rate.

# Survey instrument

The use of complementary and alternative medicine was defined by the same set of criteria used by Eisenberg, et al. (1993), with a few modifications based on categories established by the National Center for Complementary and Alternative Medicine (2000), and based on pilot research with a sample of 13 breast cancer survivors. For example, naturopathic medicine was added as a CAM therapy in this survey because Oregon is one of the 12 states where it is licensed. Specifically, the survey participants were asked if they used any of the following 15 therapies or practices in the last 12 months: relaxation/meditation, chiropractic, massage/manipulation, imagery, spiritual healing, naturopathy, lifestyle diets, herbal medicines, megavitamins/nutrient therapy, self-help/support groups, energy healing, biofeedback, hypnosis, pharmacological/immune therapy, and acupuncture.

Women who indicated the use of a specific CAM therapy were asked if their medical doctor recommended its use, and whether or not the therapy was important (on a scale of 1 to 5) in remaining free from cancer in the future. The survey also explored overall reasons for CAM use (a close-ended list of four reasons developed from the pilot study).

The CAM use survey was a portion of a larger study sponsored by the Portland Medical Outcomes Consortium on health plan comparison, and began with questions about patient satisfaction with treatment for breast cancer. In addition, sociodemographic data were abstracted from the tumor registries of the six health plans, which included insurance type, and location and age at diagnosis.

# Procedure for Data Collection

The questionnaire and the data collection protocol were approved by the institutional review board at Oregon State University. Each potential participant received a letter by mail explaining the nature and purpose of the project prior to contact for the telephone interview. The questionnaire was pre-tested, revised, and programmed for computer-assisted telephone interviewing (CATI) by the Gilmore Research Group, a survey organization in Oregon. The interviews were conducted during July and August 2000. New and changed phone numbers were called when available unless the new number was outside the Portland metropolitan area. Telephone numbers were called up to ten times to obtain an interview. The average length of the total interview was 23.4 minutes.

# Procedure for Data Analysis

Analyses were conducted on the 551 responses from participants who completed the telephone survey in its entirety. Sample size calculations (estimated CAM use prevalence in Oregon, 50 percent; Elder, Gillcrist & Minz, 1997)

indicated that a minimum of 384 responses were needed to estimate CAM use with a five percent error of estimation.

Prior to analysis, interview data were inspected for accuracy of data input, distribution, and missing values. Inconsistencies were checked and corrected. Missing data among variables was low, ranging from none to two percent, with the exception of the household income variable (14.5 percent missing). No missing data patterns were identified. Missing values were replaced through the Expectation-Maximization algorithm procedure and subsequent analysis used the data set with the imputed values.

Correlational analysis among the potential predictor variables found no problems with redundancy or extremely high correlations. There were no exceedingly high standard errors for parameter estimates. Therefore, no multicollinearity was evident among the variables to be included in the logistic regression analyses.

Participants were categorized as CAM users if they used one or more of the 15 CAM therapies. Potential predictor variables selected for correlational analysis were based on knowledge of associations with CAM use reported in the literature. In order to determine the relative importance of the factors that showed a correlation (P < .05) with CAM use, standard logistic regression was performed with CAM use (a dichotomous measure) as the dependent variable. The variables were entered simultaneously since there was no clear theoretical rationale about the order or significance of the predictors. Three outlying cases were identified upon

examination of standardized residuals of the model. Upon inspection, they appeared to be outliers because they were young women who did not use CAM. They were retained in the model. SPSS Base 10.0 (for Windows, SPSS Inc., Chicago, IL) was used to perform all analyses. All p value tests were 2-sided.

## Results

## Sample

The study sample consisted of females who had been diagnosed with breast cancer an average of 3.5 years prior to the interview. The mean age of the women at the time of the interview was 64 years (SD = 11.68) with a range of 31 to 91 years. Most study participants were white, reflecting the racial mix of the Portland, Oregon region. Seventy one percent were married or in a significant relationship. Fifty-eight percent of the women had education beyond a high school degree.

Mean household annual income level was \$35,000 to \$49,000.

## CAM Use

Two-thirds (66%) of the women had used at least one CAM therapy during the past 12 months, with an average of two therapies per participant and a range from 1 to 11 CAM therapies. Table 2 lists the 15 CAM therapies in descending order of frequency of use. The top four CAM therapies were relaxation/meditation (29%); herbal medicines (27%); spiritual healing (26%); and megavitamins/nutrient therapies (23%). Table 3 shows that the most common types of herbal medicines used were Chinese or Oriental herbs, echinacea/red root, garlic, and ginko bilboa.

The megavitamins/nutrient therapies (beyond a daily vitamin) most often used included vitamin E, vitamin C, B complex, antioxidant compounds, and calcium.

Table 2. Prevalence of CAM Use, Physician Recommendations, and Perceived Importance

Type of CAM	Used in past 12 months (%)	If yes, did your doctor recommend? (%)	Importance in remaining free from cancer (means; 1-5)*
CAM overall	363 (66%)		
Relaxation/Meditation	154 (28%)	35 (23%)	3,31
Herbs	143 (26%)	30 (21%)	2,76
Spiritual healing	143 (26%)	11 (8%)	4.15
Vitamins/nutrient therapy		43 (34%)	3.41
Massage/manipulation	105 (19%)	28 (27%)	2.35
Imagery	73 (13%)	11 (15%)	3.22
Chiropractor	72 (13%)	7 (10%)	1.88
Naturopathy	72 (13%)	12 (16%)	3.25
Support group	71 (13%)	28 (40%)	3.10
Lifestyle diet	50 (9%)	19 (38%)	4.21
Immune therapy	28 (5%)	15 (52%)	3.65
Acupuncture	26 (5%)	1 (4%)	3.00
Energy healing	10 (2%)	1 (9%)	3,36
Biofeedback	9 (2%)	2 (20%)	2.80
Hypnosis	5 (1%)	0 (0%)	3.00

N = 551

<sup>\*</sup> 1= not important; 2= a little important; 3= moderately important; 4= quite important; 5= extremely important

Table 3. Specific CAM Use among Certain Therapies

# Herbal Medicines (n = 143)

Chinese/Oriental herbs	32%
Echinacea/Red Root	24%
Garlic	14%
Ginko Bilboa	12%
Black Cohosh	7%

# Vitamin/Nutrient Therapy\* (n = 127)

Vitamin E	52%
Vitamin C	46%
B Complex	29%
Antioxidant compound	25%
Calcium	22%

# Lifestyle Diet (n = 50)

Reduce meat/fat intake	64%
Increase fruit/vegetables	48%
Reduce dairy intake	26%
Organic	24%
Increase soy intake	20%

# Immune/pharmacological Therapy (n = 28)

Co-Enzyme Q10	31%
Immunotherapy	28%
Melatonin	14%
Oxidizing agent	14%
Bee pollen	14%

# Energy Healing (n = 10)

Reiki	36%
Energy transfer	36%

<sup>\*</sup>other than daily vitamins and more than the recommended daily allowance

The majority of the women who used CAM sought the therapy without the recommendation of their doctor (Table 2). For example, among the 158 women who used relaxation/meditation, only 23% of them reported that their physician had recommended this therapy; and 21% of the 147 women who used herbal medicines reported that their physician had recommended herbs. The most frequent physician-recommended CAM (n = 43) was vitamin/nutrient therapy. Interestingly, even though only five percent (n = 29) of the women in this study reported using immune therapy, 52% of these same women reported that their physician recommended it.

The women who used the specific CAM therapies were asked to rank its importance in remaining free from cancer from 1 to 5, with 1 being "not important," and 5 being "extremely important" (see Table 2). Two CAM therapies were perceived by their users to be "quite important" in remaining free of cancer: diet and spiritual healing (M = 4.21 and 4.15). The majority of the CAM therapies were perceived to be at least "moderately important" to the users in remaining free of cancer, including immune therapy (M = 3.65), vitamins/nutrient therapy (M = 3.41), energy healing (M = 3.36), relaxation/meditation (M = 3.31), naturopathic medicine (M = 3.25), imagery (M = 3.22), support groups (M = 3.10), acupuncture (M = 3.00), and hypnosis (M = 3.00). Of the 15 CAM therapies, chiropractic medicine was perceived by the users to have the least importance in remaining free from cancer.

According to CAM users, the most important reason for using CAM was to enhance overall quality of life (41%) (Table 4). Other main reasons for using CAM included to feel more in control (21%), to strengthen the immune system (11%), and to reduce stress (10%). It should be noted here that many women expressed that they used CAM for more than one reason, and some reported that all four reasons above were important.

Table 4. Single Most Important Reason for CAM Use

Reason	% of CAM Users
To enhance overall quality of life	41%
To feel more in control	21%
To strengthen the immune system	11%
To reduce stress	10%

# Correlational Analysis

Table 5 presents the correlations of all hypothesized predictors with the dependent variable (use of CAM). Six variables were significantly associated with CAM use: education (r = .29), age (r = -.25), income (r = .24), insurance type (r = .21), being married (r = .13), and use of exercise (r = .09). CAM use was not

associated with satisfaction with medical treatment, satisfaction with how much the doctor listens, or trust in the doctor. Overall, women reported satisfaction with their conventional medical care; on a scale of 1 to 5, where 4 signified "satisfied," and 5 signified "very satisfied," women gave a mean score of 4.45 (CAM users: mean, 4.41; nonusers: mean 4.52). Likewise, "I trust my doctor" (4 = most of the time; 5 = always) had a mean score of 4.74 (CAM users: mean, 4.73; nonusers: mean, 4.75); and "My doctor listens to my concerns" had a mean score of 4.30 (CAM users: mean, 4.33; nonusers: mean, 4.25).

Table 5. Correlations of hypothesized predictors with CAM use

Variable	simple r	r <sup>2</sup>	p (2-tailed)	
Education	.29	.08	.000	
Age	25	.06	.000	
Income	.24	.06	.000	
Private insurance	.21	.04	.000	
Married/sig other	.13	.02	.007	
Exercise	.09	.01	.037	
Patient satisfaction	06	.00	.164	
Doctor listens	.04	.00	.324	
Trust doctor	01	.00	.757	

# Predictors of CAM use

When the six potential predictors were examined in a logistic regression model, results suggested that the following factors were predictive of CAM use in this population: education (odds ratio = 2.48, 95% CI = 1.68, 3.64), type of

insurance (odds ratio = 2.47, 95% CI = 1.47,4.15), and age (odds ratio = .375, 95% CI = .224, .627) (Table 6). That is, women who used CAM were more likely to be younger in age, have higher education, and have private insurance. Three factors—income, marital status, and use of exercise—did not reach the likelihood ratio test p < .05 significance level, and were removed from the model since they did not predict the use of CAM.

A test of the full model with the set of three predictors against the constant-only model was statistically significant, model chi-square (3, N = 548) = 68.39, p < .000, indicating that the null hypothesis (knowledge of the predictor variables makes no difference in predicting CAM use) be rejected. Furthermore, the Hosmer and Lemeshow statistic (goodness-of-fit test in which a good model produces a non-significant chi-square) suggested a good fit between observed and predicted outcomes, chi-square 4.716 (4), p < .32. Overall, these results suggested the logistic regression model with three predictors was fairly strong and that CAM users differed significantly from CAM nonusers in education, private insurance, and age.

Table 6. Predictors of CAM use among women diagnosed with breast cancer

Factor	Odds ratio	P	95% Confidence Interval
College education Age	2.48 0.38	.000	1.68 - 3.64 0.22 - 0.62
Private insurance	2.47	.001	1.47 - 4.15

## Discussion

Two-thirds of the 551 women in this survey had used at least one CAM therapy in the past year. Use was highest for relaxation/meditation (28%), herbal medicine (26%), spiritual healing (26%), and vitamins/nutritional supplements beyond a daily vitamin (23%).

Education, age, and private insurance were found to be significant predictors of CAM use among women in this survey. Participants who had some college or beyond were 2.5 times more likely to use CAM therapies than those with no college education. Higher education may enable information-seeking behavior, which may lead to knowledge about CAM therapies and confidence to act on that knowledge. Participants who had private health insurance were also 2.5 times as likely to use CAM. This result supports another study that identified private insurance as a predictor of CAM use among women diagnosed with breast cancer (Lee, Lin, Wrensch, Adler & Eisenberg (2000). Furthermore, in a study of CAM use among elderly patients, 31 percent of the total sample had joined specific health plans because of their coverage of two CAM therapies—acupuncture and chiropractic (Astin, Pelletier, Marie & Haskell, 2000). Younger women in the current study were also more likely to use CAM. Sollner, et al. (2000), whose study also found age as a predictor of CAM use, speculated that younger cancer patients may be more apt to try "every method available" to influence the course of the cancer.

A summary of the current study and six recent publications regarding CAM use among women diagnosed with breast cancer highlights similarities and differences by geographical region (Table 7). Although some of the variation may be attributed to differing definitions of CAM and differences in instruments and methodologies, collectively these surveys show that the use of CAM among women diagnosed with breast cancer is high, with a range from 39 percent (Massachusetts) to 91 percent (the Midwest). Collectively these studies add to the evidence that CAM use has increased in prevalence over time. According to American Cancer Society statistics, CAM use prevalence among breast cancer patients ten years ago was only 9.2 percent (Lerner & Kennedy, 1992).

As can be seen in Table 7, herbs and spiritual healing were the two most common CAM therapies; both were in the top three CAM therapies in five out of the seven surveys. Educational level and age consistently appeared as the two strongest predictors of CAM use among women diagnosed with breast cancer.

Table 7. Recent reports of CAM use among women diagnosed with breast cancer

Region	N	CAM Users (%)	Most common CAM therapies	Predictors
Oregon <sup>a</sup>	551	66%	relaxation/meditation, herbs, spiritual healing	education, age, insurance type
Mass- achusetts <sup>b</sup>	480	39%	relaxation, self-help groups, spiritual healing, megavitamins	age, marital status, education, income, chemotherapy, fear, depression, physical symptoms
Ontario Canada <sup>c</sup>	411	67%	vitamins, chiropractor, herbs, diet	support group attendance
California <sup>d</sup>	379	48%	dietary therapy/megavitamins, spiritual healing, herbs	ethnicity, age, education, income, insurance type
Oregon <sup>e</sup>	288	84%	nutrition therapy, massage, herbs	
Ohio <sup>f</sup>	112	91%	prayer, exercise, spiritual healing	religious service attendance, education, fatalism, fighting spirit
Hawaii <sup>g</sup>	49	42%	prayer therapy, herbs, vitamins	age, Catholicism, education

<sup>a. Henderson & Donatelle (2001)
b. Burstein, Gelber, Guadagnoli & Weeks (1999)
c. Boon et al. (2000)
d. Lee, Lin, Wrensch, Adler & Eisenberg (2000)
e. Morris, Johnson, Homer & Walts (2000)
f. Versch, Charle Brann & M. (2000)</sup> 

Van de Creek, Rogers & Lester (1999)

g. Gotay, Hara, Issell & Maskarinec (1999)

Among the women in the present study, CAM use did not reflect negative attitudes towards conventional medical care. Almost all women in this study reported high levels of trust in their physicians, and were very satisfied with how much their doctors listened to them and with their overall conventional medical treatment for breast cancer. Dissatisfaction and mistrust in conventional medicine or physicians were not predictive of CAM use in this group of women, contrary to a recent study that found elderly persons with negative attitudes towards conventional medicine were more likely to use CAM (Astin, Pelletier, Marie & Haskell (2000). However, consistent with findings from several recent studies, this study confirms that CAM use among cancer patients was not related to trust or satisfaction with medical care (Gotay, Hara, Issel & Maskarinec, 1999; Sollner, et al., 2000; Boon, et al., 2000).

The majority of women in the present study felt that their use of CAM therapies was at least moderately important in remaining free of cancer in the future; the highest expectations for a cancer-free future among CAM users were for diet and spiritual healing. There were also high expectations that CAM use would improve quality of life—over 40 percent of CAM users indicated that improved quality of life was the single most important reason for CAM use. They also used CAM to feel more in control (21%), to strengthen the immune system (11%), to reduce stress (10%), or a combination of these factors (18%). This confirms another study which found that most cancer patients expected CAM therapies to

improve their quality of life, boost their immune system, and to prolong their lives (Richardson, Sanders, Palmer, Greisinger & Singletary, 2000).

It has recently been stated that CAM use is "often not about cancer treatment but about feeling better and about having greater control over one's destiny" (Burstein, 2000). In addition, a relationship between CAM use and an orientation towards self-care has been suggested by several researchers (Jonas, 1998; Gotay, Hara, Issel, Maskarince, 1999; Eisenberg et al., 1998; Astin, Peletier, Marie, Haskell, 2000). The fact that the majority of the women in this study used CAM without the recommendation of their physician indicates assumption of a leadership role in their own health promotion. The women did not wait for "doctor's instructions," but adopted a broad range of health-related activities, from mind/body therapies to herbal medicines, for self-care, healing, and optimization of health and well-being.

Three limitations of this study must be acknowledged. First, the sampling frame was limited to women who spoke English and who had telephones. The sample was predominantly white, and, though this is reflective of the Portland, Oregon, population, may limit generalization to other women, in general, who have been diagnosed with breast cancer. Second, the cross-sectional nature of this study limits conclusions to associations rather than cause-and-effects. Third, the definition of CAM is broad, complex, changing, and left somewhat to the interpretation of both the researcher and survey respondent. CAM use is a complex human behavior that is difficult to capture in a single survey. For example, a

woman whose only CAM use is spiritual healing may have very different perceptions and goals than a woman who uses several herbal medicines, megavitamins, and immune therapies. Despite these limitations, the present study adds substantially to understanding CAM use among women diagnosed with breast cancer.

The results from this study suggest that although CAM therapies may be perceived by CAM users as a potential influence on the course of breast cancer, CAM therapies are actually components of a larger concept of health behavior and well-being that includes an expanded form of self-care. That is, women diagnosed with breast cancer may seek out CAM therapies as a way of being independently proactive against the disease while improving physical, mental, and spiritual health. The research literature has associated CAM use with higher mind-body awareness, positive affect, feeling more hopeful, active coping behavior, improved self-care efforts, and perceived improvement in overall health and well being (Morris, Johnson, Homer & Walts, 2000; Richardson, Sanders, Palmer, Greisinger & Singletary, 2000; Gotay, Hara, Issel & Maskarinec, 1999; Owens, Taylor & Degood, 1999; Sollner, et al., 2000).

Further studies should explore these patient-centered outcomes (psychological states, quality-of-life issues) as well as biomedical and survival outcomes of CAM use and other self care behaviors. It has been documented that the prevalence of CAM use is high in the breast cancer community. Clinical studies are underway to determine usefulness of CAM therapies for cancer

treatment. CAM users perceive benefits beyond the standard medical treatment for breast cancer. The challenge remains to document in what ways CAM use contributes to the health status and quality-of-life by women diagnosed with breast cancer. It may be that simply participating in one's own care (through CAM use, for example) has both short and long term benefits.

Future studies should also focus on CAM use as self care strategies to improve health status and quality of life, and what factors motivate the use of CAM. Since CAM use includes a complex array of therapies and practices, and reasons for CAM use are multidimensional, it may make more sense to examine individual CAM activities with specific physical and nonphysical (mind/spirit) outcomes.

In conclusion, two-thirds of women diagnosed with breast cancer are integrating CAM use with conventional medical care. These women are more likely to be younger in age, have some college education, and private insurance. It will be important for future studies to determine perceived and real benefits women are deriving from CAM use and how clinicians can use CAM as a powerful adjunct to conventional treatment. This information will help health care providers and policy makers identify patient needs that go beyond surgery, chemotherapy and radiation, and address patient-centered health-related goals and outcomes for optimal health and recovery from breast cancer.

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# ARTICLE 2: CONFIRMATORY FACTOR ANALYSIS OF THE CANCER LOCUS OF CONTROL SCALE

#### Abstract

Perceptions of control after a cancer diagnosis may have psychological and physical health significance. The control constructs (control over the cause of the cancer and control over the course of the cancer) are critical components of the Theory of Cognitive Adaptation. The Cancer Locus of Control scale reflected these theoretical components, and was administered to 543 women with a history of breast cancer. Structural equation modeling (confirmatory factor analysis) was used to refine and test the construct validation of the Cancer Locus of Control. The results supported a three-factor model (control over cause of cancer, control over course of cancer, and religious control) of the Cancer Locus of Control scale.

Perceived control over the course of the cancer had the strongest total effect on control perceptions, although mean scores of beliefs in all three dimensions indicated generally high confidence in cancer control. It was concluded that the Cancer Locus of Control scale provides a valid and reliable assessment of the three distinct control dimensions.

### Introduction

Perceptions of control after a life-threatening event such as a cancer diagnosis has been a central research topic in health psychology and behavioral medicine. One theoretical approach to the study of control is Taylor's (1983) theory of cognitive adaptation. Based on research with breast cancer patients, Taylor proposed that an important aspect of adjustment to a traumatic life experience involved an effort to regain a sense of mastery or control. The control theme refers to both perceptions of the cause of the cancer and the course of the cancer. The cause of the cancer is concerned with past events, and the course of the cancer is concerned with present and future events.

Since these distinctive dimensions of control figure centrally in the theory of cognitive adaptation, establishing construct validity of a scale designed to measure them is of central theoretical importance. In particular, Watson, Greer, Pruyn, and Van Den Borne (1990) provided a Cancer Locus of Control scale which involves three separate dimensions of the control construct among cancer patients:

(1) control over the cause of the disease; (2) control over the course of the disease; and (3) religious control. However, their initial cancer locus of control study had a small sample (N = 68), and relied on exploratory factor analysis. To date there is no independent evidence as to the validity of the Cancer Locus of Control scale.

The aims of this study are to clarify and refine the Cancer Locus of Control scale, extend the scope of factor analysis to a larger sample, and to test and confirm the factorial validity of the Cancer Locus of Control structure within a hypotheses-

testing framework. A three-factor model is hypothesized: control over the cause of cancer (with six indicators), control over the course of cancer (with seven indicators), and religious control (with three indicators). The main research question is: Does a three-factor control model with simple structure (each variable loading only on one factor) fit the data?

## Methods

# Sample

Six health care plans in the Portland, Oregon metropolitan area provided the names, addresses and phone numbers of women diagnosed with breast cancer between January 1, 1996 and December 31, 1997. Together these organizations treated over 75% of all breast cancer patients in this region. Sampling procedures used disproportional stratified sampling to ensure each health plan was sufficiently represented; that is, sampling fractions were larger for the health plans with fewer breast cancer patients.

Interviewers called the phone numbers of all 1362 women in the sample, resulting in 605 persons declared ineligible for the study because of a disconnected/wrong phone number (351), unavailability (i.e., no answer, not home, phone blocking) (157), deceased (48), hearing problems (41), or language barrier (8). Among the remaining 757 eligible participants, 588 agreed to be interviewed, for a 78% response rate.

# Survey Instrument

For this study we modified the 17-item Cancer Locus of Control scale developed by Watson, et al. (1990), which is an English version of the Dutch Locus of Control Scale for Cancer Patients originated by Pruyen, et al. (1988). The Cancer Locus of Control consists of three subscales: control over the course of cancer, control over the cause of cancer, and religious control. This scale most closely aligned with Taylor's (1983) Theory of Cognitive Adaptation, where perceptions of control over the course and cause of the disease were both important in adjustment to cancer. Even though the religious control variable was not germane to the theory, it was retained as a variable of interest as part of the Cancer Locus of Control scale.

Revisions to the Cancer Locus of Control scale were based on pilot research with a sample of 13 breast cancer survivors. The pilot study was conducted to identify any problems with the understanding of the directions and format of the instruments, sensitivity to items, and time required to complete the questionnaires. The participants were invited to comment about the wording and acceptability after completion of the interview. Based on the results of the pilot study, 16 items from the Cancer Locus of Control scale were selected, and four of those items were rephrased. For example, the item, "Getting cancer was without a doubt a matter of coincidence over which I had no influence" was rephrased as "Getting cancer was a matter of chance over which I had no influence." In addition, the original scale utilized a 4-point response format, whereas a 5-point Likert-type response format

ranging from 1 (strongly disagree) to 5 (strongly disagree) was used in this study in order to maintain consistency throughout the overall survey, and to "optimize reliability and validity" (Wikman & Warneryd, 1990).

Table 1 presents the final 16-item version of the Cancer Locus of Control scale used in this study. Six items measure the subscale, control over the cause of cancer, seven items measure the subscale, control over the course of cancer, and three items measure religious control.

Table 1. Cancer Locus of Control Scale used in present analysis

Control over Cause of cancer items (Scale: 1 = strongly disagree; 5 = strongly agree)

Causel Getting cancer was a matter of chance over which I had no influence.

Cause2 Getting cancer was a result of my behavior.

Cause3 It is partly my fault that I got cancer.

Cause4 Unfortunate events in my past contributed to the fact that I got cancer

Cause 5 Getting cancer had something to do with my personality.

Cause6 Getting cancer was especially due to something about me.

Control over course of cancer items (Scale: 1 = strongly disagree; 5 = strongly agree)

Course I can definitely influence the course of the cancer.

Course2 My doctor can definitely influence the course of the cancer.

Course3 The key people in my life can definitely influence the course of the cancer.

Course4 By taking extra care of myself I can influence the course of the cancer.

Course5 By living healthily I can influence the course of the cancer.

Course6 If I follow the advice of my doctor, I can definitely influence the course of the cancer.

Course 7 I can influence the course of the cancer by fighting against it.

Religious control over cancer items (Scale: 1 = strongly disagree; 5 = strongly agree)

Rell Whether or not I remain free from cancer is in God's hands.

Rel2 God can definitely influence the course of the cancer.

Rel3 My religion has an influence on the course of the cancer

## Procedure for Data Collection

Each potential participant received a letter by mail explaining the nature and purpose of the project prior to contact for the telephone interview. The questionnaire was pre-tested, revised, and programmed for computer-assisted telephone interviewing (CATI) by a survey organization in Oregon. The interviews were conducted during July and August 2000. New and changed phone numbers were called when available unless the new number was outside the Portland metropolitan area. Telephone numbers were called up to ten times to obtain an interview.

The average length of the total interview was 23.4 minutes, and included questions about satisfaction with treatment for breast cancer, quality of life, and use of complementary and alternative medicine in addition to cancer locus of control. The interviewers' text before the Cancer Locus of Control scale read as follows: "We are almost finished with the survey. The last set of statements is concerned with cancer and issues of control. Pick the answer that is closest to the way you feel about each statement. These are opinion statements, so there are no 'right' or 'wrong' answers. Answer according to your own feelings."

# Procedure for Data Analysis

Analyses were conducted on responses from the 551 women who completed the telephone survey in its entirety (94% of those who participated in the study.) In order to validate the Cancer Locus of Control scale, the overall analyses

proceeded in two major stages: (1) exploratory factor analysis (principal components analysis with varimax rotation) and, (2) structural equation modeling (confirmatory factor analysis). Both exploratory and confirmatory factor analyses have been used to gather evidence for validity of a scale (John & Benet-Martinez, 2000). Furthermore, it has been suggested that all exploratory analyses should be completed by confirmatory factor analysis in order to produce the solution with the greatest scientific utility, consistency, and meaning (Tabachnick & Fidell, 2001).

This study used principal components analyses to investigate the factor structure, to conduct item analysis and selection, and to replicate the findings of a previous study by Watson, et al. (1990). Confirmatory factor analysis, conducted with Amos (Arbuckle, 1994), was used to test how well the hypothesized three-factor Cancer Locus of Control measurement model fit the data (see Figure 1). In the model, ovals are used to represent the factors, or latent constructs. The double-headed arrows indicate that the three control constructs are allowed to correlate with each other. Squares represent the 16 measured variables in the Cancer Locus of Control scale. The arrow from the latent construct to the measured variable is a factor loading or regression coefficient, and represents the effect that the latent construct has on each measured variable. The other arrow pointing to the measured variable represents the measurement error, or the residual variance.

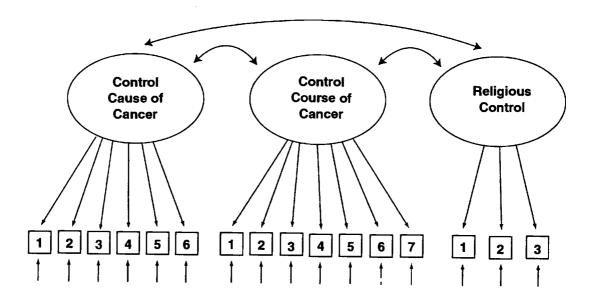


Figure 1. Hypothesized CLOC measurement model.

Several fit statistics were selected to evaluate the overall fit of the model (Figure 1) to the data: (a) the conventional chi-square statistic and the chi-square to degrees of freedom ratio, (b) goodness-of-fit index (GFI), (c) adjusted goodness-of-fit index (AGFI), (d) the comparative fit index (CFI), and (e) the root mean square error of approximation (RMSEA). Since the chi-square statistic is inflated by large sample size, it is recommended that emphasis be given to the other goodness-of-fit statistics (Dickey, 1996; Kline, 1994).

Criteria for the indices of fit used in this study are as follows: for the chisquare ratio, a value between 2 and 3 is considered acceptable, and closer to 1 is better. The GFI, AGFI, and CFI statistics range from 0 to 1, and values greater than .90 indicate a good model fit. For RMSEA, a value of .05 or less indicates a good fit, a value of .08 indicates a reasonable fit, and a value of .10 and higher is a poor fit of the model.

#### Results

# **Descriptive Statistics**

The study sample consisted of females who had been diagnosed with breast cancer an average of 3.5 years prior to the interview. The mean age of the women at the time of the interview was 64 years (SD = 11.68) with a range of 31 to 91 years. Most study participants were white, reflecting the racial mix of the Portland, Oregon region. Seventy one percent were married or in a significant relationship. Fifty-eight percent of the women had education beyond a high school degree. Mean household annual income level was \$35,000 to \$49,000.

Prior to analysis, data from 551 women were examined through various SPSS programs for accuracy of data input, distribution, and missing values. The percentage of missing data among 16 items used in this analysis ranged from 1.1% to 7.1%. No missing data patterns were identified. Missing values were replaced through the Expectation-Maximization algorithm procedure and subsequent analysis used the data set with the imputed values.

With the use of a p < .001 criterion for Mahalanobis distance, eight outliers among the participants were identified. All eight were deleted, leaving 543 cases

for analysis. The ratio of cases to variables was 32:1, well above the 20:1 ratio minimum for confirmatory factor analysis suggested by Kline (1994).

Table 8 contains the means, standard deviations, skewness and kurtosis of the 16 items of the Cancer Locus of Control scale. In general, the means were relatively low for the control over cause of cancer subscale (1.40 to 1.90 on a 5-point scale), and relatively high for both the control over course of cancer subscale (2.83 to 4.20) and the religious control subscale (3.57 to 3.94). Skewness and kurtosis were not problematic in this data set.

Table 8. Descriptive Statistics for Cancer Locus of Control Scale (N = 543)

<u>Variable</u>	M	SD	Skewness	Kurtosis
		<u></u>		
Cause 1	1.90	1.25	1.301	.492
Cause 2	1.40	.91	2.429	4.931
Cause 3	1.57	1.08	1.757	1.660
Cause 4	1.75	1.22	1.537	1.037
Cause 5	1.43	.96	2.359	4.562
Cause 6	1.60	1.05	1.789	2.150
Course 1	3.14	1.41	204	-1.319
Course 2	3.52	1.37	590	983
Course 3	2.83	1.50	.106	-1.576
Course 4	4.01	1.09	-1.409	1.479
Course 5	4.20	.95	-1.611	2.690
Course 6	3.79	1.22	984	036
Course 7	3.62	1.35	740	745
Rel 1	3.94	1.32	-1.058	193
Rel 2	3.75	1.42	855	674
Rel 3	3.57	1.51	696	-1.043

# **Factor Analysis**

Principal components analysis (PCA) with varimax rotation through SPSS was used in an initial run to estimate the number of factors and to determine which items would be retained for further analysis. Scree plot and eigenvalue analysis (i.e., eigenvalue > 1.0) identified three to four factors in the Cancer Locus of Control scale. Complexity of variables was assessed by examining loadings across factors. Fourteen of the 16 Cancer Locus of Control items were "factor pure," meaning that they loaded on only one factor. Two items, "Cause 1," and "Course 3," were complex variables (loaded on more than one factor). These results were similar to the Watson, et al. (1990) study, which suggested some structural overlap with religious control. Since a factor pure, or unifactorial scale is preferred (Kline, 1994), the 14 items which loaded on only one factor were selected for further analysis.

For the set of the selected 14 items, the Cancer Locus of Control factor analysis results were as expected. Loadings of variables on factors, reliabilities, and percents of variance are shown in Table 9. Three clear factors were extracted with eigenvalues > 1 and there were substantial loadings of items. The first component, control over the course of cancer had the strongest total effect on control, which accounted for 20% of the variance. The second factor, control over cause of cancer, accounted for 17% of the variance, and religious control accounted for 14% of the variance. Overall, these three factors explained 51% of the variance in this sample. The factor loadings (correlation of the variable with the factor)

indicated that items generally loaded highly on the scale, with a range from .547 to .870. A loading of .30 was accepted as a salient loading (Kline, 1994). Cronbach's alpha coefficients for the three factors were: control over course of cancer (.77); control over cause of cancer (.71); and religious control (.75), indicating acceptable internal consistency. The overall results are consistent with earlier factor analytic work by Watson, et al. (1990).

Table 9. Factor loading of items retained for the Cancer Locus of Control Scale

	_	
	% of variance	loading
Factor I. Control over course of cancer	19.78	
Course 7		.722
Course 2		.698
Course 1		.697
Course 6		.696
Course 4		.642
Course 5		.547
Standardized item $alpha = .$	77	
Factor II. Control over cause of cancer	16.93	
Cause 3		.695
Cause 4		.693
Cause 2		.678
Cause 5		.607
Cause 6		.570
$Standardized\ item\ alpha=.$	71	
Factor III. Religious control	14.48	
Rel 2		.870
Rel 1		.788
Rel 3		.784
$Standardized\ item\ alpha=.$	75	

# Structural equation modeling

Confirmatory factor analysis, a structural equation modeling procedure, was used to test the model amended based on the principal components analysis described above. The final model with the correlations between the latent variables, standardized coefficients, and correlations of the errors are shown in Figure 2.

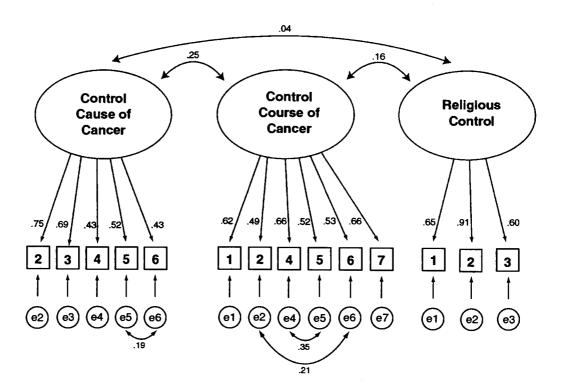


Figure 2. Final Model for the Cancer Locus of Control Scale.

As shown in Figure 2, the relatively low correlations between the three control factors (course <--> control = .25; course <--> religion = .16; cause <--> religion = .04) indicated that the control dimensions were distinguishable, thus supporting good discriminant validity. These subscales were originated to measure

three separate dimensions with three individual scores rather than combining the subscales for one composite score (Watson et al., 1990).

The standardized coefficients for all 14 indicators were significant (p < .01) and indicated that the items loaded well on the latent variables (see Figure 2). Loadings for control over the cause of cancer ranged from .43 to .75, loadings from control over course of cancer ranged from .49 to .66, and from .60 to .91 for religious control. Rel2, "God can definitely influence the course of the cancer" was strongly predictive of religious control (standardized coefficient = .91).

Modification indices provided by Amos suggested that improvements in model fit could be made by allowing some measurement errors to correlate. As shown in Figure 2, three parameters were added, one at a time: measurement errors between Course4 and Course5, Course2 and Course6, and Cause5 and Cause6 were allowed to correlate. Ad hoc adjustments have been standard in structural equation modeling, as long as the adjustments are theoretically justified or make sense empirically. In this study, both Course4 and Course 5 had similar meanings of self-action, Course2 and Course6 both referred to doctor influence, and Cause5 and Cause6 were also similar in meaning.

Table 10 presents previously discussed goodness-of-fit measures. Although the chi square statistic was significant (complicated by sample size), all other measures of goodness-of-fit,  $\chi^2/df = 2.67$ , CFI = .932, GFI = .95, IFI = .933, AFGI = .931, RMSEA = .056, generally support the hypothesis that the model fits the data.

Table 10. Goodness-of-fit statistics for the Cancer Locus of Control model

Test Statistic	Result	Good Fit?
$\chi^2$	190.181	No*
$\chi^2 \chi^2/df$	2.679	borderline/acceptable
GFI	.953	good
CFI	.932	good
IFI	.931	good
AGFI	.931	good
RMSEA	.056	acceptable

<sup>\*</sup>Note: this  $\chi^2$  value yields a result that is statistically significant (p<.001).

## Discussion

The results of this study provided a refined version of the Cancer Locus of Control scale as well as evidence for its construct validity and reliability as a measurement of a three-factor cancer locus of control structure in a sample of 543 breast cancer survivors. In the modified version of the Cancer Locus of Control scale used in this research, six items measured control over the course of the cancer, five items measured control over the cause of the cancer, and three items measured religious control. Perceived control over the course of the cancer had the strongest total effect on control perceptions, although mean scores of beliefs in all three dimensions indicated generally high confidence in cancer control. Principal components analysis replicated the results obtained by Watson, et al. (1990), where three strong factors were identified (course, cause, and religious control) with high

item loadings and acceptable internal consistency for the subscales. Furthermore, confirmatory factor analysis supported the hypothesis that the model fits the data.

Although the present study contributes valuable information about the psychometric performance of the Cancer Locus of Control scale when applied to the breast cancer survivor population, continued confirmatory factor analytic work on the scale is advocated. Measure validation is a continuous process, and further research with other populations would be informative. The present study sample was Caucasian females who had been diagnosed with breast cancer. It would be valuable to confirm the stability of the Cancer Locus of Control scale and model fit in samples including males, diverse racial and ethnic groups, and various types of cancer cases.

Future research is also needed to validate the Cancer Locus of Control measurement with reference to external criteria. Perceptions of cancer control may be associated with other attitudinal and psychosocial variables, and health-related behavior. For example, researchers could examine whether cancer control perceptions are associated with self-care behaviors needed in adjustment or recovery from a cancer diagnosis.

In conclusion, the results from the present study point researchers toward using the refined Cancer Locus of Control scale as a valid method of assessing three distinct dimensions of control perceptions among cancer patients. The Cancer Locus of Control scale may be used to further understand control

perceptions within cancer populations, and to further investigate other psychological and behavioral correlates to the three distinct control dimensions.

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ARTICLE 3: THE RELATIONSHIP BETWEEN CANCER LOCUS OF CONTROL AND COMPLEMENTARY AND ALTERNATIVE MEDICINE USE BY WOMEN DIAGNOSED WITH BREAST CANCER

## **Abstract**

Research has shown that perceptions of control influence health-related behavior and outcomes. This study explored the influence of the control constructs in the context of the theory of cognitive adaptation to the use of complementary and alternative medicine (CAM) among 551 women diagnosed with breast cancer in Portland, Oregon. The majority of these women had high perceptions of cancer control and used one or more types of CAM therapy. Multinomial logistical regression indicated that higher perceptions of control over the course of cancer significantly predicted CAM use in three categories: physical CAM therapies, psychological CAM therapies, and both physical and psychological CAM therapies. Perceived control over the cause of the cancer predictd the use of both psychological and physical CAM therapies. Religious control was associated with the use of spiritual healing, but did not significantly predict CAM use in any of the categories. The model combining the sociodemographic variables (age, education and type of health insurance) and control variables explained more variation ( $R^2$  = .23) in predicting CAM use than the model with only sociodemographic variables  $(R^2 = .14)$ , indicating that perceptions of control over the cause and the course of cancer had an independent significant influence. It was concluded that the assessment of control constructs from the theory of cognitive adjustment is useful for studying CAM use among women diagnosed with breast cancer and that

understanding the meanings that lie behind the decisions to use these therapies are essential for health care providers who are promoting the health and well-being of their patients.

## Introduction

Perceived control, locus of control, self-efficacy, and mastery are controlrelated concepts that have been widely discussed in the literature for their roles in both mental and physical health, including chronic illnesses such as cancer. Studies of men and women diagnosed with cancer generally suggest that higher perceptions of control are associated with better coping skills, emotional wellbeing, physical health, immune function, and quality of life (Dow, Ferrell, Haberman & Eaton, 1999; Gerits & DeBrabander, 1999; Tjemsland, Soreide, Matre & Malt, 1997; Ell, Nishimoto, Morvay, Mantell & Hamovitch, 1989); while low perceptions of control are associated with psychiatric morbidity, cancer recurrence. and even death (Watson, Haviland, Greer, Davidson & Bliss, 1999; Akech. Okuyama, Imoto, Yamawaki & Uchitomi, 2001; De Boer, et al., 1998; Greer, Morris & Pettingale, 1979; Pettingale, Morris, Greer & Haybittle, 1985). Hence, the potential value of maintaining or regaining a sense of control to mental and physical health after a cancer diagnosis is significant and an important avenue of further study.

Maintaining or regaining a sense of control after a cancer diagnosis may incorporate the use of complementary and alternative medicine (CAM), described as "all practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being" (National Center for Complementary and Alternative Medicine [NCCAM], 2000). During the past decade, public use and, consequently, scientific interest in complementary and alternative medicine has increased dramatically (Eisenberg et al., 1998). Among several studies investigating CAM use by cancer patients, researchers have found that women diagnosed with breast cancer are more likely to use CAM than the general public (Van de Creek, Rogers & Lester, 1999) and adults diagnosed with other forms of cancer (Morris, Johnson, Homer & Walts, 2000).

The study of CAM use behavior is relatively new, however, and up to this point there has been minimal investigation of CAM use in relation to perceived control. In fact, there has been no systematic study of perceived control as a predictor of CAM use among women diagnosed with breast cancer. Consequently, this study targets this opportunity with the aim of investigating the relationship between control and use of particular CAM therapies in a population of women diagnosed with breast cancer.

This article first discusses a theoretical basis of control (Taylor, 1983) and recent studies of CAM use, and then goes on to present data that describe the predictive value of three cancer-related control constructs to CAM use in a sample of women diagnosed with breast cancer. The central hypothesis herein is that

women with higher perceptions of cancer control are more likely to display CAM use behaviors than women with lower perceptions of cancer control.

Control in the Context of the Theory of Cognitive Adaptation

Taylor (1983) developed a theory of cognitive adaptation that illustrates how control fits into the human response to a life-changing event such as a diagnosis of breast cancer. The strength of the theory is its ability to explain psychological processes as well as behavioral efforts. The two important control constructs in the theory of cognitive adaptation are (1) control over the cause of the cancer, and (2) control over the course of the cancer. These control constructs are differentiated from Rotter's (1966) categories of "internal" and "external" control, in that a person's sense of control over the cause and course of cancer integrates "personal" control and an "other" control such as a physician or treatment, and that "both together are even better" (Taylor).

The three major themes from the theory of cognitive adaptation are (1) a search for meaning of the experience; (2) mastery over the disease in particular and over one's life in general; and, (3) restoration of one's self-esteem. Each theme has an element of control explained below:

Search for meaning. For women diagnosed with breast cancer, cognitively resolving the issues of meaning (what caused the cancer?) can result in feelings of control if the cause is attributed to something in the past or something that can be

controlled. For example, in Taylor's (1983) study, 95 percent of the women diagnosed with breast cancer had a personal theory as to what caused the cancer, and most of the causes were things that had changed or that could be controlled: stress, exposure to hormones or other carcinogens, hereditary factors, diet, and breast trauma. More recently, a study of 378 breast cancer survivors found very similar results—the cause of the cancer was most commonly attributed to stress—followed by genetics, environment, hormones, diet, and breast trauma (Stewart et al., 2001). Furthermore, these causal beliefs affected health behaviors such as making efforts to have a positive attitude, change in diet, maintaining a more healthy lifestyle, exercise, stress reduction, prayer, and the use of complementary and alternative medicine.

Sense of mastery. Feelings of control over the course of the cancer (what can be done to keep the cancer from coming back? or, what can be done to keep the cancer from growing?) are capable of influencing much health-related behavior according to the theory of cognitive adaptation. Perceptions of control of the cancer were "quite strong" among the women in Taylor's (1983) study, and influenced many health-related behaviors that were believed to control the cancer, such as self-care, diet, stopping hormone replacement therapy, meditation and imagery. In other studies, perceptions of control over the course of the cancer were also related to health-related behavior and a positive "fighting spirit" attitude (Pruyn et al., 1988; Watson, Greer, Pruyn & Van den Borne, 1990).

Restoration of one's self-esteem. A diagnosis of cancer may initially cause a person to feel victimized and out of control, and recovery efforts may typically involve efforts to regain self-esteem and feelings of control. Sometimes the perceptions of control over the cause and course of the cancer are overly-optimistic or even "illusional." However, the theory of cognitive adaptation maintains that optimistic cancer control perceptions may be valuable to mental health and enhanced coping (Taylor, 1983). Optimism as described in the theory of cognitive adaptation predicted a reduced likelihood of new cardiac events over six months among patients with heart disease (Helgeson & Fritz, 1999). Both control and optimism were identified as important psychological variables in a review article on surviving cancer (Andersen, 1994).

It has been suggested that CAM use by women diagnosed with breast cancer is "about feeling better and about having greater control over one's destiny" (Burstein, 2000). Several studies found "feeling more in control" was a perceived benefit or reason to use CAM (Boon et al., 2000; Richardson, Sanders, Palmer, Greisinger & Singletary, 2000; Sparber et al., 2000). However, there were two difficulties in these studies. First, control was conceptualized as a generalized outcome expectancy for CAM use. It may have been more appropriate to measure control constructs specific to the cancer domain—such as those pertinent to the theory of cognitive adaptation—to examine more than a single generic aspect of control and to examine the influence of each control aspect in the decision to use CAM therapies.

The second difficulty in these studies was that CAM use was conceptualized as a uni-dimensional behavior (user vs. nonuser). Since CAM use includes a wide variety of "mind" therapies (i.e., relaxation, imagery, support groups, spiritual healing, hypnotherapy, and massage), and "body" therapies (herbal medicines, nutritional supplements, naturopathic, chiropractic, diet, acupuncture, immune therapy), it seems prudent to at least examine CAM use in these categories.

Specifically, more than a single aspect of control can be hypothesized to influence CAM use, and may do so in a differential fashion dependent upon the type of CAM used.

The purpose of this study was to determine whether the control constructs of the theory of cognitive adaptation would predict sub-categories of CAM use among women diagnosed with breast cancer. A second purpose was to explore the role of religious control as a predictor of CAM use. Even though religious control was not germane to the theory, it was retained as a variable of interest as part of the CLOC scale (Watson et al., 1990), which was used in this study to measure control over the cause and course of cancer.

### Methods

#### Sample

Six health care plans in the Portland, Oregon metropolitan area provided the names, addresses and phone numbers of women diagnosed with breast cancer between January 1, 1996 and December 31, 1997. Together these organizations

treated over 75% of all breast cancer patients in this region. The sampling procedure used disproportional stratified sampling to ensure each health plan was sufficiently represented; that is, sampling fractions were larger for the health plans with fewer breast cancer patients.

Interviewers called the phone numbers of all 1362 women in the sample, resulting in 605 persons declared ineligible for the study because of a disconnected/wrong phone number (351), unavailability (i.e., no answer, not home, phone blocking) (157), deceased (48), hearing problems (41), or language barrier (8). Among the remaining 757 eligible participants, 588 agreed to be interviewed, for a 78% response rate.

# Procedure for Data Collection

The questionnaire and the data collection protocol was approved by the institutional review board at Oregon State University. Each potential participant received a letter by mail explaining the nature and purpose of the project prior to contact for the telephone interview. The questionnaire was pre-tested, revised, and programmed for computer-assisted telephone interviewing (CATI) by a survey organization in Oregon. The interviews were conducted during July and August 2000. New and changed phone numbers were called when available unless the new number was outside the Portland metropolitan area. Telephone numbers were called up to ten times to obtain an interview. The average length of the total interview was 23.4 minutes.

# **Independent Variables**

Demographic variables in this study were coded as dummy variables and included age (50 years and under; 51 years and over), education (high school graduate or less; some college or more), and insurance (private health insurance; other health insurance). It was important to include these variables because a previous study with this data (see Article 1 in this chapter) showed age, education, and insurance to be significantly associated with CAM use.

Three independent variables of interest were (1) Control over the Course of the Cancer, (2) Control over the Cause of the Cancer, and (3) Religious Control. Participants' cancer control beliefs were assessed by a modified version of the Cancer Locus of Control scale (Watson et al., 1990). The Cancer Locus of Control scale is a relatively new area-specific measure of perceptions of control over cancer, developed for prediction of health-related behavior in cancer patients. Of all the cancer control scales reviewed for potential use in this study, Watson et al's Cancer Locus of Control scale most closely aligned with Taylor's (1983) theory of cognitive adaptation, where perceptions of control over the course and cause of the disease included both internal and external control items. Even though religious control was not germane to the theory, it was retained as a variable of interest as part of the Cancer Locus of Control scale.

The modified Cancer Locus of Control scale used in this study consisted of 14 items, each with a 5-point response scale ranging from "strongly disagree" to "strongly agree." Six items measured the subscale, "control over the course of

cancer," five items measured the subscale, "control over the cause of cancer," and three items measured "religious control." Some responses were reverse-coded so that higher scores indicated increased perceived control. For each woman, item responses were totaled to create a score in each subscale. Each score was dichotomized into no/low control or medium/high control because of the low prevalence of no/low control perceptions, to allow ease in interpretation, and to avoid cells with a small number of cases in the multivariate analysis.

Construct validity as well as internal consistency reliabilities of the Cancer Locus of Control scale were examined in a previous report (Article 2).

Confirmatory factor analysis supported the three-factor model (control over the cause of cancer, control over the course of cancer, and religious control) of the Cancer Locus of Control scale. The internal consistency (coefficient alpha) was reported at .77 for the control over course subscale, .71 for the control over cause subscale, and .75 for the religious control subscale. The three control subscales, sample items from each subscale, and reliability coefficients from the present study sample are shown in Table 11.

Table 11. Sample Items and Reliability of Cancer Locus of Control Subscales Used in a Study of Women Diagnosed with Breast Cancer

Subscale/	Reliability*
Sample Item	
Control over Course of Cancer	.77
"I can influence the course of the cancer by fighting against it."	
"My doctor can definitely influence the course of the cancer."	
Control over Cause of Cancer	.71
"Getting cancer was especially due to something about me."	
"Getting cancer had something to do with my personality."	
Religious Control	.75
"God can definitely influence the course of the cancer."	
"Whether or not I remain free from cancer is in God's hands."	

# Dependent Variable

The categorical dependent variable in this study was type of complementary and alternative medicine used. Based on individual responses to the use/nonuse of 15 CAM therapies, participants were categorized into one of four groups: (1) those who did not use any CAM therapies; (2) those who used one or more physical CAM therapies; (3) those who used one or more psychological CAM therapies; and, (4) those who used both physical and psychological CAM therapies.

Following the lead of Burstein, Gelber, Guadagnoli, and Weeks (1999), this study defined physical CAM therapies as "therapies requiring physical action on or exposure of the body" (vitamins, herbs, massage, chiropractic, diet, acupuncture, immune therapy, energy healing, and naturopathy); and psychological CAM

therapies as those "involving primarily mental processes" (relaxation, meditation, imagery, support/self-help groups, spiritual healing, biofeedback, and hypnosis).

# Procedure for Data Analysis

Analyses were conducted on 551 responses from participants who completed the telephone survey in its entirety. First, interview data were inspected for accuracy of data input, distribution, and missing values. Inconsistencies were checked and corrected. Missing data among demographic and CAM use variables was low, ranging from none to two percent, with the exception of the household income variable (14.5 percent missing). No missing data patterns were identified. Missing values were replaced through the Expectation-Maximization algorithm procedure and subsequent analyses used the data set with the imputed values.

Correlational analysis among the potential predictor variables found no correlations higher than -.26 (age and education), so redundancy or extremely high correlations were not limitations in this study. There were no exceedingly high standard errors for parameter estimates. Therefore, no multicollinearity was evident.

Further evaluation of limitations for logistic regression with multiple outcomes includes adequacy of expected frequencies and outliers in the solution, that is, if the fit is inadequate (Tabachnick & Fidell, 2001). In this case, since the data had adequate model fits, there was no need to search for outliers in the solution. Also, an evaluation of adequacy of expected frequencies did not identify any potential limitations.

Next, the data were analyzed using bivariate correlation and multinomial logistic regression. Correlation coefficients were calculated to examine associations between the cancer locus of control variables, the demographic variables, and each of the 15 CAM therapies.

Multinomial logistic regression was used to determine which variables were important in predicting each of four CAM use behaviors. Multinomial logistic regression was deemed appropriate because it is an extension of logistic regression and is used when a dependent variable has more than two categories, while estimating the log odds of three or more contrasts simultaneously. As previously explained, in this study the dependent variable had four CAM use patterns. Adjusted odds ratios, *p*-values, 95% confidence intervals and goodness-of-fit statistics were computed. SPSS Base 10.0 (for Windows, SPSS Inc., Chicago, IL) was used to perform all analyses. All P value tests were 2-sided.

#### Results

### Sample

The study sample consisted of females who had been diagnosed with breast cancer an average of 3.5 years prior to the interview. The mean age of the women at the time of the interview was 64 years (SD = 11.68) with a range of 31 to 91 years. Most study participants were white, directly reflecting the racial mix of the Portland, Oregon, region. Seventy one percent were married or in a significant relationship. Fifty-eight percent of the women had education beyond a high school degree. Mean household annual income level was \$35,000 to \$49,000.

The great majority of women in the sample (93%) had medium-to-high control perceptions over the course of the cancer. Only seven percent of the sample had no or low control perceptions over the course of the cancer. Similarly, the majority of women had medium/high control perceptions over the cause of the cancer (68%) and also felt religious control over the cancer (65%).

### Correlates of Cancer Locus of Control Variables

Pearson product-moment correlation coefficients are shown in Table 12.

The results show that perception of control over the course of the cancer and perception of control over the cause of the cancer were more strongly related to CAM use than perception of religious control. Out of the 15 CAM therapies, 12 were significantly correlated to control over the cause of the cancer and six CAM therapies were significantly correlated to control over the course of the cancer.

Only one CAM therapy--spiritual healing--was related to religious control.

Relationships between the control variables and CAM therapies ranged from .01 to .17 for Course, and from .03 to .24 for Cause. These significant positive correlations suggested that an increase in the Cause and Course control variables were associated with an increase in CAM behaviors.

Table 12. Correlations of Hypothesized Predictors with 15 CAM Behaviors

<del></del>	1	2	3	4	5	6	7	8.	9	10		4.5									
1. Control over course	1.00								<u> </u>		11	12	13	-14	15	16	17	18	19	20	21
2. Control over cause	.13**	1.00																			
3. Religious control	.08	.02	1.00																		
4. Age	17**	15**	01	1.00																	
5. Education	.15**	.09*	06	26**	1.00																
6. Insurance	.06	.12**	.00	·.16**	.15**	1.00															
7. Relaxation/medication	.13**	.24**	03	.24**	.22**	.10*	1.00														
8. Spiritual healing	.10*	.15**	.14**	18**	.13**	.07	.33**	1.00													
9. Massage	.13**	.18**	02	26*	.13**	.19**	.27**	.15**													
10. Imagery	.07	.22**	05	22**	.19**	.11**	.47**	.26**	1.00												
11. Support/self-help group	.09+	.15**	.01	12**	.09*	.07	.26**	.16**	.15**	1.00											
12. Hypnotherapy	.03	.06	.03	.02	08	05	.07		.19**	.23**	1.00										
13. Energy healing	.04	.12**	.02	06	.04	.04	.20**	.03 .18**	.00	.07	.02	1.00				٠					
14. Herbai medicine	.17**	.17*	02	12**	.13**	.04	.21**		.16**	.17**	.18**	.12**	1.00								
15. Megavitamins	.12**	.09*	02	08	.21**	.00	.22**	.16**	.23**	.12**	.07	01	.09*	1.00							
16. Naturopathic	.07	.18**	04	12**	.10*	.09+		.16**	.24**	.15**	.11**	.04	.05	.37**	1.00						
17. Chiropractic	.09*	.03	.01				.27**	.19**	.19**	.18**	.12**	.02	.14**	.32**	.20**	1.00					
•				04	.02	.08	.17*	.06	.30**	.11**	.06	.02	.10*	.18**	.13**	.16**	1.00				
18. Diet	.06	.14**	05	15**	.15**	.14**	.24**	.12**	.11*	.21**	.13**	03	.14**	.19**	.21**	.25**	.03	1.00			
19. Acupuncture	.06	.14**	07	10 <b>•</b>	.06	.01	.14**	.10*	.28**	.08•	.04	02	.15**	.25**	.27**	.29**	.14**	.0Å	1.00		
20. Immune therapy	.01	.03	07	04	.04	04	.10*	•01.	.11**	.15**	.06	.15**	.02	.10*	.16**	.12**	.10	.0x .07		1.00	
21. Biofeedback	.04	.11**	07	01	.03	.02	.18**	.04	.04	.15**	.03	01	.07	.07	.08*	.11**	.10	.07	.25** .03	.09*	1.00

p < .05; p < .01 (2-tailed)

### Multivariate Analysis

This phase of the analysis used multinomial logistic regression to simultaneously evaluate potential predictors of three CAM use patterns (use of physical CAM therapies, use of psychological CAM therapies, and use of both physical and psychological CAM therapies) with "no CAM use" as the reference category. As a final result, of the 551 women in the study, 80 (15%) had used physical CAM therapies only, 97 (18%) had used psychological CAM therapies only, 186 (34%) had used both biological and psychological CAM therapies, and 188 (34%) had used no CAM therapies in the past 12 months.

Table 13 contains a summary of the final model, with odds ratios (ORs), p-values, and 95% confidence intervals (CI) for each predictor variable. The religious control variable was eliminated in the final model because it had no significance as an individual effect (likelihood ratio test, p > .05).

Table 13. The Relationship between Control and Sociodemographic Variables and CAM Use Behaviors

			<u>M use (11 = 80)</u> Group: No CAM use)			M use only (n = 97)  Group: No CAM use)	Both Phys & Psych CAM use  (Reference Group: No CAM use)				
Variable*	OR	P	95% CI	OR	Р	95% CI	OR	P	95% CI		
Control Course Control Cause Education Age Insurance	7.21 1.20 1.62 1.06 1.89	.008 .564 .090 .869	1.66-31.30 .64- 2.25 .93- 2.81 .52- 2.18 .95- 3.76	4.44 1.53 1.67 .50 2.57	.018 .146 .059 .028	1.29-15.30 .86- 2.73 .98- 2.87 .2793	9.76 2.62 2.78 .47 2.23	.002 .000 .000 .005	2.25-41.34 1.60- 4.28 1.73- 4.48 .2779 1.26- 3.94		

<sup>\*</sup>Effects of individual variables are assessed controlling for other variables in the model.

The first set of columns of Table 13 compared the Physical CAM use group to the CAM nonusers (reference category). The results indicated that women who chose to use one or more physical CAM therapies had significantly higher control perceptions over the course of the cancer (odds ratio = 7.21, 95% CI = 1.66-31.30). That is, the odds ratio of 7.21 indicated that the likelihood of choosing a physical CAM therapy as compared to no CAM therapy increased by a factor of 7.21 for each unit increase in control over the course of the cancer.

The second set of columns of Table 13 compared the psychological CAM use group to the CAM nonusers. Compared to women who chose not to use any CAM

therapies, women who chose one or more psychological CAM therapies were significantly younger (odds ratio = .50, 95% CI = .27 - .93), more likely to have private health insurance (odds ratio = 2.57, 95% CI = 1.37 - 4.82), and also had higher control perceptions over the course of the cancer (odds ratio = 4.44, 95% CI = 1.29 - 15.30).

The third set of columns of Table 13 compared the physical and psychological (both) CAM users group to the CAM nonusers group. Compared to women who did not use any CAM therapies, those women who chose to use both physical and psychological CAM therapies were significantly younger (odds ratio = .47, 95% CI = .27 - .79), more likely to have a higher education (odds ratio = 2.78, 95% CI = 1.73 - 4.48), and more likely to have private health insurance (odds ratio = 2.23, 95% CI = 1.26 - 3.94). The women were also 2.6 times as likely to have higher control perceptions over the cause of the cancer (odds ratio = 2.62, 95% CI = 1.60 - 4.28), and almost 10 times more likely to have higher control perceptions over the cause of the cancer (odds ratio = 2.62, 95% CI = 1.60 - 4.28), and almost 10 times more likely to have higher control

Table 13 illustrates that control over the course of the cancer was the only variable that predicted CAM use behavior in all three categories. The effect was strongest for women who used both physical and psychological CAM therapies. Perceptions of control over the cause of the cancer was predictive in one category—the use of both physical and psychological CAM therapies.

The overall fit of the final model was tested by a chi-square statistic,  $\chi^2$  (df = 15) = 121.35, p < .001, indicating a good model fit with the set of five predictors

(control over course, control over cause, age, education, and insurance) and CAM decision group membership. Also, goodness-of-fit with all predictors in the model was assessed by use of the Deviance chi-square test  $\chi^2$  (df = 48) = 35.26, p = .914, and the Pearson chi-square test  $\chi^2$  (df = 48) = 35.55, p = .908, indicating good fit (by these test criterion, if p > .05, then we fail to reject the null hypothesis that there is a difference between the observed and expected frequencies). These results mean that the full model with all four predictors, as a set, reliably distinguish between women who use no CAM therapies and those who use the three different categories of CAM.

To determine if the two cancer locus of control variables significantly contributed to the goodness-of-fit of the model after prediction by the demographic variables (education, age, insurance), log-likelihood ratios for models with and without the demographic variables were compared. Applying the equation recommended by Tabachnick & Fidell (2001), the models with and without the cancer locus of control predictors were  $\chi^2 = 121.35 - 75.73 = 45.62$  with df = 6, p < .05, indicating that the addition of the two perceptions of control variables (control over the course of the cancer and control over the cause of the cancer) significantly improved the model.

The final model with all five predictors (control over cause, control over course, age, education, and insurance) accounted for 23 percent of the explained variance (Nagelkerke's pseudo R-square), an improvement over the Nagelkerke's pseudo R-square of .14 with the model containing only the demographic predictor

variables. However, the result is not easily interpretable since the variance of a categorical dependent variable depends on the frequency distribution of that variable (Hosmer & Lemeshow, 1989). The lopsided split in the categories (15%, 18%, 34%) most likely resulted in a lower variance; therefore the  $R^2 = .23$  result may be underestimated. Nonetheless, it is clear that perceptions of control over the cause and the course of cancer had an independent significant influence on CAM use in this population.

#### Discussion

Findings from this study are supportive of the theory of cognitive adaptation (Taylor, 1983), in that specific control perceptions (control over the cause of the cancer and control over the course of the cancer) predicted certain health-related behaviors of women diagnosed with breast cancer. The women's perception of control over the course of the cancer was the most important predictor for three categories of CAM use behavior—physical therapies, psychological therapies, and both physical and psychological CAM therapies. Another noteworthy result was that the perceptions of control over the course and cause of the cancer explained more of the variation in predicting CAM use than demographic variables alone (age, education, and insurance.)

Perceived religious control over cancer was significantly related to the use of spiritual healing, but was not a predictor of CAM use in any of the three categories in the regression model. These findings are consistent with the findings by others

in that religious control over cancer has been associated with the use of prayer and spiritual healing but not other health-related behaviors (Pruyen et al, 1988; Watson et al., 1990). In these studies, religious control was also associated with a fatalistic attitude, which may deter one from taking action to be "in control." It may be that the religious control construct is more applicable to primary prevention behaviors than behaviors to prevent recurrence. Another explanation may be that "religion" and "religious control" have great differences in meaning and outcome among individuals, especially in the context of a cancer diagnosis. For example, "belonging to a church" was found to be associated with CAM use among black women diagnosed with breast cancer, but not among Chinese, Latino, or white women diagnosed with breast cancer (Lee, Lin, Wrensch, Adler & Eisenberg, 2000). Of course, belonging to a church is a different variable than religious control, but it illustrates that it may not be feasible to make sweeping generalizations about religious control and CAM use. However, the data presented here are too preliminary for such a conclusion.

While offering the advantages of presenting data related to theoretical cancer control constructs of interest, this study was limited in three ways. First, the study sample was composed primarily of white women, which reflects the racial composition of Portland, Oregon, but limits the generalizability of the findings. Second, data was not available for stage of disease or for cancer treatment. It may be that these two variables would have an effect on CAM use behavior and/or cancer control perceptions. Previous research found that women with late-stage

breast cancer were more likely to use CAM (Lee et al., 2000). However, other studies among women diagnosed with breast cancer did not find that CAM use varied by stage of disease (Gotay, Hara, Issel & Maskarinec, 1999) or by cancer treatment (Burstein et al., 1999; Boon et al, 2000).

The third limitation is the study's cross-sectional nature. Because the data was collected at one point in time, the direction of prediction is problematic. That is, the women's cancer control perceptions could have predicted CAM use behavior, or could have resulted from CAM use behavior. A true test of direction would make use of a longitudinal design where control perceptions and health-related behaviors were measured before and after a cancer diagnosis; unfortunately this was beyond the scope of this study.

Nonetheless, this study provides new and unique results. No previous studies have related cancer control perceptions to actual participation in CAM use. This study also offers results that are consistent with theoretical assumptions (Taylor, 1983).

# **Theoretical Implications**

The assessment of control constructs from the theory of cognitive adjustment (Taylor, 1983) appears to be useful for studying health-related behaviors such as CAM use among women diagnosed with breast cancer. The two control constructs, as measured by a modified Cancer Locus of Control scale (Watson et al, 1990), integrated internal and external control perceptions into

constructs of (1) control over the course of the cancer and (2) control over the cause of the cancer. The findings in this study are in agreement with Taylor's suggestions that most individuals diagnosed with cancer have optimistic cancer control perceptions; and those individuals also self-select behaviors that they perceive will promote remaining cancer-free. For example, the prevalence of cancer control perceptions were high among the women in this study—ninety-three percent had medium to high control perceptions over the course of the cancer, and sixty-eight percent of the women had medium to high perceptions of control over the cause of the cancer. The control constructs' predictive influence varied with type of CAM use. Overall, however, higher levels of control perceptions over the cause and the course of cancer were significant and independent predictors of CAM use.

Thus, perceptions of cancer control in the context of the theory of cognitive adaptation provide some insight into CAM use behaviors beyond demographic factors such as age and education. Indeed, until further evidence is available to describe the most influential psychological cognitions related to CAM use, cancer locus of control may be the most promising to address. In practice, knowing an individual's cancer control perceptions may provide a context for understanding CAM use. Future research focusing on perceived cancer control and CAM use in different study populations, and clinical and quality of life outcomes would provide a more complete picture to patients, policymakers, and health care providers.

### **Clinical Implications**

Two-thirds of the women in this study used at least one CAM therapy and were in one of three categories: (1) use of physical CAM therapies, (2) use of psychological CAM therapies, and, (3) use of both physical and psychological CAM therapies. There were demographic and perceived control variations across the three patterns of CAM use. For example, only perceived control over the course of cancer was a predictor to the use of physical CAM therapies; while perceived control over the course of cancer and control over the cause of cancer, and age, education, and type of insurance all predicted the use of both physical and psychological CAM therapies. These differences make clear the heterogeneity among women diagnosed with breast cancer and shows that CAM use is not a one-dimensional (use/nonuse) behavior.

CAM use is common among women diagnosed with breast cancer and represents multifaceted behaviors that are influenced by control perceptions. Whether or not being "in control" through the use of CAM has positive clinical outcomes remains an important topic for future research. In the meantime, CAM use reflects what women diagnosed with breast cancer are "thinking and doing when not in the doctor's office" (Burstein, 2000). Understanding women's CAM use and the meanings that lie behind these behaviors is essential for health care providers who are promoting the health and well-being of those diagnosed with breast cancer.

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### **CONCLUSION**

The findings of this study contribute to the psycho-oncology and health behavior literature by examining CAM use in conjunction with demographic and control variables in a sample of women diagnosed with breast cancer from a single geographic area. In general, the data from this study support the five hypotheses. Following is a brief discussion of each hypothesis.

Hypothesis #1: As suggested by previous research, sociodemographic variables (age, income, education level, marital status, patient satisfaction, patient-doctor trust, doctor listens, exercise, and insurance status) are predictive of CAM use among women diagnosed with breast cancer. Partial support was found in that age, education level, and insurance status were the variables found to be significant predictors of CAM use among women in this study. Income, marital status, and use of exercise were significantly correlated with CAM use, but were not significant predictors in the logistic regression model. Patient satisfaction, patient-doctor trust, and doctor listens were not correlated with CAM use, indicating that CAM users are not necessarily unhappy with the conventional medical system.

Hypothesis #2: Control beliefs, as measured by the Cancer Locus of

Control Scale (control over the cause of cancer, control over the course of cancer,
and religious control over cancer) are conceptually distinct constructs that will
show evidence of discriminant validity. Evidence to support this hypothesis was
found through the use of confirmatory factor analysis on a refined version of the

Cancer Locus of Control scale. Results supported the use of the refined Cancer Locus of Control scale as a valid method of assessing three distinct dimensions of control perceptions among women diagnosed with breast cancer.

Hypothesis #3: As suggested by the theory of cognitive adaptation, women with higher perceptions of control over the cause of the cancer and over the course of the cancer will be more likely to display CAM use as behaviors to influence the disease. The findings in this study support the theory of cognitive adaptation in that higher levels of control perceptions over the cause and the course of cancer were significant and independent predictors of the use of both physical and psychological CAM therapies. Women with higher perceptions of control over the course of the cancer were also more likely to use only physical CAM therapies or only psychological therapies, as compared to women who did not use CAM.

Hypothesis #4: Perceptions of religious control over cancer will have no or limited influence on CAM use by women diagnosed with breast cancer. Consistent with the hypothesis, religious control over cancer was not a significant predictor of CAM use in the multinomial regression model. However, the religious control variable was significantly correlated to one CAM therapy—spiritual healing.

Hypothesis #5: The two control variables, control over the cause of cancer and control over the course of cancer, will explain more of the variation in predicting CAM use than the sociodemographic variables alone. Support for this hypothesis was found. Specifically, the model containing only the sociodemographic predictors explained 14 percent of the variation; the addition of

both forms of cancer control raised the explained variance to 23 percent. Thus, perceptions of cancer control in the context of the theory of cognitive adaptation provide some insight into CAM use behaviors beyond demographic factors such as age, education, and insurance status.

At the very least, the above findings suggest that health care professionals should be aware of the prevalence of CAM use among women diagnosed with breast cancer, and should be sensitive to issues of control. Obviously, given the substantial number of women currently using CAM treatments and therapies—without valid data on their effectiveness—there is an urgent need for randomized clinical trials and outcome studies that provide a scientific basis for their efficacy and safety.

There are several more directions in which the research should continue. With the general foundation of predictors of CAM use provided by this study, models could be developed that include additional factors to offer a more comprehensive conceptualization of CAM use. For example, in the present study, the number one reason women use CAM is to enhance the overall quality of life. Another recent study among women diagnosed with breast cancer found that sense of control was significantly related to greater quality of life (Shapiro et al., 2001). Hence, quality of life measures are likely to tap into person-centered, broader dimensions of CAM use among women diagnosed with breast cancer.

A model is offered (Figure 3) as a way of exploring CAM use in greater depth, and for conceptualizing and testing the hypothesis that perceptions of control

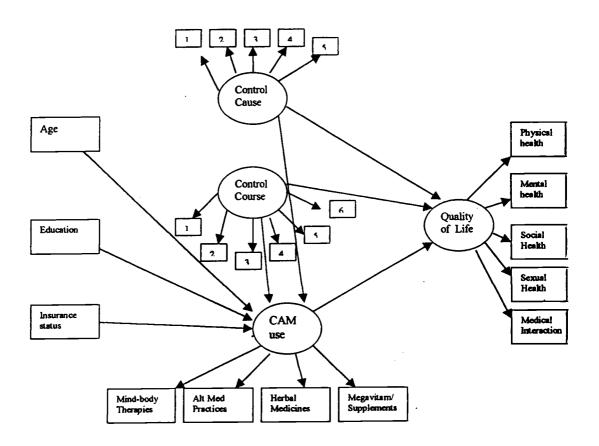


Figure 3. Hypothesized model of CAM use, control, and quality of life

and CAM use are related to achieving optimal quality of life. The model is amenable to statistical analysis such as structural equation modeling. Specifically, the model allows for direct and indirect relationships to be examined between sociodemographic variables, sense of control, CAM use, and quality of life. The model is an attempt to account for both CAM use and quality of life using the theoretical control concepts from the theory of cognitive adaptation, and also draws on the findings of the current study. This model has the potential to confirm that quality of life benefits accrue from CAM use and cancer-related sense of control.

In summary, the findings from this study suggest that the majority of women diagnosed with breast cancer use one or more CAM therapies, and perceptions of control over cancer play a role in the decision for CAM use. Part of the popularity of CAM use among women diagnosed with breast cancer may be the fulfillment of mental and physical health needs beyond surgery, radiation, and chemotherapy. This implies that providing reliable information about CAM therapies, and recognizing and enabling a sense of control are salient interventions for patient-centered, comprehensive care for women diagnosed with breast cancer.

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# **APPENDIX**

### **CAM USE SURVEY**

Now I'd like to ask you about things you may do on your own. I will ask you if you have every used any of the 18 therapies or practices in the past year.

Q 83. In the past 12 months, have you used relaxation or meditation techniques?

Yes

No

Don't know/not sure

Q83A Did your medical doctor recommend that you use relaxation or meditation?

Yes

No

Don't know/not sure

Q83B How important is meditation or relaxation in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 84. In the past 12 months, have you used a chiropractor?

Yes

No

Don't know/not sure

Q84A Did your medical doctor recommend that you use a chiropractor?

Yes

No

Don't know/not sure

Q84B How important is chiropractic medicine in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 85. In the past 12 months, have you used massage or manipulative therapy?

Yes

No

Don't know/not sure

Q85A Did your medical doctor recommend that you use massage or manipulative therapy?

Yes

No

Don't know/not sure

Q85B How important is massage or manipulative therapy in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 86. In the past 12 months, have you used imagery?

Yes

No

Don't know/not sure

Q86A Did your medical doctor recommend that you use imagery?

Yes

No

Don't know/not sure

Q86B How important is imagery in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 87. In the past 12 months, have you used spiritual healing?

Yes

No

Q87A Did your medical doctor recommend that you use spiritual healing?

Yes

No

Don't know/not sure

Q87B How important is spiritual healing in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 88. In the past 12 months, have you used naturopathic medicine?

Yes

No

Don't know/not sure

Q88A Did your medical doctor recommend that you use naturopathic medicine?

Yes

No

Don't know/not sure

Q88B How important is naturopathic medicine in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 89. In the past 12 months, have you used lifestyle diet modifications?

Yes

No

Don't know/not sure

Q89A Did your medical doctor recommend that you use lifestyle diet modifications?

Yes

No

Q 89B What type of diet modification have you use?

Q89C How important is diet modification in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 90. In the past 12 months, have you used herbal medicines?

Yes

No

Don't know/not sure

Q90A Did your medical doctor recommend that you use herbal medicines?

Yes

No

Don't know/not sure

Q90B What types of herbal medicines do you use?

Q90C How important is herbal medicine in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 91. In the past 12 months, have you used megavitamin or nutrient therapy, other than daily vitamins?

Yes

No

Don't know/not sure

Q91A Did your medical doctor recommend that you use megavitamins or nutrient therapy?

Yes

No

Don't know/not sure

Q91B What types of vitamins or nutrient therapy have you used?

Q91C How important are vitamins or nutrient therapy in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 92. In the past 12 months, have you used support or self-help groups?

Yes

No

Don't know/not sure

Q92A Did your medical doctor recommend that you use a support or self-help group?

Yes

No

Don't know/not sure

Q92B How important is a support group or self-help group in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 93. In the past 12 months, have you used energy healing?

Yes

No

Don't know/not sure

Q93A Did your medical doctor recommend that you use energy healing?

Yes

No

Don't know/not sure

Q93B How important is energy healing in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 94. In the past 12 months, have you used biofeedback?

Yes

No

Don't know/not sure

Q94A Did your medical doctor recommend that you use biofeedback?

Yes

No

Don't know/not sure

Q94B How important is biofeedback in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 95. In the past 12 months, have you used hypnosis or hypnotherapy?

Yes

No

Don't know/not sure

Q95A Did your medical doctor recommend that you use hypnotherapy?

Yes

No

Don't know/not sure

Q95B How important is hypnotherapy in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 96. In the past 12 months, have you used acupuncture or acupressure?

Yes

No

Q96A Did your medical doctor recommend that you use acupuncture or acupressure?

Yes

No

Don't know/not sure

Q96B How important is acupuncture or acupressure in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 97. In the past 12 months, have you used pharmacological or immune therapy?

Yes

No

Don't know/not sure

Q97A Did your medical doctor recommend that you use pharmacological or immune therapy?

Yes

No

Don't know/not sure

Q97B What types of pharmacological or immune therapy did you use?

Q97C How important is pharmacological or immune therapy in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 98. In the past 12 months, have you used exercise?

Yes

No

Don't know/not sure

Q98A Did your medical doctor recommend that you use exercise?

Yes

No

Q 98B What types of exercise?

Q 98C How important is exercise in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

Q 99. In the past 12 months, have you used prayer?

Yes

No

Don't know/not sure

Q99A Did your medical doctor recommend that you use prayer?

Yes

No

Don't know/not sure

Q99B How important is prayer in determining whether you remain free from cancer in the future? Is it...

Not important

A little important

Moderately important

Quite important

Or extremely important

O 100. In the past 12 months, have you used any other treatments or practices?

Yes

No

Don't know/not sure

Q100A What type of treatment or practice have you used?

Q100B Did your medical doctor recommend that you use this?

Yes

No

Q100C How important is this in determining whether you remain free from cancer in the future? Is it...

Not important A little important Moderately important Quite important Or extremely important