BELIEFS AND TREATMENT PRACTICES OF WOMEN WITH BREAST CANCER USING ALTERNATIVE/COMPLEMENTARY THERAPIES

by

Lynda Georgie Balneaves

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BY

LYNDA GEORGIE BALNEAVES

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF NURSING

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DEDICATION

To all the women who participated in this study who took me along the journey they have travelled since being diagnosed with breast cancer. Thank you for sharing your joys, hopes and sorrows with me.

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ABSTRACT

The purpose of this study was twofold; methodological and descriptive. First, the study tested the appropriateness, reliability and validity of a questionnaire, the Beliefs and Treatment Practices Survey - Breast Cancer (BTPS-BC), which explored the beliefs and alternative/complementary treatment practices of women with breast cancer. Second, the beliefs, alternative/complementary treatment practices, preferred treatment decision making role and quality of life of a sample of women with breast cancer were examined. Descriptive data was used to generate hypotheses about potential relationships between study variables and the use of alternative/complementary therapies (ACTs) by women with breast cancer.

A convenience sample of 52 women with breast cancer from three outpatient oncology units completed four questionnaires, the Beliefs and Treatment Practice Survey - Breast Cancer (BTPS-BC), the EORTC QLQ-C30 (version 2), Degner and Sloan's (1992) Decisional Preference Card-Sort and a demographic form. The sample was divided into two groups, women using only conventional medical therapies and women using both conventional and alternative/complementary therapies. The two sub-samples were compared in terms of beliefs about cause of cancer, beliefs about medical and alternative/complementary therapies, satisfaction with health care providers, encouragement to use alternative/complementary therapies, will to live, preferred treatment decision-making role, and quality of life. Demographic data for each group of women were also compared.

Findings revealed that 67.3 percent of the women were using some form of alternative/ complementary therapy. The three most popular therapies were meditation/relaxation therapies (63.5%), vitamins/tonics (57.7%), and spiritual/faith healing (53.8%). An association was found between the use of alternative/complementary therapies and education level (Chi-square = 7.1, p = .008), with 68.6 percent of women with breast cancer using ACTs having completed post-secondary education. A relationship between prefered treatment decisional role and alternative/complementary therapy use was also apparent (Chi-square = 11.7, p = .003). Women using alternative/ complementary therapies were found to prefer a more active or collaborative role in treatment decisions (94.3%) than women who used only conventional medical treatment. No significant relationships were found between the use of ACTs and beliefs about cause of cancer, treatments, satisfaction with health care providers, will to live and quality of life.

This study has implications for future patient and health care professional education strategies related to alternative/complementary therapies. As well, the findings will have direct impact on future intervention studies exploring the efficacy and impact of alternative/complementary therapies by highlighting selected variables which may influence outcome measures.

CHAPTER ONE

STATEMENT OF THE PROBLEM

The diagnosis and treatment of breast cancer has been reported by women to be a traumatic and stress-ladened event (Feather & Wainstock, 1989a; Northouse, Cracchiolo-Caraway, Appel, 1991; Royak-Schaler, 1991). Breast cancer has traditionally been treated using conventional medical therapies such as surgery, chemotherapy, radiotherapy, and hormone therapy. For some women diagnosed with breast cancer, conventional medical cancer treatments may be the only treatment options they choose. However, a survey by the Support, Advocacy and Networking (SAN) Subcommittee at the National Breast Cancer Forum in Montreal, Canada in 1993 revealed that alternative/complementary therapies (ACTs) are being used by some women in conjunction with conventional medical therapies. In some instances, women with breast cancer may elect to use ACTs only. Exact documentation of the number of women with breast cancer who use ACTs either alone or in conjunction with conventional treatment does not exist. As well, information about the underlying motivations and beliefs held by women with breast cancer who use ACTs is absent from the literature. There is a paucity of studies examining the effect of ACTs on quality of life and clinical outcomes of individuals with breast cancer. Without this knowledge regarding the types of ACTs being used by women with breast cancer in Canada, health care professionals are faced with an unknown treatment entity which may impact directly or indirectly on conventional treatments and clinical outcomes. As well, development of knowledge in this area will improve communication between health care professionals and women who choose to explore treatment options beyond the traditional medical model. By understanding the rationale held by women using ACTs, health care professionals can provide more empathetic and appropriate counselling regarding the use of ACTs in conjunction with conventional treatments or alone. Furthermore, preliminary studies of ACT use in general cancer populations suggest ACTs may have a positive effect on quality of life (Bagenal, Easton, Harris, Chilvers, & McElwain, 1990; Cunningham & Tocco, 1989; Spiegel, Bloom, Kraemer & Gottheil, 1989). Thus, research exploring ACT use by women with breast cancer may identify treatments that could improve the lives of these individuals.

Studies exploring the use of ACTs in general cancer populations have reported that between 9 and 81 percent of cancer patients have used treatments considered "unconventional" by the medical profession (Cassileth, Lusk, Strouse, & Bodenheimer, 1984; Lerner & Kennedy, 1992; Montbriand, 1993). However, studies specific to the incidence of ACT use by women with breast cancer have not been conducted. As well, the motivations of individuals who use ACTs have been explored extensively in general cancer populations, but not with women diagnosed with breast cancer. In Canada, Montbriand (1993) reported a relationship between ACT use in people with cancer and decision making. Individuals who preferred a more active role in treatment decisions were found to be more likely to use ACTs. Other motivations correlated with ACT use in general cancer populations include possessing alternate beliefs about treatment and causes of cancer, having a strong will to live, experiencing an unsatisfactory patient-physician relationship and being encouraged by significant others to explore ACTs (Cassileth et al., 1984; Danielson, Stewart & Lippert, 1988; McGinnis, 1991; Yates et al., 1993). A paucity of research exists, however, on the impact of ACTs on the quality of life of women with breast cancer. The majority of studies exploring ACT use in cancer populations has focused on the effect of these therapies on physiological outcomes, such as mortality, time to recurrence and tumour progression (American Cancer Society, 1993a; 1993b; Bagenal et al., 1990; Cassileth, Lusk, Guerry, Blake, Walsh, Kascius & Schultz, 1991). However, Cassileth et al. (1991) and McGinnis (1991) indicate that a majority of individuals with cancer who use ACTs do so in an attempt to improve their current physical and emotional functioning, rather than as a cure for their illness.

Past research with the breast cancer population has shown that these women comprise a cancer population with distinctive issues and concerns. Women with breast cancer have demonstrated a desire to participate in care decisions, shown most publicly through the development of lobbying and funding groups such as the Canadian Breast Cancer Initiative. As well, women with breast cancer are unique as a cancer population because of the significant impact treatment has on body image and sexuality (Fallowfield & Clark, 1991; Feather & Wainstock, 1989b). Women with breast cancer may choose ACTs as a means to regain control of care decisions and develop a "sense of self" that may have been lost during invasive conventional treatment (Frank-Stromborg & Wright, 1984; Hailey, Lavine & Hogan, 1988; Montbriand, 1993). Thus, the congruency between the concerns held by women with breast cancer and the suggested motivations associated with the use of ACTs by individuals with cancer supports the study of ACT use in this cancer population.

Therefore, the purpose of this study was to first examine the methodological issues related to the use of a questionnaire, entitled the Beliefs and Treatment

Practices Survey - Breast Cancer (BTPS-BC) (Appendix A). The BTPS-BC was developed from a questionnaire originated by Yates (1991), which explored the beliefs and treatment practices of a general cancer population. Phase I of the study explored the appropriateness, reliability, and validity of the BTPS-BC with a sample of women diagnosed with breast cancer. Secondly, the study examined the actual beliefs and treatment practices of women diagnosed with breast cancer who use ACTs. More specifically, the study described the types of ACTs used by women with breast cancer and the factors associated with the use of ACTs, including beliefs about treatment and causes of cancer, satisfaction with the patient-physician relationship, encouragement by others, the desire for increased decisional control, and the women's perceptions of their quality of life.

Background Information

Conventional Treatment of Breast Cancer

Approximately 17,700 new cases of breast cancer are diagnosed each year in Canada, with approximately 730 women being diagnosed in Manitoba (Statistics Canada, 1995). Diagnosis is typically preceded by an abnormal breast examination, mammogram and needle biopsy. Treatment, depending on the staging and classification of the breast cancer, may include surgery (mastectomy or lumpectomy), chemotherapy, radiotherapy, and/or hormone therapy. These treatments, despite their anti-neoplastic properties, pose a significant threat physiologically and emotionally to women with breast cancer. In many cases, the discovery of a breast lump, diagnosis of breast cancer, surgery and the start of adjuvant treatment may all occur within the short time period of two to three weeks. Some women with breast cancer have reported feeling "rushed" and "pressured" by physicians regarding conventional treatment decisions (Hailey et al., 1988).

Between 25 and 47 percent of women with breast cancer report experiencing severe psychological distress during the cancer journey, especially during the diagnostic and terminal phase of the disease (Royak-Schaler, 1991). According to Feather and Wainstock (1989b), the loss of a breast may also negatively affect a woman's body image and sexuality, disrupting relationships with significant others. Women undergoing a mastectomy have also reported severe distress related to their surgery, resulting in impaired coping in family and personal relationships (Maguire, Tait, Brook et al., 1980). As well, the rigorous chemotherapy protocol for breast cancer, traditionally a combination of the cytotoxic drugs cyclophosphamide, methotrexate and 5-Fluorouracil (CMF), may result in severe nausea and vomiting, fatigue and hair loss. Tierney, Taylor and Closs (1992) reported women with breast cancer found tiredness to be the most difficult side-effect of anti-neoplastic therapies. Radiotherapy, usually used in conjunction with a lumpectomy, has also been associated with decreased energy, skin reactions, and fibrosis of underlying tissue. Thus, it is not surprising that women with breast cancer have reported clinically that the "cure was almost worse than the disease". In fact, the side effects of conventional medical cancer treatments can be so devastating, over half of all cancer patients may consider withdrawing from treatment (Love, Leventhal, Easterling & Nerenz, 1989).

Thus, women with breast cancer undergoing conventional medical treatments are a vulnerable and stressed population. The decision to have conventional treatment needs to be made within days following diagnosis, when women are just beginning to cope with the devastating knowledge of having breast cancer. The side effects of medical treatment also contribute to women with breast cancer's level of distress, causing some women to re-consider their treatment decisions.

Alternative/Complementary Cancer Therapies

Alternative/complementary therapies (ACTs) are those treatments which are considered to be beyond the scope of conventional medical treatments. Three major groups of ACTs exist: biological, psychological and spiritual. Biological ACTs include herbal therapies, natural health practices (e.g., homeopathy, traditional chinese medicine), diets, immune system boosters, and anti-neoplastics (Ontario Breast Cancer Information Exchange Project, 1994). To date, there has been limited scientific proof supporting the efficacy of these treatments with respect to mortality and recurrence of cancer (American Cancer Society, 1993a; 1993b; Brown, 1987; Fallowfield & Clark, 1991).

The majority of biological ACTs are based upon the belief that cancer is either caused by an imbalance of nutrients within the body, a malfunction of the body's immune system or an inadequate diet. Through interventions such as detoxification, immune boosting and nutritional supplements, cancer can be slowed or resolved. Unfortunately, many biological ACTs have been found to be harmful, and in some instances, fatal side effects have been reported (American Cancer Society, 1993a; 1993b; Lerner & Kennedy, 1992; Ontario Breast Cancer Information Exchange Project, 1994). One of the most dangerous side effects identified with biological ACTs is the delay in the initiation of conventional medical treatment (Alpha Institute, 1993). These dangers have motivated medical and governmental committees to closely examine the efficacy and safety of unconventional biological cancer therapies. However, despite the lack of empirical evidence supporting the efficacy of biological ACTs, approximately 70 percent of cancer patients using ACTs have been reported to select physical or biological ACTs (Lerner & Kennedy, 1992).

Less attention has been given by researchers to psychological ACTs such as relaxation therapies, meditation and support groups. However, Cunningham and Tocco (1989) and Spiegel et al. (1989) have reported psychological benefits in individuals with cancer who use psychological ACTs as an adjuvant to conventional medical treatment. For example, Cunningham and Tocco (1989) used a prolonged psycho-educational intervention, involving relaxation, mental imagery and goal setting which resulted in an improvement in cancer patients' self-report of depressed mood, symptoms and quality of life. However, the small sample size (N=60) and lack of randomization limits the confidence in these findings. Further research exploring the effect of psychological ACTs are needed.

The major goal of psychological ACTs is to improve the emotional well-being of individuals with cancer (Ontario Breast Cancer Information Exchange Project, 1994). This includes improved quality of life and coping abilities and facilitation of conventional treatments. However, some ACT therapists and researchers, believe psychological ACTs may have a beneficial effect on physiological outcomes. Spiegel et al. (1989) reported that women with metastatic breast cancer (N=86) who had attended group therapy sessions for one year had a significant higher survival rate than women randomized to the control group. At the ten year follow-up, Spiegel et al. (1989) found that women who had received the psychosocial intervention lived longer by approximately 18 months. However, Cassileth et al. (1991) found no significant difference in survival time between cancer patients who attended an alternative therapy centre and those who received conventional treatment. However, Cassileth et al.'s (1991) study was restricted to a non-random sample of cancer patients with end-stage disease. Thus, this study's findings could not be generalized to individuals with less advanced cancer. Despite the lack of existence evidence of the efficacy of psychological ACTs on physiological outcomes, a large percentage of cancer patients, approximately 24 to 49 percent, have been reported to use psychological ACTs (Cassileth et al., 1984; Lerner & Kennedy, 1992).

Spiritual ACTs involve the use of faith and prayer to improve physical, emotional and spiritual well-being. To many ACT therapists, faith is considered the most important component of a successful intervention, be it alternative or conventional (Siegel, 1990; Simonton, Matthews-Simonton & Creighton, 1992). In his book Love, Medicine and Miracles, Bernie Siegel (1990) writes about four faiths that are critical for surviving a serious illness: faith in oneself, faith in one's doctor, faith in one's treatment and one's spiritual faith. According to Siegel (1990), spirituality is not necessarily the connection with an organized religion, but more "the ability to find peace and happiness in an imperfect world...". However, Yates (1991) reported the distinction between spirituality and the use of faith-based ACTs and religiosity was not perceived by many individuals participating in her study of ACT use in a general cancer population.

Dossey (1993) in his book, Healing Words, reviewed numerous scientific studies which have explored the impact of spiritual/faith therapies on physiological and psychological outcomes. Dossey (1993) concluded that there is sound scientific evidence supporting the efficacy of prayer on physical outcomes. However, the lack of underlying theory explaining the mechanism of prayer has prevented the wide-spread acceptance of the benefits of spiritual ACTs in the medical and scientific community (Dossey, 1993).

Dossey also discusses the role of "prayerfulness" or the acceptance of the reality of an illness, in the healing process. The belief that cancer occurs for a reason, perhaps unforseen, helps patients transcend the pain and suffering of the disease and achieve healing without necessarily a cure (Dossey, 1993). However, Montbriand (1994) cautions that not all spiritual ACTs are helpful for cancer patients. Use of some spiritual therapies, such as psychic surgery which purports to remove tumours from the body without invasive procedures, can prevent individuals from seeking conventional medicine which could be effective. As well, spiritual ACTs, including faith healing and evangelical prayer meetings have encouraged "healed" cancer patients to donate thousands of dollars to their religious organizations. In Canada, however, Montbriand (1993) reported only approximately 8 percent of cancer patients using ACTs chose to use spiritual therapies.

Fallowfield and Clark (1991) suggested that the toxicity and overwhelming side effects of conventional cancer therapies have led many cancer patients to explore alternative/complementary treatments which appear less invasive and toxic. Montbriand (1993) also proposed that the decision to use ACTs may allow women with breast cancer an opportunity to regain control of the treatment decision process. ACTs have also been reported to help cancer patients cope physiologically and emotionally with the side effects of conventional treatment, resulting in improved quality of life (Cunningham, Lockwood & Cunningham, 1991; Spiegel et al., 1989). For advanced cancer patients, ACTs may be the only remaining treatment option and source of hope available following failure of conventional medical therapies. ACTs may also be more congruent interventions for individuals who hold alternate beliefs about cancer treatment and the cause of their cancer (Yates, 1991).

In summary, hundreds of alternative/complementary therapies exist. Despite limited empirical evidence supporting the efficacy of physical, psychological and spiritual ACTs, a clinically significant number of cancer patients chose to use therapies considered "unproven" by health care professionals. However, the empirical studies which have examined the effect of ACTs on physiological and psychological outcomes of cancer patients have been limited primarily because of sampling methodology (i.e., small samples, staging of disease). As well, further replication is needed of studies that have demonstrated a significant improvement in survival time and quality of life of individuals with cancer who have used ACTs. A review of the literature also suggests that further physiological research is required exploring the physical response to psychological and spiritual interventions. Possibly, the underlying motivations supporting the decision to use ACTs may play a larger role in physical and psychological outcomes than the actual treatments. Thus, future research exploring the efficacy of ACTs needs to examine not only physiological and quality of life indicators, but the motivations of individuals with cancer to use ACTs.

The Mind-Body Connection

An important theory related to ACTs, particularly psychological and spiritual ACTs, is the relationship between the mind and physiological changes within the body, otherwise know as "the mind-body connection". Popular alternative interventions developed by Bernie Siegel (1990) and the Simontons (1992) have emphasised the role of the mind and emotions in physical health. One well-known example of the mind-body connection which is acknowledged in scientific research is the "placebo effect". Medical scientists and alternative/complementary therapists alike have acknowledged the impact of positive expectations of an intervention on physical outcomes. The physiological explanation for such an effect is based on the premises of psychosomatic health, which has been validated in numerous disease processes, including hypertension and ulcers. However, some medical researchers have dismissed the placebo effect as being "unproven" and "insignificant" and encourage individuals with cancer to avoid ACTs based on mind-body theory (Brown, 1987). In contrast, many alternative/complementary therapists do not support the exclusion of medical therapies. Instead, alternative/ complementary therapists are reported to encourage a holistic approach to health which views the mind and body as an integrated system (Siegel, 1990).

Women with breast cancer in Canada have been found to support the "mind-body connection" and holistic care as being important factors related to their illness experience (National Breast Cancer Forum, 1994). Personality, coping ability, stress and socioeconomic status were variables women themselves believed were involved in the development and progression of their disease (National Forum on Breast Cancer, 1994). Recommendations for research following the National Forum on Breast Cancer (1994) included examination of the psychosocial dimensions of breast cancer and the "mind-body connection" and the influence of psychological and social factors on quality and quantity of life of women with breast cancer. Women with breast cancer participating in the National Forum on Breast Cancer (1994) also recommended research to define and evaluate the effectiveness of non-conventional cancer treatments available in Canada.

Despite the reported prevalence of ACT use in cancer populations and the demand for research exploring ACTs, health care professionals have been slower to acknowledge ACTs as adjuvant therapies to conventional cancer therapies. Opponents of ACTs often consider these therapies as "quackery" that promote false hope in a desperate population. The mind-body connection has been criticized as placing the responsibility of the development of cancer on the individual, leading to guilt and emotional burden (McGinnis, 1991; Siegel, 1990). As a result, therapies promoting the mind-body connection have been considered by some individuals to be destructive and dangerous to the emotional well-being of cancer patients (Brown, 1987; McGinnis, 1991).

There is some evidence that a lack of support for ACTs by health care professionals may cause patients who use ACTs to keep their treatment decisions private (Eisenberg, Kessler, Foster, Norlock, Calkins & Delbanco, 1993; Montbriand & Laing, 1991). A survey conducted by the American Cancer Society of over 5,000 cancer patients and family members reported that 35 percent of cancer patients failed to disclose their use of ACTs to a physician or health care provider (Lerner &

Kennedy, 1992). This secrecy may contribute to poor communication between patients and health care professionals and prevent an open exchange of information and support. As well, the disbelief expressed by health care professionals regarding the efficacy of ACTs may disrupt the belief system underlying cancer patients' sense of hope and optimism in their treatment (Isaac, 1994).

Thus, despite the physiological evidence of the validity of the mind-body connection, many health care professionals discredit ACTs based on mind-body ideology as being "unproven" and promoting false hope. However, some women with breast cancer using ACTs have expressed the belief that the mind-body relationship played a major role in the development of their cancer. By discouraging the use of ACTs, health care professionals may be undermining women's beliefs systems and limiting dialogue with clients.

The National Breast Cancer Forum

An important step towards improved communication between health care professionals and women with breast cancer occurred in 1993 at the National Forum on Breast Cancer in Montreal, Canada. Health care professionals, researchers and survivors of breast cancer came together to discuss the impact of breast cancer and goals for the future in prevention, treatment and research. The Forum resulted in several priorities for breast cancer research.

One area identified as a research priority was the need for studies of the use of ACTs by women with breast cancer and the treatments' impact on physiological and psychosocial outcomes and quality of life (National Forum on Breast Cancer, 1994). A survey conducted by the Support, Advocacy and Networking (SAN) Subcommittee of the National Forum on Breast Cancer reported that one third of women attending the Forum had used ACTs (National Forum on Breast Cancer, 1994).

Empirical studies from Canada, the United States and Australia have attempted to examine the prevalence, impact and motivations of ACT use in cancer patients (Cassileth et al., 1991; Cassileth, Lusk, Miller, Brown & Miller, 1985; Cassileth et al., 1984; Eisenberg et al., 1993; Feigen & Tiver, 1980; Lerner & Kennedy, 1992; Yates et al., 1993). However, the variation in results and lack of replication limits conclusions. As well, research on the utilization of ACT has not been specific to the breast cancer population. Therefore, studies exploring the prevalence and motivations of ACTs in breast cancer populations are needed to understand unique issues and practices related to ACTs which may be pertinent to women with breast cancer.

Forum participants also emphasised the need for a more holistic approach to treatment and care, including an acknowledgement of the "mind-body connection" (National Forum on Breast Cancer, 1994). Forum participants suggested that medical professionals have failed to consider the role of emotions and stress on physiological changes within the body, including the development of cancer. In the clinical setting, women with breast cancer have also expressed concern regarding fragmented treatment and care that fails to consider the "whole" person. In contrast, ACT providers were described by women with breast cancer as being supportive of their psychosocial and spiritual needs and conducive to providing women an active role in health care (National Forum on Breast Cancer, 1994).

Stories by women with breast cancer who use ACTs, the large percentage of women with breast cancer reporting use of ACTs, absence of scientific literature to examine ACT use in this population, and increasing pressure by women with breast cancer for research to examine these therapies contributed to two National Forum on Breast Cancer Report (1994) recommendations. The first recommendation was that research be conducted to explore why women with breast cancer use ACTs. A second recommendation called for documentation of the psychological and physiological effects of these therapies. This study aimed to address in part the first recommendation and provided descriptive data on this area of research.

Statement of the Problem and Research Questions

This study addressed two sets of research questions: (1) methodological and (2) descriptive.

1. Methodological Aim: The study tested the appropriateness, reliability and validity of the BTPS-BC for use with women diagnosed with breast cancer.

2. Descriptive Aim: The study also described the types of ACTs used by this population, the beliefs influencing ACT use by women with breast cancer, women's perceptions of their quality of life, and the preferred treatment decision making role(s) chosen by women who use ACTs.

Specific research questions which guided this study were as follows:

I. <u>Methodological</u>:

1. To what extent was the BTPS-BC reliable, valid and appropriate for use with a breast cancer population, considering the apparent internal consistency, clarity, content validity and internal consistency of the questionnaire?

II. Descriptive (Hypothesis Generating):

a. Motivations - Beliefs about cause of cancer and treatment:

1. What did women with breast cancer who used ACTs believe led to the development of their cancer and did these beliefs differ from women with breast cancer who used only conventional treatments?

2. What were the beliefs about treatment held by women with breast cancer who use ACTs and did these beliefs differ from women with breast cancer who used only conventional treatment?

b. Motivations - Patient/physician relationship and encouragement by others:

3. How did women with breast cancer who used ACTs perceive the quality of their relationship with their medical cancer specialist and did this perception differ from women with breast cancer who used only conventional treatment?

4) Did women with breast cancer who used ACTs receive encouragement by others regarding their choice of treatment?

c. Demographic and treatment variables:

5. What were the demographic characteristics of women with breast cancer who used ACTs and those women who used only conventional treatment?

6. What types of ACTs were used by women with breast cancer?

d. Decision making role:

7) What role in treatment decision making did women with breast cancer who used ACTs prefer and does this role differ from the preferred treatment decision making role of women who used conventional treatment only?

8) Did the actual role played by women with breast cancer who used ACTs and those who used only conventional therapy match their preferred decision making role?

e. Quality of life:

9. What was the perceived quality of life of women with breast cancer who used ACTs and for women who used only conventional therapies?

Conceptual Framework

To study variables associated with ACT use by women with breast cancer, a flexible, open, patient-centred, conceptual framework was required. Flexibility was a key attribute in selecting a framework because conflicting beliefs may exist when women with breast cancer enter both the conventional and alternative/complementary health care systems. For example, conventional surgical and antineoplastic interventions are based on a medical model emphasising the physiological development and spread of cancer. In contrast, visual imagery therapy, is supported by the belief that positive mental energy may reduce tumour size and magnify the effect of conventional treatments (Simonton et al., 1992). Used in combination, these treatments force an individual to accept competing paradigms with diverse explanations of cause and change related to cancer.

The Health-Error-Change (H-E-C) framework is a meta-theory developed from a social work perspective which allows multiple theories to be applied both in practice and research (Kristjanson, Tamblyn & Kuypers, 1987). This model prevents premature conceptual closure because it allows exploration of multiple theoretical constructs, which would not be possible with a single conceptual model. The H-E-C model is composed of three domains: health, error and change (Appendix B). From these domains, three key questions are developed which provide the foundation for scientific inquiry: 1) What is the ideal? (Health); 2) What error is preventing the ideal state from occurring? (Error); and 3) What change should occur to achieve the ideal? (Change) (Kristjanson et al., 1987). Together, the three domains influence how the health problem, goal and action are defined and determined.

The first domain, "Health", represents the condition of an individual at a given time, and may range from a limited, immediate goal to an overall assessment of well-being (Kristjanson et al., 1987). This construct includes a person's demographic characteristics, medical history and their internal definition of health (i.e. quality of life). The second domain, "Error", is the circumstance which accounts for the patient's actual experience, limiting his/her ability to reach the ideal condition. This domain prompts one to ask "why isn't the healthy state occurring?". This domain allows for both alternative and conventional perspectives on the etiology of disease and will have a direct impact on the action taken to regain the ideal health condition. The final domain is "Change", where choices may lead to an action that will change the error and lead to the patient's definition of a healthy state. Together, these three domains interact and have a profound effect on each other. The choices made in each domain lead to an intervention or action which may alter as alternate perspectives are accepted or considered.

The researcher proposed that the application of the H-E-C framework to this study would permit the following speculation: that breast cancer patients hold a subjective perspective of their overall well-being, which is developed from a personal assessment of important health and life variables, such as functional ability, performance of roles, happiness, and satisfaction. As well, it was purported that the diagnosis of cancer and subsequent treatment, both conventional and ACTs, would affect women with breast cancer's assessment of well-being and the level of congruence between ideal health and what is experienced. For the purpose of this study, the construct "health" was operationalized as "quality of life", allowing physical, emotional and spiritual dimensions to be included in the definition of health (Appendix B).

Cancer was envisioned as the "error" which prevents the ideal healthy state from occurring (Appendix B). Women with breast cancer could hold various beliefs regarding the etiology and progression of cancer. These beliefs might include genetics, stress, exposure to a carcinogen(s), punishment for a "sin", injury to the breast and presence of a "cancer personality" (Mathieson, 1995; Yates et al., 1993). The belief(s) present in this domain could affect the choices made in the "change" domain, specifically the decision to use either conventional and/or ACTs. For example, the belief that stress was a major factor in the development of breast cancer could influence a woman's decision to use relaxation and imagery techniques. However, if a conventional belief about cause of cancer is held (i.e., genetics), conventional treatments might be the only logical intervention. Thus, it was proposed that beliefs about treatment and their relationship to the believed etiology of cancer might influence what action was chosen (i.e. conventional versus ACTs). As well, quality of life, beliefs about cause of breast cancer and beliefs about treatment might impact how the problem(s) (i.e. breast cancer) and goal(s) (i.e. will to live) held by women with breast cancer was perceived.

The H-E-C framework is situated within the health care system, where traditionally, health care providers have assumed responsibility for defining patients' problems, goals, changes and actions. In relation to breast cancer, only recently have women been included by physicians in the decision to undergo either a mastectomy or a lumpectomy. Thus, the treatment decision-making role performed by women with breast cancer may have a significant impact on what change and action occurs. As well, the preferred treatment decision making role of women with breast cancer may influence the process by which a woman considers treatment alternatives. The chosen treatment decision making role may also reflect the desire by women with breast cancer to play an active role in the change domain and accept responsibility for the resulting action. Overall, the treatment decision making process was considered to be representative of the movement among the domains of the H-E-C model (Appendix B).

Previous treatment or health care decisions was also purported to influence how health and error were defined and what type of changes and actions are undertaken by an individual. For example, the daily use of ACTs as part of self-care and health maintenance might predispose individuals to use ACTs following the diagnosis of a serious illness. ACTs could represent a lifestyle choice rather than a distinct treatment decision. For instance, the use of meditation and relaxation techniques as a method of daily stress management could lead to the incorporation of psychological therapies as part of treatment following the diagnosis of cancer.

The researcher also recognized that the H-E-C framework, as applied in this study, would require analysis within a social context. Women with breast cancer not only make treatment decisions based on personal interpretation of health, error and change, but are influenced by societal factors. Two major influences on health care decisions identified in the literature are social support and the patient-physician relationship (Cassileth et al., 1984; Yates et al., 1993). Yates et al. (1993) found encouragement by others, including family members, friends and health care professionals, significantly increased the likelihood of an individual with cancer choosing ACTs. Advice by significant others may influence how health, error and change are defined and what goals and actions are considered socially acceptable. The quality of the patient-physician relationship was also found by Cassileth et al. (1984) to be related to the decision to use ACTs. Individuals with cancer who used ACTs were found to express less satisfaction with their physician(s) than individuals using conventional medicine only. However, Yates (1991) reported a significant majority of individuals with cancer who chose ACTs were satisfied with the care they received through conventional medicine. It appears that discrepancy warranted further study, especially with the Canadian breast cancer population who have reported dissatisfaction with conventional medicine and their relationships with physicians (National Forum on Breast Cancer, 1994).

The model emphasizes that there is no one solution to a given problem (Kristjanson et al., 1987). Decisions will occur in each domain, based on information and assumptions perceived by the patient. Thus, the flexibility and openness of the H-E-C Model was deemed to be appropriate in guiding research on the motivations influencing women with breast cancer's decision to use ACTs.

Gibb's Model

The H-E-C Model can be further refined through Gibbs' (1972) paradigm of a theoretical system. Gibb's (1972) paradigm links theoretical constructs into concepts, which are then specified by referentials, which are operationalized as referents. Relationships among constructs, concepts, referentials and referents are demonstrated through axioms, propositions, theorems and hypotheses respectively. This refined conceptual framework guided both theoretical and methodological decisions within this study. Overall, the refined versions of the H-E-C Model represents the personal belief system and practice of women with breast cancer selecting treatment, both conventional and unconventional.

The six originating constructs within the H-E-C Model were: 1) the problem; 2) goal(s); 3) health; 4) error; 5) change; and 6) action. The axioms existing among these constructs are described in the schematic diagram of the H-E-C Model (see Appendix B).

The construct "problem" is defined as an issue which is identified by both the client and health care professionals as being representative of the move away from the client's self-description of health. A problem can be redefined as assumptions regarding health, error and change are identified by clients and health care professionals. The specific concept identified in this study is the diagnosis of breast cancer. Breast cancer is further delineated by the stage of disease, which is operationalized through the TNM Tumour Classification and Staging System (International Union Against Cancer, 1987).

The construct "goal" is defined as the intent of the action or change in behaviour. In this study, the related concept to the construct "goal" is "living with breast cancer". This referential is further defined as "the will to live with breast cancer". The concept, "Will to live", has been suggested by Hall (1990) to represent hope, allowing the terminally ill individual with cancer to live with some degree of normalcy. As well, literature has also suggested "will to live" may influence treatment decisions and the efficacy of therapies (Yates et al., 1993). For example, Yates et al. (1993) reported "will to live" to be correlated with ACT use in a general cancer population. "Will to live" is operationalized through the "Will to Live" scale on the BTPS-BC.

The construct "health" is defined as a subjective interpretation of well-being. "Health" is further refined using Gibb's paradigm as being "quality of life". As a concept, "quality of life" is composed of several dimensions, including physical, emotional, role, cognitive, and social functioning (Aaronson et al., 1993). Work by the European Organization for Research and Treatment of Cancer (EORTC) has resulted in the development of a quality of life scale appropriate for individuals with cancer. The EORTC QLQ-C30 (version 2) includes subscales specific to physical, emotional, role, cognitive and social functioning and symptoms related to conventional treatments (Aaronson et al., 1993) (Appendix A). The EORTC QLQ-C30 (version 2) scale served as the referent for the concept "quality of life".

The "error" construct is defined as the circumstances preventing the ideal healthy state from occurring. This construct, for the purpose of this study, is refined into the concept "beliefs about cancer". This concept describes the beliefs held by women with breast cancer regarding the etiology of the development of their cancer.

Thus, the referential is beliefs about causes of breast cancer. The "Internal/Controllable Causes of Cancer" and "External/Uncontrollable Causes of Cancer" subscales on the BTPS-BC were used to operationalize this referential.

The fifth construct "change" is defined as the domain where choices are made to change the error and regain the preferred healthy state. Two concepts are associated with this construct: 1) beliefs about treatment; and 2) decision making preference. These concepts are further refined as beliefs about breast cancer treatment and decision making preference of women with breast cancer. These concepts are related to the construct "change" because they influence women with breast cancer's decision to use alternative or conventional treatments. Work by Yates et al. (1993) and Montbriand (1993) revealed that the level of preferred involvement in treatment decision has a significant impact on the treatments chosen by individuals with cancer. As well, Yates (1993) found that individuals who held alternate beliefs about cancer treatments were also more likely to chose therapies other than conventional medicine. Preferred decision making role was operationalized using Degner and Sloan's (1992) decisional preference card-sort (Appendix A). This procedure has been used extensively with the sample population and has demonstrated acceptable reliability and validity estimates. Beliefs about treatment for breast cancer will be assessed using the "Mechanisms of Medical Treatments", "Outcomes of Medical Treatments", "Mechanisms of Alternative/ Complementary Therapies", and "Outcomes of Alternative/Complementary Therapies" subscales on the BTPS-BC.

The final construct, "action", was defined as the actual behaviour which occurs to correct the error and return to the healthy state. The two concepts related to the action construct are treatment action and actual decision making role. These concepts were further refined to the referential level as treatment action for breast cancer and actual decision making role by women with breast cancer. The treatment chosen by women with breast cancer was assessed using the BTPS-BC. Actual decision making role played by women with breast cancer was operationalized using Degner and Sloan's (1992) decisional preference card sort procedure.

The social context in which the H-E-C Model (Kristjanson et al., 1987) is situated is represented by the constructs of social support and the patient-physician relationship. The concepts related to these two constructs are encouragement to use ACTs and satisfaction with health care providers. Further refinement to the referential level relates these concepts to the experiences of women with breast cancer. Social support is operationalized on the BTPS-BC as the "Encouragement to use ACTs" subscale. The quality of the patient-physician relationship is assessed using the "Satisfaction with Health Care Professionals" scale on the BTPS-BC.

In summary, Gibb's (1972) paradigm of a theoretical system was an appropriate model for the study of women with breast cancer's beliefs and treatment practices. It allowed the global constructs of the H-E-C Model (Kristjanson et al., 1987) to be further refined and operationalized.

Definitions

The definitions used in this research study are documented in Appendix B in terms of constructs, concepts and operational definitions. The constructs are congruent with the H-E-C Model and the concepts and operational definitions illustrate how the H-E-C Model provides a framework to examine the beliefs and practices of breast cancer patients.

Assumptions

Several assumptions provided a foundation for this research study. Firstly, it was assumed from the literature and from the National Forum on Breast Cancer (1994) that there are antecedent causes of ACT use in women with breast cancer. Certain motivations and promoting factors were presumed to exist which encourage this population to make specific treatment decisions. Decisions about therapy options are not made randomly.

Secondly, this study assumed that women with breast cancer would be able to articulate their beliefs about their disease and treatment decisions to the researcher. The participants in this study were presumed to be able to honestly express their experiences and treatment decisions.

Summary

Recent studies have indicated that a significant proportion of individuals with cancer are using alternative/complementary therapies (ACTs) in conjunction with conventional medical treatments or alone. Suggested motivations behind the use of ACTs in general cancer populations include increased sense of control over treatment decisions, improved physiological and psychosocial coping and provision of support and hope. Alternative beliefs regarding cause of cancer and treatment have also been suggested to influence the decision to use ACTs. However, the disbelief expressed by health care professionals regarding the effectiveness of ACTs in cancer prevention, diagnosis or treatment has prevented open and honest communication from occurring between patients, physicians and alternative/complementary therapists.

To date, limited research had been conducted specifically on the motivations and alternative treatment practices of women with breast cancer, despite the support by survivors of breast cancer, health care providers and researchers. Understanding of the "what" and the "why" associated with ACT use in this population will hopefully lead to increased discussion between women with breast cancer and their health care providers regarding treatment choices. This study examined the beliefs and decision making role preferences of women with breast cancer who use ACTs and the impact of these treatments on quality of life. As well, the study tested the appropriateness of the BTPS-BC, a survey of beliefs and treatment practices, with a breast cancer population. Findings from this study provided a knowledge base for future ACTs research with women diagnosed with breast cancer and progressed towards the development of a valid and reliable instrument.

The Health-Error-Change Model (Kristjanson et al., 1987) was judged to be an appropriate framework to guide the exploration of the beliefs and treatment decision making roles associated with ACT use by women with breast cancer. The model allowed multiple solutions to a health issue to co-exist in a societal context, corresponding to the use of both conventional treatments and ACTs by cancer patients. As well, the H-E-C Model allowed the researcher to examine the way that data enriched the theory, rather than theory influencing the results.

The constructs described by the Health-Error-Change Model (Kristjanson, 1987) were further defined and operationalized for this study through Gibb's (1972) paradigm of a theoretical system. Gibb's (1972) model allowed the main concepts of beliefs about treatment and cancer, decision making preference, and quality of life to be examined under the main constructs of health, error and change. As well, Gibb's model incorporates related study concepts of staging and classification of breast cancer, cancer treatment (both conventional and ACTs) and will to live with breast cancer.

CHAPTER TWO

REVIEW OF THE LITERATURE

The majority of breast cancer research has focused on the physiological outcome of conventional medical treatments and the physical and psychosocial impact of the disease on patients and family members. Few studies have been undertaken to examine the use of alternative/complementary therapies (ACTs) in women with breast cancer and the effect on physical, psychosocial, and quality of life indicators. However, since the 1970s, nursing research has placed a greater emphasis on the information and support needs of women with breast cancer and their desire for increased control in the treatment decision making process (Degner & Sloan, 1992; Hack, Degner & Dyck, 1994; Kalinowski, 1991; Pierce, 1993; Suominen, 1992). This research provides a foundation of knowledge on which women's decisions to use unconventional treatments may be based. The following literature review will explore four areas of research pertinent to a study of ACT use in women with breast cancer: conventional treatment of women with breast cancer, alternative/complementary cancer therapies, the treatment decision making process including beliefs about cancer and treatment, and quality of life as an outcome measure for breast cancer patients.

Conventional Treatment of Women with Breast Cancer

The breast cancer trajectory is typically of a long duration, with a prolonged preclinical and clinical time period of possibly decades. However, the marked heterogeneity of the disease makes prognosis and treatment variable among breast cancer patients. Screening for breast cancer, through physical examination and mammography, has been the primary tool in the prevention and early detection of the disease. Harris, Morrow and Bonadonna (1993) have suggested screening has been responsible for an approximate 25 percent reduction in breast cancer mortality. This reduction, however, may be present only in women 50 years and older.

The National Cancer Institute of Canada reports that one in nine women will experience breast cancer (Statistics Canada, 1995). Risk factors include age, family history of breast cancer, reproductive history, a high fat/low fibre diet, hormone usage and exposure to carcinogens. However, 70 percent of women presenting with breast cancer do not have any identifiable risk factors (Harris et al., 1993). As a result, screening for all women, especially over the age of 50 years, is supported as the best method for early detection of breast cancer. Perhaps as a result of improved screening, the incidence of breast cancer has risen by approximately 4 percent in the past 10 to 13 years (Harris et al., 1993). Unfortunately, cancer research exploring the etiology of breast cancer has not markedly reduced the prevalence of breast cancer in North America.

Following the detection of a mass through palpation or mammography, four procedures are available to diagnose breast cancer: fine-needle aspiration, core-cutting needle biopsy, incisional biopsy, or excisional biopsy. Fine-needle aspiration has become increasingly popular because of the speed and relative painlessness of the procedure. One disadvantage of fine-needle aspiration is a false-negative rate of approximately 10 percent, thus supporting the use of excisional biopsy for all palpable masses (Harris et al., 1993). Typically, a positive mammogram is followed within a short time period by either a fine-needle aspiration and/or excisional biopsy. These diagnostic procedures may be ordered for women with positive mammograms before they have been consulted regarding the results of the mammogram. As well, for some women with breast cancer, mastectomy or lumpectomy may occur at the same time as a positive breast lump biopsy. Thus, women with breast cancer are placed into the conventional medical system, often without a chance to become informed about treatment options such as ACTs.

Carcinomas of the breast are either classified as ductal or lobular, corresponding to the physiology of the breast. Common breast carcinomas include carcinoma in situ, infiltrating ductal carcinomas, and infiltrating lobular carcinoma. Treatment of breast cancer is primarily based on the local and regional involvement of the disease. Local involvement occurs within the breast tissue, with direct infiltration occurring along mammary ducts and breast lymphatics. Regional involvement is most common in the axillary, internal mammary and supraclavicular lymph node regions. Approximately 40 percent of women diagnosed with regional breast cancer metastases have involvement of the axillary nodes (Harris et al., 1993). Histological examination of the axillary nodes during mastectomy is often conducted to determine prognosis of the disease. Distant metastases from carcinoma of the breast is most prevalent in the bone, lungs, liver, brain, ovary and adrenal (Fallowfield & Clark, 1991).

Staging of breast cancer is used to describe the extent of the disease, to develop a prognosis and to prescribe treatment. The most common staging system is the tumour-nodes-metastases (TNM) system used by the International Union against Cancer (UICC, 1987). This system describes the size of the primary tumour, the condition of regional lymph nodes and the presence or absence of distant metastases.

Breast surgery remains the primary treatment of women with breast cancer. A modified radical mastectomy is the standard surgical procedure in North America, involving removal of the entire breast and a portion of the axillary lymph nodes. Becoming more popular in recent years is breast-conserving surgery and irradiation, following results of trials by the National Surgical Adjuvant Breast and Bowel Project (NSABP) and European Organization for Research and Treatment of Cancer (EORTC) and the National Cancer Institute, which showed comparable mortality and morbidity rates with mastectomy (Fisher, Redmond, Poisson et al., 1989; van Dongen, Bartelink, Fentiman, et al., 1987; Staus, Lichter, Lippmann et al., 1992). Lumpectomy involves excision of the primary tumour and a tissue margin of surrounding normal breast tissue and axillary dissection. The advantage of breast-conserving surgery over mastectomy is comparable clinical outcomes with preservation of the cosmetic appearance of the breast. However, adjuvant radiation may cause extreme, prolonged fatigue, gastrointestinal disturbances and skin irritations. Lumpectomy is also limited because 30 to 50 percent of breast lumps are unsuitable for breast conserving surgery because of size or proximity to the nipple (Fallowfield & Clark, 1991). As well, approximately 30 percent of women who are provided the option between the two types of surgeries will chose mastectomy (Fallowfield et al., 1990). Research studying the rationale behind this phenomenon is absent from the literature. Harris et al. (1993) commented that the most difficult aspect of patient evaluation for mastectomy versus lumpectomy is consideration of the patient's wishes regarding breast preservation. Discussion is important between patients and physicians regarding impact of surgery on appearance, psychological adjustment, sexual adaptation and functional ability. This decision may have limited impact on survival, but considerable effect on quality of life.

Despite earlier research reporting breast removal as a traumatic event for women, with significant impact on sexuality and body image, more recent studies have shown mastectomy patients experience similar sexual dysfunction in comparison to other control groups (Schover, 1991). Feather and Wainstock (1989b) demonstrated in a random sample of mastectomy patients (N=456) that women viewed sexuality as being "beyond the presence of breasts". As well, women with breast cancer had a more positive attitude and openness regarding their disease and treatment than women in earlier studies (Feather & Wainstock, 1989a). However, Royak-Schaler (1991) in a review of the literature found between 25 and 47 percent of breast cancer patients experienced severe distress following surgery, lasting from six months to two years. Adjuvant treatments, including chemotherapy and radiotherapy, have been suggested to increase distress, although limited sample sizes and variability of cancer staging between studies prevents conclusive results.

Standard adjuvant chemotherapy for breast cancer involves a 6 month cycle of the multi-drug regimen of oral cyclophosphamide, methotrexate and 5-Fluorouracil (CMF). Other anti-neoplastic agents and therapies considered more experimental are cisplatin, mitomycin C, taxol and high-dose chemotherapy with bone marrow transplant. Dosage of the chemotherapeutic drugs is dependent on staging of cancer, myelosuppression, and toxicity of the agents. Despite the decreased toxicity of chemotherapy, women with breast cancer usually experience nausea and vomiting, fatigue, mouth sores, gastrointestinal disturbance and alopecia, which can significantly impact quality of life. Hailey et al., (1988) found women with breast cancer (N=27) reported chemotherapy as being the worst aspect of treatment, including surgery. In one study, significantly more women undergoing chemotherapy following surgery were anxious and depressed when compared to women experiencing only a mastectomy (Maguire et al., 1980).

Newer adjuvant treatments include hormone therapy for patients with breast tumours which are estrogen receptor (ER) positive. Hormone therapy is used with breast tumours that are hormone dependent and responsive to hormone manipulation, usually by the drug Tamoxifen. Moderate but significant improvement in survival rates of node-positive and node-negative patients with strongly ER-positive tumours has supported the efficacy of this treatment (Breast Cancer Trials Committee, 1987; Rose, Thorpe, & Anderson, 1985). Taxol, a drug derived from the Pacific yew tree, has also shown remarkable promise, interfering with cell division within the breast tumour. However, the threatening side effects and hypersensitivity reaction experienced by some patients has restricted the widespread use of Taxol. Future trials are indicated to explore the long-term effects of these experimental treatments.

In summary, conventional medicine addresses breast cancer as a symptom of known physiological risk factors, amenable to prevention and screening procedures. Conventional medical therapy for breast cancer are tumour-focused, with the primary goal being removal of the carcinoma and prevention of metastases through adjuvant treatment. However, despite advances in chemotherapy and breast-conserving procedures, breast cancer mortality and morbidity has not significantly changed in the past decade. Breast cancer remains one of the leading causes of death among women in North America and may have a profound impact on the quality of life of both women with breast cancer and their families.

Alternative/Complementary Cancer Therapies

For some women with breast cancer, treatment options include therapies considered alternative or complementary by the health care system. The medical literature defines ACTs as "unsound methods of cancer treatment" with two central characteristics: 1) promotion without sufficient preclinical data to justify use in patients and 2) unmethodical treatment of patients that cannot detect therapy-related responses (Harris et al., 1993). The Ontario Breast Cancer Information Exchange Project in 1994 developed a guidebook of "unconventional" cancer therapies available to women with breast cancer. "Unconventional" therapies were defined as treatments falling outside the domain of the more widely practiced conventional therapies of surgery, chemotherapy and radiation (Ontario Breast Cancer Information Exchange Project, 1994). This term was considered the most appropriate and neutral, presenting neither a medical or alternative therapy bias.

Limited knowledge exists in the area of alternative/complementary therapies (ACTs) used by women with breast cancer. The majority of the literature reviewed from 1975 to 1995 focused on ACT use in general cancer populations. The review of literature related to ACT use by individuals with cancer can be categorized into seven main areas: prevalence; types of ACTs; characteristics of ACT consumers; timing of use of ACTs; motivations behind use of ACTs; the effect of the patient-physician relationship on ACTs; and the benefits and risks of ACTs.

Prevalence of alternative/complementary therapies.

Several studies have measured the prevalence of ACT use in cancer patients, with a wide range of results being reported. Eisenberg et al. (1993) randomly surveyed 1539 households in the United States to discover the prevalence and patterns of ACT use in the general population. One in three respondents reported using at least one ACT in the past 12 months, with 24 percent of respondents identified as people with cancer. A national survey by the American Cancer Society (ACS) (N=36,000) revealed that nine percent of cancer patients had used ACTs, the majority of treatments being either psychological (49%) or related to diet (38%) (Lerner & Kennedy, 1992). The ACS study also reported that nearly all cancer patients using ACTs also received conventional treatment (Lerner & Kennedy, 1992). In contrast, Cassileth et al.'s (1984) study of both conventional and unconventional cancer treatment patients revealed that 54 percent of patients using conventional therapy (N=325) also used unconventional treatments. However, Cassileth et al.'s (1984) research may be limited because a portion of respondents were recruited from a health care facility offering ACTs, limiting the external validity of the findings.

In Australia, Feigen and Tiver (1980) found 49 percent of cancer patients (N=202) receiving conventional therapy had made no significant changes in their lifestyle or sought ACTs. However, 27 percent of the sample did make significant changes following diagnosis of cancer, the majority through alteration of diet (Feigen & Tiver, 1980). Similarly, Yates et al. (1993) reported 40 percent of advanced stage cancer patients in Australia (N=152) used at least one ACTs during conventional medical treatment.

In Canada, there has been limited research on ACT prevalence in cancer patients. An exception is the work by Montbriand (1993), who reported 81 percent of cancer patients surveyed in a biomedical setting had used ACTs. Montbriand (1993) concluded that involvement in conventional medical treatment by cancer patients does not preclude their utilization of ACTs. Future studies planned by the Sociobehavioural Network of the National Cancer Institute of Canada include a large scale epidemiological study examining the prevalence and types of ACTs used by cancer patients in Canada. This work will contribute valuable knowledge of the treatment practices of Canadian cancer patients.

Thus, despite conflicting evidence in the literature regarding the prevalence of ACT use in cancer patients, a clinically significant number of individuals diagnosed with cancer likely use ACTs. As well, it could be hypothesized that a significant number of Canadian women with breast cancer are using ACTs, as 30 percent of all new cases of cancer in women are carcinomas of the breast (Statistics Canada, 1995). Therefore, a descriptive study is warranted to document the extent of ACT use in this cancer population.

Types of alternative/complementary therapies.

The hundreds of available ACTs can be divided into three major categories: physical, psychological and spiritual. This section will briefly explore each type, summarizing the underlying rationale and providing examples of treatments. For a more detailed description of each category of ACTs, the reader is directed towards books such as Choices in Healing, by Michael Lerner (1994) and A Guide to Unconventional Cancer Therapies, by the Ontario Breast Cancer Information Exchange

Project (1994).

Physical therapies include diets, megavitamins, devices, immune therapy, manipulative "hands-on" interventions and metabolic therapies (Ontario Breast Cancer Information Exchange Project, 1994). The majority of physical therapies are based on the underlying assumption that cancer is caused by nutritional imbalances or a disturbance in the body's immune system (Ontario Breast Cancer Information Exchange Project, 1994). An historical overview of ACTs has revealed that each decade sees a new "fad" develop in physical alternative cancer therapy, with cyanide treatment (Laetrile) in the 1970s and immune therapy in the 1980s, being two notable therapies (McGinnis, 1991). Harris et al. (1993) suggested that ACTs mirror the current scientific trends, for example, the promotion of immunoaugmentative and antineoplastic alternative therapies in the 1990s when immunotherapy promises to be the newest medical breakthrough in breast cancer research.

Limited empirical evidence exists which supports the efficacy of the majority of biological treatments. Many physical ACT therapists use testimonials and singular case studies to support the effectiveness of their treatments (e.g., Gerson Institute, Pamphlet). The American Cancer Society (ACS) has played an active role in refuting the credibility and efficacy of many biological alternative therapies. For example, therapies such as hyperoxygenation and Cancell/Entelev have been closely examined by the ACS through a review of the literature and were found to have no empirical evidence of affecting the course of cancer (ACS, 1993a; 1993b). The ACS has also explored the expensive Mexican border clinics which offer physical treatments such as metabolic therapy (ACS, 1991). The majority of these regimens involve radical lifestyle changes, including highly restrictive diets, enemas and large doses of nutritional supplements. The ACS recommends individuals with cancer avoid treatment in these clinics as the therapies are perceived to be dangerous, expensive and based on faulty assumptions about the etiology of cancer (ACS, 1991). The Ontario Breast Cancer Information Exchange Project (1994) also emphasized the numerous side effects and hazards of using metabolic and diet treatments.

Montbriand and Laing (1991) suggested patients who chose physical ACTs are externally controlled and assume a therapy that will provide a "quick" cure. Montbriand and Laing (1991) also concluded that physical ACTs closely resemble conventional medical treatment because they are controlled by a therapist rather than the individual with cancer and focus on the physiological nature of cancer. Montbriand (1993) also reported that the majority of cancer patients using ACTs (71%) selected physical practices instead of psychological or spiritual interventions (N=213). This may reflect cancer patients' beliefs in a physiological rather psychological etiology of cancer.

Psychological ACTs include relaxation, guided imagery, biofeedback, hypnotherapy and meditation (Ontario Breast Cancer Information Exchange Project, 1994). Psychological ACTs are often based on the concept of emotions and stress as the cause of cancer, with the reduction of stress leading to decreased tumour activity (Brown, 1987). Pioneers of psychological ACTs, such as Carl and Stephanie Simonton and Bernie Siegel, regard the mind-body connection as being paramount in the prevention and treatment of cancer. For example, in the book, Getting Well Again, the Simontons teach cancer patients to visualize the destruction of cancer cells by your body's cellular defenders (Simonton et al., 1993).

Patients who chose psychological types of ACTs have been found to be internally controlled and prefer an active role in treatment decisions (Cassileth et al., 1984; Montbriand & Laing, 1991). However, Cassileth et al. (1984) suggested psychological treatments create personal responsibility, which may lead to guilt if the therapies fail to meet patients' expectations. The Ontario Breast Cancer Information Exchange Project (1994) also cautions breast cancer patients that psychological therapies may be frustrating if they involve detailed imagery or meditation techniques.

Several studies have been conducted which support the effectiveness of psychological ACTs in improving the well-being of individuals with cancer. Spiegel et al. (1989) found that women with metastatic breast cancer who underwent group therapy for one year had a significantly (N=86; p<.0001) longer survival time (approximately 18 months) than women not receiving the intervention. The group therapy involved weekly 90 minute meetings which encouraged patients to discuss ways to cope with the diagnosis of cancer and the side effects of conventional treatment. Spiegel et al. (1989) suggested that the social support received from group therapy may have helped the women mediate the stress experienced with having breast cancer. As well, social support may have facilitated compliance to conventional treatments or improved psychological variables such as mood (Spiegel et al., 1989). However, the confidence in these findings is limited because of the lack of replication studies confirming Spiegel et al.'s (1989) research conclusions.

Cunningham and Tocco (1989) explored the impact of a psycho-educational intervention on 53 patients diagnosed with cancer. The intervention involved relaxation training and education in coping skills. Using self-report questionnaires (i.e. Profile of Mood States [POMS], Symptom Checklist [SCL-90-R]), Cunningham and Tocco (1989) found a significant improvement in overall mood in individuals who received the psycho-educational intervention. As well, Cunningham and Tocco (1989) examined the persistence of the effects of the intervention by interviewing patients three months following completion of the program. Results showed individuals who received the psycho-educational intervention had a significant improvement in mood, which was maintained until the 3-month follow-up ($N=39$; $p<0.02$, 2-tailed t-test). However, individuals in the follow-up study were not randomized, which may have influenced the type of patients involved in the psycho-educational intervention. Notwithstanding this limitation, Cunningham and Tocco's (1989) research has suggested a relationship between psychological ACTs and improved psychological well-being that warrants further testing in a randomized clinical trial.

Spiritual ACTs encompass interventinos such as faith healing, prayer, laying on of hands, and the wearing of charms. These ACTs place control in the hands of a greater power and allow patients to "submit" to fate (Montbriand & Laing, 1991; Vastyan, 1986). Vastyan (1986) discussed how the diagnosis of cancer threatens one's mortality and may lead to transcendence, when new perceptions about life are developed and repriorization occurs. The use of spiritual ACTs may be part of this existential journey. Little research has been undertaken to explore the efficacy of spiritual therapies used by cancer patients. However, Dossey (1993) in his book Healing Words summarizes a number of studies which have examined the effect of prayer and spiritual healing on other disease processes. Dossey (1993) reports that most studies reported an improvement in physical and emotional health following spiritual activities, such as praying or laying on of hands. The difficulty in isolating prayer as an independent variable and the "placebo effect" have been criticisms of this research. However, numerous controlled trials using a variety of subjects, including cells, plants, animals and human beings, have demonstrated statistically significant results from spiritual healing. This discrepancy in the scientific literature requires further examination to determine the validity of spiritual healing as an ACT.

Despite the lack of acceptance by conventional health care providers and limited evidence of the efficacy of physical, emotional and spiritual ACTs, cancer patients continue to participate in these therapies. The questions thus arise: 1) what promotes cancer patients to use ACTs; and 2) do certain patient characteristics influence the type of ACTs selected?

Characteristics of patients who use alternative/complementary therapies.

Sociodemographic factors reported to be associated with the use of ACTs include age and socioeconomic status. Eisenberg et al. (1993) found ACT use more prevalent in the 25-49 years age group than those cancer patients who were younger or older. Yates et al. (1993) also reported a relationship between age and ACT use, with cancer patients 40-60 years of age being six to ten times more likely to use ACTs than patients who were older. The researchers attributed this difference to the belief systems held by this age group (Yates et al., 1993). The literature also revealed a high socioeconomic status (including having achieved post-secondary education) was associated with ACT use (Eisenberg et al., 1993; Lerner & Kennedy, 1992; McGinnis, 1991; Montbriand, 1993; Yates et al., 1993). However, Lerner and Kennedy (1992) suggested that ACT use was more prevalent in higher income groups because of the cost attributed to some alternative treatments. In contrast, Yates et al. (1993) found that the effect of socioeconomic status on ACT use reflected differences in beliefs rather than income levels. Individuals situated in higher socioeconomic groups had beliefs about cancer and treatments which were different from individuals in lower socioeconomic groups (Yates, 1993). Thus, from the literature, it is uncertain whether alternate beliefs about cancer and treatment are unique to individuals from higher socioeconomic levels or are an artifact of having achieved higher education and income levels.

Relationships have been suggested between sociodemographic variables, such as education, income and age and the use of ACTs by individuals with cancer. However, it is unclear if the relationships between these variables and treatment decisions are causal. As well, limited research exists which explores the sociodemographic characteristics of women with breast cancer who use ACTS. Further research is needed to explore the nature of the relationships between sociodemographic variables and the use of ACTs by women with breast cancer.

Timing of alternative/complementary therapies in cancer trajectory.

A contradiction exists in the literature regarding the effect of time since diagnosis on the use of ACTs. Lerner and Kennedy (1992) reported ACTs are used most frequently by cancer patients who have been living with the disease for a significant period of time. As well, 44 percent of ACTs (N=36,000) were undertaken by patients after they had begun conventional treatment, with 17 percent of ACT use occurring before the commencement of conventional therapies (Lerner & Kennedy, 1992).

However, in another study, Cassileth et al. (1984) found no relationship between time since diagnosis and type of therapy chosen, with 43 percent beginning ACTs when metastases occurred, and 42 percent when diagnosed with local tumours or before diagnosis (N=378). However, these results must be viewed cautiously because the sample included a disproportionate number of patients with a high socioeconomic status. Perhaps the participants in this study were better able to afford alternative therapies and access ACT information than the general cancer population.

Cassileth et al. (1984) also reported 64 percent (N=325) of cancer patients using both types of therapies sought conventional treatments first, then added complementary therapies. Surprisingly, 40 percent of patients who used both types of treatments decided to discontinue conventional therapy entirely after approximately eight months of standard treatment (Cassileth et al., 1984). No rationale for this treatment decision were discussed by the researchers. However, Lerner and Kennedy (1992) developed understanding of the reasons why patients terminate the use ACTs. More than half of ACTs were terminated because they were considered ineffective, unnecessary, too expensive or were accompanied by unwanted side effects (Lerner & Kennedy, 1992).

Inconsistent results reported in the literature reveal the need for further knowledge about the effect of time since diagnosis on treatment decision. A prolonged disease trajectory may stimulate cancer patients to investigate alternative or complementary treatments as faith in conventional treatments diminishes. However, cancer patients appear to choose conventional treatment first, before turning to ACTs.

Further research is needed to explore the impact of time from diagnosis on treatment decisions by women with breast cancer and the timing of ACTs in the disease trajectory.

Factors associated with the use of alternative/complementary therapies.

Several factors have been identified as being related to ACT use in cancer populations. These factors include recent societal changes, social support, characteristics of cancer as a disease, and patients' beliefs about cancer, treatment, decisional control. First, the trend towards consumerism and the search for new and better services has contributed to ACTs' popularity (Fletcher, 1992). As well, society's dissatisfaction and mistrust of the health care system has encouraged cancer patients to approach ACT providers who use a more "holistic" approach to treatment and disease (Brown, 1987; Easthope, 1993; Engelking, 1994; Fletcher, 1992). Use of ACTs could also be a reaction to the discrepancy between medicine's assurance that cancer "can be beaten" and the 50 percent mortality rate of the disease (Engelking, 1994).

The social movement towards holistic health, combining body, mind and spirit has also supported the use of ACTs by cancer patients. Engelking (1994) described holism as the manifestation of society's rejection of a disease-oriented, technology-driven, paternalistic health care system. As well, the self-care movement, promoting fitness, proper nutrition and positive mental attitude is linked to the holistic philosophy underlying ACTs (LaCroix, 1985).

Social pressure from family and friends has also been put forth as a promoting factor of ACTs (Danielson et al., 1988; McGinnis, 1991; Montbriand, 1995; Yates et al., 1993). Yates et al. (1993) discovered encouragement by significant others to use therapies considered beyond the scope of western medicine caused ACT use to increase. Montbriand (1995) in a study of 252 cancer patients found social group influence to be the most important theme impacting the use of ACTs. The media and lay literature were also identified as contributing to ACT use by increasing the visibility of ACTs and the public's knowledge (Brown, 1987; Lerner & Kennedy, 1992).

The traumatic experience of being diagnosed with cancer may also encourage patients to seek ACTs in an attempt to increase their chances of survival (Danielson et al., 1988; Fletcher, 1992). Lerner (1994) suggested that the emotional burden of cancer and the fear it creates causes patients and family members to be vulnerable to "miracle cures". Montbriand (1993) also suggested, following interviews with over 300 cancer patients, that individuals who use ACTs believe using both conventional and unconventional therapies will increase their odds of survival.

Several studies have explored the impact of cancer patient's beliefs about cancer and treatment on treatment decisions (Cassileth et al., 1984; Lerner & Kennedy, 1992; Yates et al., 1993). Often, patients using ACTs believe cancer is preventable and reversible by altering factors such as diet, stress, and environmental conditions (Brown, 1987; Cassileth et al., 1984; LaCroix, 1985). Lerner and Kennedy (1992) found 58 percent of patients using ACTs believed the therapies would cure their disease. Cancer was thus seen as a symptom of underlying dysfunction or toxicity, rather than as a distinct disease. Some cancer patients who used ACTs also regarded conventional treatment as harmful and ineffective (Brown, 1987; Cassileth et al., 1984). For some cancer patients, ACTs are used as a method of coping with the toxic side effects of conventional medicine.

Danielson et al. (1988) also commented, based on clinical experience, that cancer patients involved in ACTs are highly stressed and have experienced a loss of control. Use of ACTs was believed to reflect a patient's desire to regain control and decrease stress (Danielson et al., 1988). Similarly, Montbriand and Laing (1991) and Montbriand (1993) hypothesized patients use ACTs as a control strategy, with the treatments allowing the patient to assume responsibility for their disease and treatment. Through qualitative interviews of 75 patients with cancer, Montbriand and Laing (1992) identifed three control theories: "perceived control", "internal-external control" and "illusion of control". Montbriand and Laing (1992) concluded that individuals vary considerably in how they use ACTs to develop a sense of control about their illness.

Cancer patients who used ACTs have also been found to prefer an active role in their health care (Cassileth et al., 1984; Yates et al., 1993). Yates et al. (1993) reported that a strong desire for control caused a six-fold increase in ACT use. However, the instrument used to assess the need for control had questionable reliability (Kendall Tau B = -.31), thus limiting confidence in the results. Montbriand and Laing (1991) also hypothesized that patients may use covert strategies, including ACTs, to regain control following the diagnosis of a life-threatening illness. Recent work by Montbriand (1995) also revealed individuals with cancer who maintained a high interest in ACTs also preferred decisional control over treatment choices.

Therefore, the use of ACTs in cancer populations may be related to increased consumerism and holism in society, dissatisfaction with the medical health care system, fear created by cancer, encouragement by others and the media, and alternative beliefs towards cancer and its related treatments and desire for control. However, these factors have not been explored specifically in women with breast cancer. Possibly, factors such as gender issues (e.g., sexuality), the relative speed of diagnosis and treatment, and the chronic nature of the illness promote ACT use in this specific cancer population. Further research is needed to identify factors that women with breast cancer perceive as influencing their treatment decision making and use of ACTs.

The Patient-Physician Relationship

The majority of discussion articles on ACTs were found to examine the patient-physician relationship and how physicians can improve communication and prevent ACT use by patients (Brown, 1987; Danielson et al., 1988; Lerner, 1993). Danielson et al. (1988) suggested ACTs may reflect deficiencies in the patient-physician relationship, especially in communication and holistic approach. The lack of communication between patients and physicians regarding ACTs is evident in Eisenberg et al.'s (1993) study which revealed that 72 percent of subjects failed to inform their physician about their use of ACTs. Similarly, Lerner and Kennedy (1992) found 35 percent of cancer patients did not inform their physician about their involvement with ACTs. In contrast, Cassileth et al. (1984) reported 75 percent of cancer patients told their doctors about their ACTs, with 30 percent of doctors expressing support.

Despite medicine's biased perspective of ACTs, some medical doctors recommend ACTs to patients. Lerner and Kennedy (1992) found 31 percent of patients were informed about ACTs by their physician. Similarly, Cassileth et al. (1984) found

36 to 65 percent of physical ACTs were recommended by or received from a medical doctor.

Thus, the quality of the patient-physician relationship may influence cancer patients' decision to use ACTs. The lack of communication between patients and physicians regarding ACTs is especially disturbing because of the invasive nature of some ACTs and possible side effects. As well, the benefits of ACTs may be hidden because of inadequate communication between patients and physicians. Hence, the quality of the patient-physician relationship of women with breast cancer and the impact of the patient-physician relationship on ACT use warrants further study.

Benefits and Risks of Alternative/Complementary Therapies

Cassileth et al. (1984) reported that 35 to 61 percent of cancer patients perceived ACTs as having a positive effect on their cancer. Cancer patients perceived an even higher positive effect (53-79%) of ACTs on their general health (Cassileth et al., 1984). ACTs may be perceived by cancer patients as a positive lifestyle change and not exclusively a cancer remedy. Engelking (1994) also suggested patients who use ACTs may experience a more supportive partnership with ACTs therapists, resulting in decreased anxiety and increased satisfaction with care. Quality of life rather than disease parameters may then be a more appropriate outcome measure for women with breast cancer who are using ACTs.

Despite positive findings related to ACT use, Cassileth et al. (1991) found patients using conventional therapies had significantly higher quality of life scores than patients using ACTs. Patients who use ACTs may have higher expectations of cure and thus experience greater disillusionment when ACTs fail to improve disease outcomes (Cassileth et al., 1991). These results, however, must be considered with caution because stage of cancer was not controlled in Cassileth et al.'s (1991) study, possibly influencing quality of life scores.

Research supporting the antitumour activity of physical therapies has been anecdotal and limited to single case studies, with no scientific evidence justifying their purported efficacy on disease outcomes. In fact, Montbriand (1993) revealed the numerous toxic side effects associated with some alternative biological interventions. However, the much quoted studies of Cassileth et al. (1985; 1991) on the negligible impact of ACTs on survival rates of cancer patients were undertaken with samples of advanced cancer patients with terminal prognoses, possibly biasing the results. As well, Cassileth et al.'s (1991) study of the survival of cancer patients using ACTs was limited by the small sample size (N=156) which lacked adequate power to allow subtle differences in survival outcomes to be detectable.

Several side effects and risks of ACTs have been identified in the literature. Lerner and Kennedy (1992) reported 6 percent of cancer patients using physical ACTs resulted in side effects such as vomiting, anorexia, weight loss, fatigue and diarrhea. However, these side effects are similar to those experienced by cancer patients undergoing conventional treatments such as chemotherapy and radiotherapy. Specific risks associated with ACTs have included cyanide toxicity deaths from the use of Laetrile and ruptured bowels from self-administered enemas. As well, physicians surveyed by Lerner and Kennedy (1992) believed delay in seeking conventional treatment to be the most serious side effect of ACT use.

Despite the lack of substantial clinical evidence of the efficacy of ACTs in treating cancer, patients have been found to believe in the positive impact of ACTs on overall health. Limited research has been conducted to examine the positive outcomes of ACTs with cancer patients. Perhaps biomedical outcome measures, such as survival rates and tumour size are not appropriate measures to evaluate the benefits of ACTs. Exploratory research is required with women with breast cancer, which may reveal outcome measures congruent with the needs met by the use of ACTs.

Treatment Decision Making Process of Women with Breast Cancer

In recent years increased emphasis has been placed on research exploring the decision making process by women with breast cancer. This shift may reflect an increased demand by women with breast cancer to play a more active role in the treatment decision making process (Degner & Sloan, 1992). As well, preference of an active role in treatment decision has been linked with increased use of ACTs in cancer populations (Montbriand & Laing, 1991; Yates et al., 1993). However, research has been inconsistent with regard to the level of control preferred by women with breast cancer. Six major studies have been identified exploring the treatment decision making process with cancer patients, including individuals with breast cancer.

Degner and Sloan (1992) developed a card-sort technique which demonstrated the ability to rank order individuals' preferred level of control over treatment decisions. Subjects were presented with five cards demonstrating differing levels of participation in the patient/physician decision making process. Each card was paired and then contrasted with other cards, until preference order was unfolded. Three categories of decision making roles were apparent: active, collaborative and passive (Degner & Sloan, 1992). Degner and Sloan (1992) found 12% of patients with cancer

(N=436) preferred an active role, while 59% of the sample preferred to let their physician make treatment decisions. In contrast, 64% of individuals randomly selected from the general public (N=482) stated they would prefer an active role in decision making when presented with the scenario of being diagnosed with cancer. Degner and Sloan (1992) suggested that the crisis of being diagnosed with cancer may cause patients to assume a passive role, which may change over time as patients gain knowledge about their diagnosis and disease. As well, a passive role may allow responsibility for failure of treatment to be held by the physician rather than the patient (Degner & Sloan, 1992).

In 1994, Hack, Degner and Dyck interviewed and conducted the card-sort technique with 35 women diagnosed with Stage 1 or 2 breast cancer. The researchers hypothesized that individuals preferring an active role in decision making would also desire greater information regarding treatment and prognosis (Hack, Degner & Dyck, 1994). Twenty-three percent of women reported preferring an active role in treatment decisions, with 57 percent electing a collaborative role where the physician and patient together make decisions regarding treatment. Hack, Degner and Dyck (1994) suggested the increased number of individuals choosing an active role in decision making in comparison to the study by Degner and Sloan (1992) was related to the dissimilarities in the two studies' samples. In Degner and Sloan's (1992) study, a variety of cancers were represented, with women with gynecological cancer having the highest preference for an active role. The homogeneity of the sample in Hack, Degner and Dyck's study (i.e., women with breast cancer) may account for the increased number of patients preferring an active role, suggesting that the breast cancer population may be unique with respect to decision making role preferences.

Hack, Degner and Dyck (1994) also reported that women who preferred an active role also felt greater control over their body, health and life than women who chose a collaborative or passive role in decision making. Women choosing an active role in decision making also wanted information regarding their medical care and prognosis. Patients preferring a passive role felt that only physicians possessed the knowledge necessary to make treatment decisions and wanted limited information regarding their disease (Hack, Degner, & Dyck, 1994).

Montbriand and Laing (1991) explored the decision making process of cancer patients by interviewing 75 cancer patients receiving biomedical treatment. Ethnographic interviews revealed that 89 percent of the sample were using ACTs, which patients reported reduced their feelings of helplessness and lack of control. By using ACTs cancer patients reported feeling in control of an adverse situation and expressing their freedom of choice (Montbriand & Laing, 1991). Montbriand and Laing (1991) also related patients' decision to use ACTs to having an external and internal locus of control. Patients appeared compliant with their physician's medical regime, but covertly demonstrated an internal locus of control by using ACTs (Montbriand & Laing, 1991). However, the crisis of being diagnosed with cancer caused some patients to change their orientation of control, becoming passive in the treatment decision making process. Montbriand and Laing (1991) also suggested that cancer patients using ACTs were creating an "illusion of control", where a situation governed by chance was given the illusion of being controllable.

Further work by Montbriand (1993, 1995) with over 300 individuals with cancer led to the development of a decisional tree, describing the pathways taken by cancer patients to arrive at the conclusion to use ACTs. Using a cognitive, ethnographic approach, a decision making tree related to treatment choice was initially pilot tested with 48 individuals with cancer in a biomedical setting. Two basic outcomes were apparent: a) to choose alternate along with biomedical health care or b) to choose biomedical health care only. Three types of informants were also identified: High Interest, Regular, and Biomedical Only. The High Interest group were individuals searching for additional alternatives since being diagnosed with cancer. The Regular group was composed of individuals who had used alternative health care practices in the past and were not interested in searching for new alternatives. The Biomedical Only group were individuals intending to use only conventional medical interventions. Ten main themes were identified which influenced the decision to use either biomedical and/or alternative health care: preferred treatment methodology; secrecy about alternatives; social group influence; consideration about cost; perceived stress; desired decisional control; beliefs about cure, change, and searching; and faith in the practice. These main themes compose the main trunk of the decisional tree, resulting in the decision to use alterative and/or biomedical interventions.

Phase two of the study involved testing the decisional tree with 252 individuals diagnosed with cancer (Montbriand, 1995). The predictability of the decision tree model was established at 90.4 percent (Montbriand, 1995). Fifty-six of the informants were High Interest group members, 121 were Regular group members and 75 were Biomedical only group members (Montbriand, 1995). Montbriand (1995) reported that High Interest group members were generally younger than other subjects and had a higher socioeconomic status than member of the Biomedical Only group. As well, High Interest group members indicated stress was a major reason they were searching for alternative treatments and they had broader view of what could be a cure for cancer (Montbriand, 1995). High Interest group members, according to Montbriand (1995), also preferred decisional control and were self-motivated to search for alternate care. Regular and Biomedical Only group members were less stressed than High Interest group members and were less likely to believe that a cure for cancer existed outside of the biomedical world (Montbriand, 1995). Furthermore, Regular and Biomedical Only group members preferred less decisional control and were unmotivated to search for a cure beyond conventional treatment.

Yates et al. (1993) conducted a study in Australia of 152 advanced cancer patients. She reported that desire for control over treatment decisions was predictive of the subjects' use of ACTs. Using a detailed questionnaire, Yates et al. (1993) found that subjects who reported a strong desire for control were six times more likely to use ACTs than those who held a moderate or weak desire for control. However, the scale used to determine desire of control was a two-item scale, thus limiting the reliability of the results. Despite this limitation, multiple logistic regression analysis of the results determined that desire for control over treatment decisions remained an important predictor of the use of ACTs (Yates et al., 1993). Correlation analysis also revealed a relationship between age and desire for control. Yates et al. (1993) suggested that younger individuals with cancer may be more sceptical of medical treatment and prefer to play an active role in decisions regarding care.

In summary, research by Degner and Sloan (1992) and Hack, Degner and Dyck

(1994) revealed that a significant number of individuals with cancer, particularly women with breast cancer, prefer to play an active or collaborative role in the treatment decision making process. For some individuals with cancer, one possible method of expressing an active role may be to select treatment considered alternative by biomedical caregivers. The decision to use ACTs may also reflect cancer patients' desire to create the "illusion of control" in a situation that may have occurred through chance. As well, preliminary research suggests that the decision to use ACTs and playing an active role in treatment decisions may be a function of age and socioeconomic status. Possibly, younger individuals with cancer with higher income and educational levels may hold beliefs which encourage independence in treatment decisions and exploration of alternative medicine. However, research related to treatment decisions has been limited to general cancer populations. Further study is required to examine the role of preferred decision making role in the use of ACTs in breast cancer populations.

Quality of Life and Women with Breast Cancer

In recent years, there has been increased emphasis placed on the need to assess the impact of cancer and conventional treatments on the "quality of life" (QOL) of individuals diagnosed with cancer (Aaronson et al., 1994). Clinicians and researchers working with cancer patients have acknowledged the importance of functional, psychological and social health as well as physiological outcome measures such as tumour progression and recurrence. However, the lack of a unanimous definition for the concept "quality of life" has made assessment and comparisons among individuals with cancer difficult. A review of the literature revealed several definitions and theories of QOL currently used in health research: 1) discrepancy theory, 2) satisfaction with life and needs, 3) general happiness, 4) health, 5) attainment of personal goals, and 6) social utility.

Discrepancy theory as a definition of QOL has been espoused by Calman (1984). Calman (1984) defined QOL as measuring the discrepancy between hopes and an individual's actual experiences. The smaller the discrepancy, the greater the QOL experienced. According to this definition, QOL can be improved only by an individual either lowering his/her hopes or changing their experiences. Calman (1987) extended this definition to include physical, psychological, interpersonal, socioeconomic and spiritual dimensions. A criticism of discrepancy theory as a definition of QOL is that individuals who hold great ambition or aspire to goals currently beyond their reach are assessed as having a low QOL.

A second conceptualization of QOL is an individual's satisfaction with life and needs. Oleson (1990) defined QOL as the "cognitive experience manifested by satisfaction with life domains of importance to the individual and an affective experience manifested by happiness with important life domains". Satisfaction definitions of QOL thus identify subjectivity as being a key attribute of QOL. This allows individuals control over what life dimensions are considered important to their definition of quality of life. Hornquist (1982) also defined QOL as being the satisfaction of personal needs, which are priorized by individuals.

QOL has also been conceptualized as the level of happiness experienced by an individual. Baltusch and Waltz (1987) conceptualize QOL as the balance between euphoric and dysphoric feelings states. Bertero and Ek (1993) also identified having a positive attitude towards life, including enjoying life, as the superior defining dimension of leukaemic patients' QOL. Dubos (1976), however, cautions researchers about the difficulties associated with using traditional medical assessments to measure happiness. As well, Holmes (1989) criticizes defining QOL as happiness because it would lead to a hedonistic perspective.

"Health" as a definition of QOL has been supported in the past by health care researchers as being the most important dimension of QOL. However, Flanagan (1982) and Dimenas and his colleagues (1990) both caution defining health by objective measures alone, such as physical functioning scales. Instead, patients should be allowed to define what they interpret to be "good health". The recent publication of a special edition of the Journal of Palliative Care (September, 1992) devoted to QOL issues indicated that health may no longer be a prerequisite to a high QOL.

A fifth definition of QOL is the attainment of personal goals. This conceptualization is related to satisfaction of needs, but focuses more on successes and failures (Ferrans, 1990). However, conceptualization of QOL as the accomplishment of personal goals has been criticized as narcissistic. Gerson (1976) instead proposed that individuals attain personal goals while existing in the larger community and respecting social order. This conceptualization also reflects a subjective perspective of QOL.

The final conceptualization of QOL found in the literature was QOL as an individual's social utility in a community. Shaw (1977) expressed QOL as an equation, QL= NE, with NE representing a patient's natural physical and intellectual abilities. Edlund and Tancredi (1985) also defined QOL as being the ability to lead a socially useful life. The definition may include fulfilment of social and family roles, employment and contribution to the national economy (Edlund & Tancredi, 1985). However, this conceptualization of QOL has been criticized as being reductionalistic, with limited application to clinical practice (Ferrans, 1990). Despite this appraisal, social utility definitions of QOL are frequently used in health care policy, using instruments such as Karnofsky's Functional Scale (Karnofsky & Burchenal, 1949).

Despite the variation in conceptualizations of QOL, two key attributes of QOL were apparent in the literature. Firstly, the subjective nature of QOL is identified in the majority of definitions as being paramount over objective assessments. Ferrans (1990) felt subjective assessment of QOL rather than objective evaluations of QOL by health care professionals were necessary because of the differences in value systems between the two groups. Aaronson et al., (1994) also emphasised that QOL was a subjective concept that must be determined by cancer patients and not by observers. Secondly, QOL is often defined as being multidimensional, including physical, psychological, social and spiritual dimensions. Ferrans (1990) emphasised that QOL was more than just health, and by having a multidimensional construct, individuals are able to define QOL based on what dimensions are important to them.

A number of QOL instruments have been developed which assess the multidimensional nature of QOL. However, few QOL tools have been specific to individuals with cancer, who may have unique concerns such as side effects of cancer treatments and threat to mortality. As a consequence, few clinical trials have explored QOL as an outcome measure of new cancer protocols and treatments (Aaronson et al., 1994). In response to this paucity of QOL instruments for cancer patients, the European Organization of Research and Treatment of Cancer (EORTC) developed a core questionnaire which would address the multidimensional nature of QOL and general health issues specific to individuals with cancer. The result, the EORTC QLQ-C30 (version 2), is a 30 item instrument which explores patients' subjective interpretation of physical, role, cognitive, emotional and social functioning and symptoms related to cancer and cancer treatment (Aaronson et al., 19930. A global quality of life question is also included in the EORTC QLQ-C30 (version 2). Aaronson et al. (1990) reported in a study of 346 individuals with cancer from twelve countries that the EORTC QLQ-C30 (version 2) was valid and reliable across cultures. In future studies, the EORTC hopes to develop instruments specific to cancer diagnoses, such as lung and breast cancer.

A review of the literature revealed a variety of studies exploring the concept of quality of life with women with breast cancer. Several studies explored the effect of conventional treatment (surgery, chemotherapy and radiotherapy) on the quality of life of breast cancer patients. Carlsson and Hamrin (1994) in a review of 26 articles concluded that there were insignificant differences in QOL between women who had breast conserving surgery and women who had a mastectomy. Adjustment to the diagnosis of breast cancer was best determined by pre-morbid history of psychiatric disorders rather than quality of life assessments (Carlsson & Hamrin, 1994).

Similarly, Hughes (1993) explored the quality of life of newly diagnosed breast cancer patients (N=52) who were given the choice between breast-conserving surgery and mastectomy. Hughes (1993) reported that no difference in quality of life was evident between women who had a lumpectomy and women who had a radical mastectomy. As well, no significant decrease in physical, social and role functioning was apparent in the two treatment groups. Hughes (1993) concluded that breast cancer had limited impact on QOL. This result was attributed to the women being more appreciative of life following diagnosis and being thankful that the cancer was diagnosed in its earliest, most curable stage.

Ferrans (1994) studied long-term survivors of breast cancer (N=61) who had undergone surgery (97%), chemotherapy (46%) and radiotherapy (30%) approximately 10 years ago. Using a questionnaire and interview, Ferrans (1994) found the majority of women (95%) thought the conventional treatments they had undergone in the past had been worthwhile. Most women reported feeling healthy and were practicing healthier lifestyles since being diagnosed. Some of the women also reported having repriorized what was important in their life after being diagnosed with breast cancer. Unfortunately, 12 out of 61 women reported that they were still experiencing depression related to altered body image (Ferrans, 1994). Women who had experienced a relapse, in particular, expressed the need for extra support (Ferrans, 1994). However, Ferrans (1994) reported the majority of women no longer felt cancer was influencing their quality of life.

Thus, quality of life has been explored with women diagnosed with breast cancer who have undergone conventional treatments. However, a lack of literature exists which explores the quality of life of women who have chosen ACTs in conjunction with medical therapies or alone. Preliminary research was conducted by Cassileth et al. (1991) on a sample of general cancer patients who used ACTs, with subjects using ACTs reporting lower QOL scores than individuals using conventional treatments. However, women with breast cancer have been reported to be a group with unique issues that may influence use of ACTs and quality of life. Thus, research is needed to study quality of life in relation to ACT use in the breast cancer population.

Summary

A review of the literature revealed that women with breast cancer are a unique cancer population with specific issues related to conventional cancer treatments. Women with breast cancer often move through the diagnosis and treatment phase of the cancer trajectory in a short period of time which prevents adequate discussion and exploration of treatment alternatives. Traditional conventional treatments of surgery, chemotherapy and radiotherapy place intense physical and psychological demands on women with breast cancer, influencing their perceived quality of life. For some women with breast cancer, ACTs may become a valid treatment option when compared to the toxic and invasive conventional treatments. Three main categories of ACTs exist: physical, psychological and spiritual. Unique characteristics and motivations are associated with each type of ACTs, allowing the individualized needs of people with cancer to be addressed. Studies have reported that a significant number of individuals with cancer use ACTs, despite the lack of empirical evidence supporting the efficacy of ACTs in cancer care. Possibly, cancer patients use ACTs as a way of regaining control over their health care which has been subsumed by the health care system. For women with breast cancer, ACTs may represent a chance to play an active role in treatment decisions. As well, individuals with cancer have reported improved well-being rather than hope for a cure as being the motivator for using ACTs. Thus, quality of life rather than disease parameters may be a more appropriate measure of ACTs efficacy in cancer patients. Research is needed to explore the associations between conventional treatments, ACTs, treatment decisions and quality of life in the breast cancer population.

CHAPTER THREE

METHODOLOGY

The design of the study was structured into two phases: 1) an instrument testing and refinement phase to examine the appropriateness of the revised questionnaire, entitled the BTPS-BC, for use with a breast cancer population; and 2) a descriptive and hypothesis-generating phase to elicit the types of treatments used by these women (i.e., conventional therapies and ACT), beliefs women with breast cancer hold regarding their disease and treatment, and factors perceived by the women as influencing their treatment and care decisions. Potential factors measured included beliefs about treatments and causes of cancer, the quality of the patient-physician relationship, encouragement by others, preferred decision making role, and perceived quality of life. An exploratory, quantitative methodology using the BTPS-BC and existing tools (i.e., Degner and Sloan's decisional preference card-sort, EORTC quality of life instrument) was used in phase two of the study. This chapter provides rationale for the methodology selected and details the study design, study limitations, and ethical considerations.

Selection of the Research Methodology

The first phase of the study, instrument testing and refinement, was selected because of the absence of a tool that measures the use of ACTs with a breast cancer population. Yates' (1991) questionnaire of beliefs and practices of people with cancer had shown preliminary evidence of reliability and validity with a general cancer population; however, refinement and testing of the questionnaire appeared necessary to address issues specific to this study's population (i.e., women with breast cancer).

Firstly, revisions to the questionnaire were recommended by Ms. Yates, based on the results of her thesis research study, which demonstrated conceptual ambiguity on some scales and lack of precision of response options (Yates, 1994). Also, research with women with breast cancer has revealed that these individuals are a unique cancer population. For example, Fallowfield and Clark (1991) emphasized the distinct attributes of women with breast cancer in comparison to other cancer patients, particularly in terms of impact on sexuality and body image. As well, women with breast cancer have been found to prefer a higher level of involvement in treatment decision-making than general cancer populations, which may influence their perceptions of ACT use (Degner & Sloan, 1992). Lastly, women with breast cancer at the Canadian Breast Cancer Forum advocated research exploring the efficacy of ACTs specific for breast disease, perceiving their needs and interest in ACTs as being unique from the general cancer population in Canada (National Forum on Breast Cancer, 1994). Thus, instrument testing was required with women with breast cancer to ensure the BTPS-BC, was appropriate to explore ACT use in a breast cancer population.

The second phase of the study, hypothesis generation using an exploratory, quantitative design, was considered to be appropriate for two reasons. Firstly, a review of the literature indicated that substantial research has been conducted to examine ACT use in general cancer populations. Motivations such as desire for control, alternate beliefs about cancer and treatment and quality of the patient-physician relationship have been identified as being associated with ACT use by individuals with cancer (Cassileth et al., 1984; Montbriand, 1993; Yates et al., 1993). Thus, a descriptive design, using a revised questionnaire of beliefs and treatment practices of cancer patients, was appropriate because it allowed exploration of associations between previously identified variables within a more specific cancer population (i.e. women with breast cancer). Secondly, a quantitative methodology was appropriate because instruments with acceptable reliability and validity estimates which measure the study's variables already existed (i.e., Yates' questionnaire (1991), EORTC QLQ-C30 (version 2) and decisional control preference card-sort).

Design of the Study

Phase I - Pilot Study

The first phase of the study used Imle and Atwood's (1988) methodology of an expert panel of women with breast cancer to assess the clarity, apparent internal consistency and content validity of the BTPS-BC. This phase was necessary to ensure the revised questionnaire was relevant to women with breast cancer and applicable to a Canadian population.

Population, Sample Criteria and Setting

The population for the pilot study consisted of all women in Manitoba who had been diagnosed with breast cancer, following tissue biopsy.

Six women with breast cancer were recruited from the Victoria General Hospital Outpatient Oncology Unit. These women included individuals known to the researcher through clinical experience and women identified as appropriate by clinic nurses. All women were able to speak and read English and were over the age of 18 years. Women with all stages of cancer were accepted as panel members. A variety of medical treatments, including surgery, chemotherapy, radiotherapy and hormone therapy were experienced by panel members. As well, panel members represented the full range of ACT use, from no ACT use to complete adherence to an ACT regimen.

Recruitment Procedure

Identified women were approached by clinic nurses, who asked if they would be interested in participating in a pilot study exploring the beliefs and treatment practices of women with breast cancer (Appendix C). All women approached expressed interest in participating in the pilot study and gave permission to have their names and phone numbers released to the researcher. The women were subsequently contacted by phone by the researcher, who explained the purpose and process of the pilot study (Appendix C). Arrangements were then made to meet the panel members individually at a place of convenience (i.e. their home). All panel members were given the opportunity to read and sign a consent form prior to participating in the pilot study (Appendix C).

Data Collection Protocol

The methodology developed by Imle and Atwood (1988) involved a three-step process: assessment of item clarity; assessment of apparent internal consistency of subscales; and content validity of subscales. Item clarity assesses how clearly an item conveys a portion of a concept. Items selected randomly from all subscales were combined and presented to panel members, who described the clarity of each item (Appendix C). Next, panel members were presented with the seven unlabelled scales of the BTPS-BC and asked the following questions: 1) "Do these items belong together?"; and 2) "Does each item belong in the set?" (Appendix C). This measure of apparent internal consistency assessed the homogeneity of the scales' items (Imle & Atwood, 1988). Finally, panel members assessed content validity by comparing the subscales and the corresponding items with the labels of the subscales and concept definitions (e.g., beliefs about cancer). Panel members responded to the following four questions for each scale: 1) "Does the label and definition fit the whole set of items?"; 2) "For each item, does it belong to the label and definition?"; 3) Is each item unique?"; and 4) Is anything left off the list that you think should be there?" (Appendix C). Content validity assesses how well each subscale fits the overall domain and if redundancy of items has occurred. Scale directions were also assessed for format, clarity and reading level (Imle & Atwood, 1988).

Data Analysis

Items and scales were modified according to panel members' recommendations and extent of agreement about questionnaire items using percent agreement. Imle and Atwood (1988) recommended using a percent agreement of greater than or equal to 83.3 percent (5/6 panel members) to determine the appropriateness of the questions and items for use with a breast cancer population. Overall, the pilot study ensured that qualitative validity of the revised questionnaire was retained while quantitative validity and reliability were gained (Imle & Atwood, 1988).

Phase II - Descriptive and Hypothesis Generation

Population and Sample Criteria

At the time of the study, the population consisted of all women in Manitoba who are/were diagnosed by a tissue biopsy as having breast cancer. A tissue biopsy was a prerequisite for this population as some alternative therapies, for example, bacille Calmette-Guerin immune therapy, diagnose cancer based on other physiological indices not recognized by the Canadian Cancer Society as being valid physical indicators of cancer.

The sample was anticipated to consist of approximately 35 women with breast cancer undergoing conventional therapies only; 2) 35 women with breast cancer who were using both conventional therapies and ACTs; and 3) women with breast cancer identified as using only ACTs. The latter subsample was not defined by size because it was predicted that a small number of women with breast cancer would have foregone or withdrawn from conventional treatment (Cassileth et al., 1984). Unfortunately, due to data collection time constraints and difficulties accessing ACT therapists, recruitment of women with breast cancer using only ACTs was not feasible for this study. The elusive and sensitive nature of this population of women with breast cancer using only ACTs warrants a more in-depth, qualitative methodology, which was beyond the scope of this study. Phenomenology or ethnography perspectives are indicated in future research to explore the unique experiences of women with breast cancer who have refused conventional medical treatment and are using only ACTs.

Participants from all stages of breast cancer took part in the study. Time since diagnosis was measured for each participant but was not a limiting factor of recruitment. Participants were required to speak and read English and be over the age of 18 years of age. Participants receiving chemotherapy, radiotherapy, surgery, and/or hormone therapy were included in the study.

Setting

The subsamples of women using conventional therapies only or conventional therapies and ACT were drawn from three centres: 1) Manitoba Cancer Treatment and Research Foundation (MCTRF) outpatient oncology clinic at Health Sciences Centre;

2) MCTRF outpatient oncology clinic at St. Boniface General Hospital; and 3) Victoria General Hospital outpatient oncology clinic. The two MCTRF clinics operate within tertiary, teaching hospital environments. A variety of medical treatments, including chemotherapy, radiotherapy and hormone therapy are provided on an outpatient basis. The Victoria General Hospital outpatient oncology clinic functions within a community hospital setting, providing patients with chemotherapy and follow-up care.

Sampling Methodology

Convenience sampling was used at the outpatient clinics because of the practicality of this method (Polit & Hungler, 1991). Approximately 730 women are diagnosed with breast cancer in Manitoba each year and half of these newly diagnosed women are treated by MCTRF. Therefore, recruitment of a sample of approximately 70 women in six months (January, 1996 to June, 1996) from this facility and the community clinic was deemed to be feasible. As well, demographic data from Degner et al.'s study (under review) of breast cancer patients sampled from these settings (N=1012) revealed that the women from these clinics range in time since diagnosis from 0 to 6 months (27.5%) to 25+ months (55.2%). Thus, it was possible to recruit both newly diagnosed and recurrent breast cancer patients.

The total sample size of 70 women was justified because it provided a sufficient number of subjects to conduct the quantitative analysis and was feasible within the boundaries of the thesis research time frame.

Recruitment Procedure

Two methods of recruitment occurred from January 1996 to June 1996, depending on the clinical setting. At MCTRF outpatient oncology clinics, clinic nurses identified women with breast cancer who met the sampling criteria and were interested in learning more about the research study. After the women had completed their medical appointment, the researcher approached potential subjects in person to explain the study as described in "Explanation of Study to Potential Subjects" (Appendix D). Interested subjects were then contacted at home by the researcher several days following initial contact and an appointment was made to complete the instruments at a place of convenience (e.g., in their home).

At the community oncology clinic, potential subjects were identified by clinic nurses and their home phone numbers were provided to the researcher. The researcher contacted all identified women by phone and explained the study using the "Explanation of Study to Potential Subjects" (Appendix D). Appointments were then made with interested subjects to complete the instruments at a place of convenience (e.g., their home). This method of recruitment was recommended by the community oncology clinic nurses because of their inability to discuss the research project with potential subjects because of time constraints. All potential subjects contacted by phone by the researcher were told that their name and number had been provided by their clinic nurse and were assured that they were under no obligation to participate in the study. The high response rate and enthusiasm of women from the community oncology clinic reassured the researcher that this method of recruitment was acceptable to potential subjects.

Consenting subjects from all three sites were given the opportunity to read and sign the consent form prior to participating in the study (Appendix D). When possible, administration of the instruments was avoided within the clinical setting to protect patient confidentiality regarding treatment choices.

Data Collection Instruments

The instruments used in this study consisted of the BTPS-BC, a card sort which explored preferences in treatment decision making (Degner & Sloan, 1992), the EORTC QLQ-C30 (version 2) quality of life tool (Aaronson et al., 1993), and a personal demographic form (Appendix A).

The Belief and Treatment Practices Survey - Breast Cancer (BTPS-BC).

The BTPS-BC originated from a questionnaire developed in Australia by Yates (1991). The questionnaire of cancer patients' beliefs about cancer and treatment (Yates, 1991) was a 171-item survey which explored the beliefs and treatment practices of people with cancer. The questionnaire was pilot-tested by Yates (1991) in Australia with a sample of 152 advanced cancer patients. The questionnaire consisted of three sections. The first section explored disease information, the use of medical and alternative therapies and practitioners, future intentions regarding ACTs, and reasons why individuals would use ACTs. The second section consisted of eight scales related to beliefs and attitudes, including: 1) beliefs about cancer; 2) beliefs about medical treatment; 3) beliefs about ACTs; 4) attitudes to alternative practitioners; 5) attitudes to medical practitioners; 6) need for control over treatment decisions; 7) will to live; and 8) encouragement to use alternative therapies. The last section explored miscellaneous information, including amount spent of ACTs, adherence to ACTs, time spent using ACTs, prognosis of disease, and demographic data.

A variety of response options were used throughout the questionnaire. Items exploring use of ACTs had a "yes" or "no" response option. The "Beliefs about Cancer", "Beliefs about Medical Treatment", "Beliefs about Alternative Treatment" and "Need for Control over Treatment Decisions" scales were structured as a 1 to 5 Likert-type response scaling ("Very true", "Mostly true", "Partly true", "Not true at all" and "Don't know"). The "Encouragement to use Alternative Cancer Therapies" scale were formatted as a 1 to 4 Likert scale ("Very true", "Mostly true", "Partly true", and "Not true at all"). The "Attitude to Medical Practitioners" and "Attitude to Alternative Therapists" scales used a 5-point Likert-type response scale ("Strongly agree", "Agree", "Unsure", "Disagree" and "Strongly disagree").

Factor analysis was used by Yates (1991) to eliminate extraneous items and refine the eight scales. As a result of the factor analysis, one new scale was added, "Beliefs in the Adverse Effects of Medical Treatment", representing a sub-dimension of the "beliefs about medical treatment" scale. Revisions were also made to the seven other scales.

The revised scales measuring "Beliefs about Cancer", "Beliefs about Medical Treatment", "Beliefs about Alternative Treatment" and "Will to Live" had reported reliabilities, as measured by Cronbach's alpha coefficient, of 0.75, 0.61, 0.89, and 0.87 respectively (Yates et al., 1993). The new subscale, "Beliefs in the Adverse Effects of Medical Treatment", had a Kendall Tau B's correlation of .29. This low reliability was reflective of the two-item construction of the scale. Yates (1991) included the "Beliefs in the Adverse Effects of Medical Treatments" scale in data analysis because she believed this scale measured an important concept related to ACT use.

The "Satisfaction with Oncologist" and "Opinion of Alternative Cancer Therapist" scales were reported by Yates (1991) to have Cronbach's alpha coefficient of 0.88 and 0.94 respectively. For the "Encouragement to use Alternative Cancer Therapies" scale, Yates (1991) reported an internal consistency estimate of a Kendall Tau B, of 0.37. Yates (1991) justified inclusion of this scale, despite the moderate reliability estimate, based on a review of the literature which supported social influence as a motivating factor of ACT use.

The "Desire for Control" scale also achieved a low internal consistency estimate, with a Kendall Tau B correlation of -0.31. Yates (1994) recommended that the "desire for control" scale be replaced in future research with a more reliable and valid instrument measuring decisional control.

For the present study, numerous revisions to Yates' (1991) questionnaire were necessary to reflect the unique perspective of women with breast cancer in the Canadian health care system. As well, modifications suggested by Yates (1994) were made to improve the reliability, validity and readability of the instrument. All items composing the beliefs and attitudes scales prior to Yates' (1991) factor analysis were included on the BTPS-BC. This was done to ensure that items relevant to Canadian women with breast cancer were not excluded prematurely from the survey.

All scales, with the exception of the "attitudes towards alternative practitioners" and the "need for control over treatment decisions" scales, were included on the BTPS-BC. The "attitudes towards alternative practitioners" scale was omitted from the BTPS-BC because of the scale's poor performance in Yates's (1991) study. Australian advanced cancer patients were unable to express an opinion about alternative therapist, with between 64.4 and 80.0 percent of responses falling in the "unsure" category.

On the advice of Yates (1994), the "Need for Control over Treatment Decisions" scale was eliminated from the BTPS-BC in favour of a more reliable and valid instrument (i.e., Degner and Sloan (1992) decisional preference card-sort). In addition to demonstrating sound psychometric estimates, the decisional preference card-sort has also been used extensively with a breast cancer population.

Scales measuring women with breast cancer's future intentions regarding ACTs and alternative/complementary therapists were also included on the BTPS-BC. These scales were used by Yates (1991) in her original questionnaire but data from the scales did not constitute a major portion of her research. However, in the present study, women with breast cancer's future intentions regarding ACTs were considered to be an important component of treatment practices and decisions.

An additional revision to Yates' (1991) questionnaire involved standardizing the response indexes throughout the BTPS-BC. This was done on the advice of Yates (1994), who suggested that a common response option for the scales would improve the readability of the instrument. As a result, a 5-point Likert-type scale, ranging from "Strongly Agree" to "Strongly Disagree" was used on all scales of the BTPS-BC. As well, Yates (1994) recommended the "yes" or "no" option for the questions exploring ACT use be modified to a 4-point Likert response scale (Never, Rarely, Occasionally, Frequently) that would estimate frequency of ACTs use.

Demographic information and medical history questions were also removed from the questionnaire and placed on a separate personal demographic form (Appendix

A). Data related to the participants' disease and medical treatment were obtained from the patient's chart upon approval by both the patient and facilities. When possible, staging of breast cancer followed the TNM classification of malignant tumours, as recommended by the International Union against cancer (UICC, 1987). Further revisions to the questionnaire involved eliminating items that were not applicable to a breast cancer population (e.g., "What type of cancer do you have?"). Thus, prior to pilot testing, the BTPS-BC was comprised of 124 items and predicted to take approximately 45 minutes to complete.

Preferred Treatment Decisional Role Card-Sort.

Following administration of the BTPS-BC, the treatment decision making card-sort was presented to participants. The card-sort technique developed by Degner and Sloan (1992) consists of five cards with written statements and illustrations which depict varying degrees of treatment decision-making control by the patients (see Appendix A). The cards are divided into three types of control over decision making: 1) active (card A and B); 2) passive (card D and E); and 3) collaborative (card C) (Degner & Sloan, 1992). The cards were presented in pairs by the researcher and the participants were asked to indicate which of the two cards they preferred. This process continued until all five cards were ordered by preference. The order of presentation was fixed, so that order effects were controlled (i.e., Card B, D, C, A, E). The decision making card-sort took approximately five to ten minutes to complete.

Bilodeau (1995) found that women who performed the card-sort made a distinction between treatment decisions related to surgery and adjuvant treatments, such as chemotherapy. For the purposes of this study, subjects were encouraged to consider treatment decisions related to adjuvant treatment, which would encompass ACTs. Following the ordering of cards by preference, participating women were presented all five cards at one time and asked to pick which card best described the actual role they played in their treatment decision making process with their physician(s). This procedure revealed the discrepancy between actual decision making role played and the treatment decision making role women with breast cancer would have preferred to have performed.

Several benefits of using paired comparisons as a data collection technique have been identified in the literature (Coombs, Dawes, & Tversky, 1970; Hack, Degner, & Dyck, 1994; Sloan & Yueng, 1994). Hack, Degner and Dyck (1994) hypothesized that the card-sort technique was more motivating than paper-and-pencil measures or direct questioning because it allowed subjects to actively lay out their preferred order of alternatives. Sloan, Doig and Yueng (1994) also reported that subjects creating a rank order of items were able to identify top and bottom choices, but found discrimination between middle items difficult. The use of paired comparison allows constant comparison and ranking of items. Likert-scale response for items has been used as an alternative to rank ordering, however, the possibility of tied scores reduces the practicality of this approach (Sloan & Yueng, 1994). As well, Likert-type scaling can result in a "ceiling-effect" as a consequence of subjects giving the highest value as a response to each item. This effect may be a result of social desirability, with subjects being intrinsically compelled to respond to items in a certain manner (Sloan & Yueng, 1994). The paired comparison forces subjects to choose one item over another, thus preventing a ceiling effect.

Card-sort methodology is based on an unidimensional model called unfolding theory, developed by Coombs (1976). Unfolding theory suggests that people have a set of preferential choices which are transitive and may be represented by a rank order of stimuli from most to least preferred. It is assumed that each individual has an ideal point, with stimulus points being ranked in order according to how near the corresponding stimulus points are to the ideal point (Coombs, 1976). The preferential choice between two stimuli is interpreted to mean one point is nearer the individual's ideal point than the other point. The underlying assumption of unfolding theory is that there exists a psychological dimension which accounts for the observed behaviours, for example, treatment decision making (Coombs, 1976). Theoretically, each individual and stimulus may be represented by a point on a dimension called a "J Scale". By "folding" the J Scale at an individual's ideal point, a rank of order of stimuli given in order of increasing distance from the ideal is formed. This rank order is called an "I Scale". An unfolding of the ordered preference would then uncover what criteria people were using to rank the items.

The hypothetical rank order of the dimension "decision making" in Degner and Sloan's (1992) card-sort is from most involvement to least involvement in the treatment decision making process. This is represented by the cards, A, B, C, D, and E, with A and E representing extremes on the scale. When five items are present in a rank order, there are only 11 possible I Scales that are considered "valid" (Sloan & Yueng, 1994). This is explained by: $\begin{bmatrix} n \\ 2 \end{bmatrix} + 1$, where n is the number of stimuli.

The criterion of "50% + 1" of observations falling into the "valid" responses of the scale was recommended by Coombs (1976) as support for the hypothetical dimension.

However, the lack of a strict rule for the goodness of fit has limited the use of Coomb's unfolding methodology.

The data developed using Coomb's unfolding theory is considered to be "pseudo-categorical" (Sloan & Yueng, 1994). In order to perform more powerful and traditional statistical analyses, the data is transformed into ordinal level data by creating a six level ordinal score representing preferred involvement in treatment decision-making: active-active, active-collaborative, collaborative-active, collaborative-passive, passive-collaborative, and passive-passive (Hack, Degner and Dyck, 1994). These levels are determined by the patients' two most preferred cards. The data can also be analyzed using an eleven point ordinal score, using the combination of the five decisional roles and their midpoints. A final method of analysis simply involves classification of data based on the three types of decisional roles: active, collaborative and passive. By using a combination of all three types of classification, judgments can be made regarding sampling adequacy and comparability of data to earlier research (i.e., Hack, Degner & Dyck, 1994).

The EORTC QLQ-C30 (version 2).

Quality of life of cancer patients can be dramatically affected by adjuvant treatments such as chemotherapy, radiotherapy and surgery (Osoba, 1991). A review of the literature has suggested that ACTs may alleviate some of the side effects of conventional medical treatments (i.e., anxiety, fatigue, nausea and vomiting) (Cassileth et al., 1984; Cassileth et al., 1991). Participation in ACTs has also been suggested to create an "illusion of control" and a more holistic perspective of the cancer trajectory, which may improve the perceived quality of life of individuals with cancer

(Montbriand & Laing, 1991). As well, Aaronson and colleagues (1994) have acknowledged the increased recognition by researchers and clinicians of quality of life as an outcome measure of cancer and its related treatments. Thus, quality of life was considered an important outcome measure in this study exploring ACT use in women with breast cancer.

Several quality of life measures, such as the FLIC, QL Index and the Quality of Life Index, have been used in psychosocial cancer research (Graham and Longman, 1987; Schipper, Clinch, McMurray & Levitt, 1984; Spitzer, Dobson, Hall, Chesterman et al., 1981). However, Osoba, Aaronson and Till (1991) recommended that a multidimensional "core" Quality of Life instrument with acceptable psychometric properties be used when creating a quality of life profile of cancer patients. The need for a core quality of life questionnaire, which was applicable cross-culturally, led to the development of the European Organization for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life in 1986. The first-generation questionnaire, the EORTC QLQ-C36, was designed to be cancer specific, multidimensional, self-administered and applicable across cultural settings (Aaronson et al., 1993). Further refinement resulted in the second generation EORTC QLQ-C30, a 30-item questionnaire with five functional scales (physical, role, cognitive, emotional and social) and three symptom scales (fatigue, pain, and nausea). Single items also evaluate common symptoms, such as appetite loss, sleep disturbance, dyspnea, constipation and diarrhea, as well as the financial impact of cancer. Aaronson et al. (1993) reported in a multinational study of 346 lung cancer patients that the EORTC QLQ-C30 took approximately 11 minutes to complete and required minimal assistance.

The EORTC QLQ-C30 also demonstrated acceptable psychometric properties, with mean item-scale correlations across all nine dimensions of 0.53 to 0.59 (Aaronson et al., 1993). Cronbach's alpha coefficients for the multi-item scales ranged from 0.52 to 0.89, with the role functioning scale being the weakest scale (Aaronson et al., 1993). Aaronson et al., (1993) reported that all inter-scale correlations were statistically significant (p<.01), however the moderate size of the correlations (-0.63 to 0.62) revealed the distinct dimensions of quality of life.

More recent refinement of the EORTC QLQ-C30 involved replacement of the original role functioning and quality of life scale items with items tested clinically as the newest scale version, the EORTC QLQ-C30 (version 2) (van Pottelsberghe, 1995). The results of the testing of the EORTC QLQ-C30 (version 2), however, have not been formally published. Nevertheless, the near identical EORTC QLQ-C30 has shown to be a feasible and psychometrically sound instrument to measure cancer patients' quality of life. Thus, the EORTC QLQ-C30 (version 2) was used to measure women with breast cancer's perceived quality of life (Appendix A).

The EORTC QLQ-C30 (version 2) was administered to subjects after completion of Degner and Sloan's (1992) card-sort. Participants were expected to report varying degrees of symptom distress, depending on the type of treatment being administered (i.e., chemotherapy, radiotherapy, surgery, and ACT) and individual differences.

Scoring of the EORTC QLQ-C30 (version 2) involved two steps. First, the raw scores for the individual items within each scale were added and then divided by the number of items within the scale. The scales were then linearly transformed so that all scales ranged from 0 to 100, with a higher scale score representing a higher level of functioning (EORTC, 1995). A range of 0 to 100 was created for ease of presentation and interpretation (Aaronson et al., 1994). Scoring algorithms for the functional/ symptom scales and items were provided by the EORTC.

Field notes.

Qualitative notes were made by the researcher throughout participant interviews. Information recorded in the field notes included more specific information regarding types of ACTs being used, difficulties in interpretation of items on the BTPS-BC, and contextual data which may have influenced the quality of the interview. Where appropriate, the field notes were used to expand on study findings or to provide future guidance in the administration of the BTPS-BC.

Data Analysis

Statistical Analysis

Psychometric assessment of the BTPS-BC.

The psychometric properties of the revised questionnaire were examined statistically using Cronbach's alpha coefficient and where appropriate, compared to Yates et al.'s (1993) findings. Nunnally (1978) recommends an alpha value equal to or above 0.80 to demonstrate internal consistency reliability of a scale. However, according to Brink and Woods (1989), a pre-set criteria of .70 or greater is acceptable for an immature scale that has been subject to limited testing. Thus, for the BTPS-BC, a value of 0.70 was used as a criterion for internal consistency of the scales. Inter-item correlations were also performed on the scales, with a criterion of 50% of items between 0.30 and 0.70. This criteria indicated the items were associated, but not redundant (Carmine & Zeller, 1978). A reliable questionnaire would have greater than half the items matching this criteria. As well, item-to-total correlations were conducted with the items on each scale, with a recommended criterion of 50% of the items between 0.40 and 0.70 (Nunnally, 1978).

Factor analyses were also conducted to examine the internal validity of the BTPS-BC's scales. Principle axes factoring with varimax rotation was considered the appropriate factor method for this study because it would allow exploration of the theoretical structure underlying each scale (Kim & Mueller, 1988). Criteria for evaluation of factor analysis results included: factor loadings of at least 0.40, differences in factor loadings between factors of at least 0.15, eigenvalues >1.0, consideration of explained variance, scree plot distribution, and conceptual interpretability of factors (Kim & Mueller, 1978).

The Beliefs and Treatment Practices Survey - Breast Cancer (BTPS-BC).

Descriptive statistics, including frequencies and measures of central tendency and dispersion, were used to summarize categorical and interval data from the revised questionnaire of cancer patients' beliefs and practices (Yates, 1991). This data was used to compare disease and treatment beliefs of women with breast cancer who used conventional treatments versus women who used ACTs in conjunction with conventional therapy.

Sample distributions in the quantitative data were also examined for normalcy, using Shapiro-Wilks statistics. The distribution of the data for the "Internal/ Controllable Causes of Cancer", "External/Uncontrollable Causes of Cancer", "Mechanisms of Medical Treatments", and "Mechanisms of Alternative/

Complementary Therapies" subscales was found to approximate a normal distribution. As a result, parametric statistics (i.e., t-tests) were used to explore the associations among participants' beliefs represented by the subscales and the use of ACTs.

For the "Outcome of Medical Treatments", "Outcome of Alternative/ Complementary Therapies", "Satisfaction with Health Care Professionals", and "Will to Live" subscales, a non-normal distribution was indicated by the Shapiro-Wilks statistic. Non-parametric statistics (i.e., Wilcoxon Ranked-Sum Test) were used to examine relationships among these study variables and the use of ACTs.

Preferred Treatment Decisional Role Card-Sort.

Card-sort data was analyzed using unfolding theory, a scaling method which determined if subjects' ordering of cards was consistent with the hypothetical rank order of the treatment decisional roles (Degner & Sloan, 1992). The three level scoring system ranging from 1 to 3 was used to describe the three levels of preferred treatment decision control (active, collaborative and passive) because of the small sample size of 52 women. Non-parametric statistics (i.e. Chi-square) was used to analyze the data as a normal distribution was not present. Degner and Sloan (1992) also recommended that Chi-square tests be used to compare distributions of preferences for subsamples (i.e., conventional only and conventional with ACTs).

EORTC QLQ-C30 (version 2).

The reliability of the EORTC QLQ-C30 (version 2) was estimated using Cronbach's alpha coefficient (criteria of .70) (Nunnally, 1978). The EORTC QLQ-C30 (version 2) was analyzed using descriptive statistics, including measures of central tendency and variance. A Shapiro-Wilks test revealed a positively skewed distribution for the quality of life data, warranting non-parametric statistics to explore the associations between functional ability, symptom distress and ACT use.

Personal demographic form.

Descriptive statistics were used to describe the sample characteristics such as age, education level, stage of disease and time since diagnosis. Statistical tests included frequency and percent distribution. This analysis allowed a description of women with breast cancer who used ACTs in conjunction with conventional treatments to be developed. As well, demographic data from this study was compared with Degner et al.'s (under review) study of 1012 breast cancer patients in Manitoba. This analysis provided information regarding the representativeness of the study's sample to the breast cancer population in Manitoba. Chi-square statistics were used to compare the relationships among demographic variables and the use of ACTs.

Ethical Considerations

The major ethical consideration in this research study was the confidentiality of the data and subjects' identity. The literature revealed a significant number of cancer patients (30-70%) did not discuss ACT with their physician (Cassileth et al., 1984; Eisenberg et al., 1993; and Lerner & Kennedy, 1992). Cancer patients using ACTs may fear negative feedback from their medical practitioners and attempt to keep their treatment decisions private. However, the purpose of this study was to explore ACT use in women with breast cancer, revealing possibly hidden treatment practices. Participants in the study were assured that their responses would remain confidential and have no effect on the care they received.

Subjects' confidentiality was also ensured in the study by coding the questionnaires and keeping corresponding names locked in separate filing cabinets. Data will be maintained for seven years according to the Medical Research Council of Canada Research Guidelines.

The nature of the proposed research study was not invasive and presented minimal risk to participants. Subjects were informed that they had the right to withdraw from the study at any point and could refuse to answer questions to which they felt uncomfortable responding. Subjects were also assured that their participation in the study would in no way effect the care they were receiving. However, one risk from the study, which may be specific to cancer patients who use ACTs, was the creation of doubt about treatments, both conventional and ACTs. For some subjects, their faith in their chosen treatment(s) might have been shaken by the intensive exploration of the motivations behind their treatment decisions. Thus, the researcher carefully explored participants' perceptions and anxieties regarding ACTs and conventional treatment throughout the study. Specifically, subjects were informed that statements on the questionnaire which may create doubt about medical treatments or ACTs (e.g., "the treatments weaken the body's natural reserve") were views that have been expressed by some cancer patients, and are not representative of a specific medical opinion. Subjects were also de-briefed following completion of the study's instruments, allowing time for women to express any concerns or feelings generated by their participation in the study.

Summary

The rationale for design and methods were discussed in this chapter. Instruments used in the study included the BTPS-BC, Degner and Sloan's (1991) treatment decision making preference card sort, the EORTC QLQ-C30 (version 2) quality of life tool, and a personal demographic form, which were used to explore women with breast cancer's beliefs about cancer and treatment. Relationships among demographic, personal and environmental variables and type of treatment used were explored using a combination of descriptive, parametric and non-parametric statistics.

CHAPTER FOUR

DATA ANALYSIS

This chapter describes the analysis and findings of Phase I and Phase II of the research study. The aim of Phase I was to pilot test the BTPS-BC questionnaire with an expert panel of six women with breast cancer. The questionnaire's clarity, apparent internal consistency and content validity were assessed using methodology recommended by Imle and Atwood (1988). The aim of Phase II of the research study was to describe and explore participants' responses to the BTPS-BC survey, Degner and Sloan's (1992) decisional preference card-sort, the EORTC QLQ C30 (version 2) quality of life scale and a personal demographic form. The intent of the analysis was to respond to the research questions in Chapter One by exploring the beliefs, practices and sociodemographic characteristics of women with breast who use ACTs in conjunction with medical treatments and comparing the findings to women who have chosen to use only conventional medical treatments. As well, Phase II of the research study provided a further psychometric assessment of the BTPS-BC. This chapter describes the findings of Phase I and Phase II.

Phase I - Pilot Study

The first phase of analysis involved a pilot study of the questionnaire of the beliefs and practices of people with cancer (Yates, 1991). An expert panel of six women with breast cancer who met the study's sampling criteria provided an assessment of the appropriateness, clarity, apparent internal consistency and content validity of the BTPS-BC survey for a breast cancer population.

Characteristics of Panel Members

Table 1 outlines selected demographic characteristics of panel members. All panel members were married, ranged in age from 31 to 65 years, and had achieved a high school diploma. Half of the panel members had pursued post-secondary education and obtained a university degree. Four of the panel members were diagnosed with Stage 2 breast cancer, with the remaining two women having experienced metastatic recurrence (Stage 4). Time since diagnosis ranged from 18 months to approximately twenty-two years. A wide range of conventional treatments had been experienced by panel members, including surgery, chemotherapy, radiotherapy and hormone therapy. Five of the six panel members had explored or used ACTs since they were diagnosed with breast cancer. However, the full range of commitment to using ACT was present in the expert panel, ranging from completely adhering to an ACT regimen to only partially following an ACT protocol.

Table 1 **Sociodemographic Characteristics of Expert Panel Members**

Sociodemographic Variable	N	Percentage	Sociodemographic Variables	N	Percentage
Marital Status			Stage of Disease		
Married	6	100%	Stage 2	4	80.0%
			Stage 4	2	20.0%
Age					
31-40 yrs	1	16.6%	Time since Diagnosis		
41-50 yrs	2	33.3%	13-24 months	1	16.6%
51-65 yrs	3	50.0%	25-60 months	3	50.0%
			60+ months	2	33.3%
Education					
high school diploma	1	16.6%	Income *		
some college	1	16.6%	$31,000-40,000	1	20.0%
college degree	3	50.0%	more than $50,000	4	80.0%
graduate degree	1	16.6%			

Total N = 6 * missing one value

Questionnaire Directions and Scaling

The directions for the BTPS-BC were assessed for format, clarity and reading level, as recommended by Imle and Atwood (1988). All panel members agreed the directions for each scale on the questionnaire were clear and understandable. As well, panel members were asked to assess the appropriateness of the four types of response categories used throughout the questionnaire. Panel members reported the response categories (i.e., yes/no; never/rarely/occasionally/frequently; definitely/ probably/uncertain/probably not/never; and strongly agree/agree/uncertain/ disagree/strongly disagree) were appropriate for the respective scales.

Clarity of Items

An evaluation of item clarity involved an assessment of how clearly an item conveyed a portion of a concept represented by a scale. Items were selected randomly from all scales, combined, and then presented to panel members. Random selection of items was used because the inclusion of all 124 items from the BTPS-BC would have made the pilot study a laborious process for panel members. Instead, participants in the pilot study were asked to rate selected items as "clear" or "unclear" and provide any additional comments they felt appropriate to explain their rating. Additional items were also included which were felt to be potentially difficult to interpret, based on the researcher's clinical experience with women with breast cancer.

Four panel members had difficulty interpreting item H "My cancer was the result of a disturbance" on the "Cause of Cancer" scale. As a result, the item was changed to read "...the result of a disturbance in my body" to improve the clarity of this item.

Two participants expressed concern with item A "Medical treatments cure my cancer" and item C "Medical treatments cause a remission of my cancer" on the "Efficacy of Medical Treatment" scale. These items were interpreted by the panel members as being "too certain" of the outcome of medical treatments. Subsequently, the items became "Medical treatments <u>can</u> cure my cancer" and "Medical treatments <u>could</u> cause a remission of my cancer", which allowed the participants' beliefs in the potential efficacy of medical treatments to be assessed. One participant also noted the negative interpretation of items J and L on the "Efficacy of Medical Treatment" scale and the "Efficacy of ACTs" scale respectively, which referred to medical treatments and ACTs as "weakening" the body's natural reserves. In response, the items were changed to read "...strengthen the body's natural reserves". The grammar of item I "Alternative/complementary therapies are easy to understand how they work" on the

"Efficacy of ACTs" scale was cited as a concern by four panel members. This statement was changed to read "It is easy to understand how ACTs work". As well, the similar statement G on the "Efficacy of Medical Treatment" scale was edited correspondingly.

One panel member expressed concern about item I, "Conventional health care professionals give hope", on the "Satisfaction with Health Care Professionals" scale. This participant conceptualized hope as a continuum ranging from fantasy to reality. She believed women with breast cancer wanted health care professionals to provide hope only if it was based on a realistic prognosis. As a result, the statement was changed to read "...give realistic hope". Another addition was made to item K, "Conventional health care professionals sometimes make you angry" on the "Satisfaction with Health Care Professionals" scale when one participant suggested the statement should be changed to read "Health care professionals sometimes make you feel angry". Another participant was uncertain about what kinds of knowledge was being referred to in item M, "Conventional health care professionals are up-to-date in their knowledge" on the "Satisfaction with Health Care Professionals" scale. Subsequently, "...about my disease", was added to clarify this item.

A last correction to improve item clarity was on item H on the "Will to Live" scale, which was altered to read "I am determined to beat cancer". The former version of item H, "I am determined to beat this", was perceived by one panel member to be ambiguous.

With the exception of four items, the cumulative responses during the pilot test of the BTPS-BC resulted in an 83 percent agreement rate for all items on all scales.

This level of agreement met the criteria recommended by Imle and Atwood (1988) for the clarity of scale items at the 0.05 level of significance.

Apparent Internal Consistency

Panel members were then presented with the seven unlabelled scales of the BTPS-BC and asked the following questions: 1) "Do these items belong together?"; and 2) "Does each item belong in the set?". This estimate of apparent internal consistency assessed the homogeneity of the scales' items (Imle & Atwood, 1988).

Three participants recommended changing item E on the "Reasons for using ACTs" scale from "Alternative/complementary therapies" to "Alternative/ complementary practices", which would reflect a person's daily life instead of a person's treatment regimen. Five participants reported item K, "My cancer can be cured by a change in lifestyle", on the "Cause of Cancer" scale was not consistent with the scale's underlying concept of etiology of cancer. As a result, this statement was altered to read "My cancer was caused by my lifestyle". Three participants were disturbed by item H on the "Efficacy of Medical Treatments" scale, which referred to the patient as being at fault if medical treatments were unsuccessful. However, the panel members agreed that the item was an important item on the scale because it explored the role of patient compliancy, attitude and faith on the outcome of medical treatments. As well, three participants found item F, "My family wants me to have these treatments", on the "Will to Live" scale not consistent with the underlying concept of the scale. Instead, panel members stated that this item was more reflective of the "Encouragement to use ACTs" scale. As a result, this item was removed from the "Will to Live" scale.

Overall, with the alteration or removal of three items from separate scales, all panel members supported the apparent internal consistency of the items for each scale. This level of agreement (6/6) established the internal consistency of the questionnaire items at the 0.05 level of significance (Lynn, 1986).

Content Validity

Finally, panel members assessed content validity by comparing scales and the corresponding items with the labels of the scales and concept definitions (e.g., beliefs about cancer). Panel members responded to the following four questions for each scale: 1) "Does the label and definition fit the whole set of items?"; 2) "For each item, does it belong to the label and definition?"; 3) "Is each item unique?"; and 4) "Is anything left off the list that you think should be there?". This content validity assessment helped determine how well each scale fit the overall domain and if redundancy of items had occurred.

On the "Reasons for using ACTs" scale, panel members indicated the label and definition of the scale fit the item set. Suggestions were made by panel members regarding statements that would reflect additional motivators of ACT use, including "ACTs provide a more positive mental attitude" and "ACTs are healthier ways to live". Since these motivators could be included with the item, "I believe ACTs will improve my quality of life", no changes were made by the researcher. However, one panel member suggested that ACT use was helpful in managing the negative side effects of medical treatment. This item has been previously cited in the literature as a motivating factor in ACT use and was therefore added to the scale (National Breast Cancer Forum, 1994).

All panel members agreed the label and definition of the "Cause of Cancer" scale were congruent with the selected item set. One panel member suggested natural estrogen as a possible cause of cancer but agreed that this causative agent should be included with item C, which refers to environmental pollution as a cause of cancer.

The labels and definitions for the "Efficacy of Medical Treatments", "Efficacy of Alternative/complementary Therapies" and "Satisfaction with Health Care Professionals" scales were considered by all panel members to fit the selected item sets. No suggestions were made regarding the addition of supplementary items.

Four participants reported that item A, "People important to me have tried to convince me to use alternative/complementary therapies", on the "Encouragement to use ACTs" scale, was redundant because other items on the scale referred to encouragement to use ACTs by family members, friends and physicians. Consequentially, this item was removed from the scale. One participant was adamant that other health care professionals, such as nurses and social workers, had played a key role in influencing her decision to use ACTs. To assess the influence of other health care professional on women with breast cancer's use of ACTs, the statement "Other health care professionals have tried to convince me to use alternative/complementary therapies" was added to the scale.

Two panel members recommended the addition of items to the "Encouragement to use ACTs" scale which would describe the support they had received to continue using ACTs. Social support was considered by these individuals to be a concept that was distinct from the theme of "encouragement" represented by items A to C on the scale. As a result, four items were added to the scale which explored social support to use ACTs from family members, friends, physician(s) and other health care professionals.

On the final scale, "Will to Live", two panel members recommended that items should be added which explore the reality of death in the face of a terminal diagnosis. These participants were receiving palliative treatment for Stage 4 breast cancer and found it difficult to relate to the concept of "will to live" in the face of a terminal diagnosis. However, two other panel members believed the scale's items were too negative and aroused sad feelings about their future with breast cancer. Therefore, to balance these two contrasting perspectives, no items exploring cancer patients' acceptance of a terminal diagnosis were added to the scale.

With the deletion of one item and addition of six items, all panel members agreed the selected items were representative of the definitions and labels of the associated scales. As well, except for one item, the items on each scale were perceived by the panel members to be unique and not redundant.

Conclusion

The findings of the pilot study indicated that the pre-set criteria for item clarity, apparent internal consistency, and content validity were met by the majority of items and scales on the BTPS-BC. Minor alterations in language and meaning were made to thirteen items in the questionnaire based on the recommendation of panel members. These recommended changes were necessary in order for the language and meaning of the questionnaire to be appropriate and understandable by Canadian women with breast cancer. Two items were removed from the questionnaire because of redundancy and lack of apparent internal consistency. Six items were added to the scale to ensure concepts/variables considered important by panel members were included in the questionnaire. The resulting questionnaire of 128 items was used in Phase II to explore women with breast cancer's beliefs and treatment practices.

Phase II - Instrument Testing - Data Analysis

In Phase II of the research study, the BTPS-BC was tested to determine the psychometric properties of the instrument. A factor analysis of the revised scales of the questionnaire was also undertaken by the researcher to explore the potential subdimensions present in the seven scales and determine the scales' internal validity. Following additional revisions to the scales as a result of the factor analysis and secondary reliability assessments, exploration of the study's research questions (Chapter 1 - Statement of the Problem) was undertaken. Firstly, demographic statistics were calculated for participants and non-participants, using frequency distributions. Secondly, frequencies were also calculated for the types of conventional and unconventional treatments being used and considered by participants. Normalcy testing, using Shapiro-Wilks statistic, was also undertaken to determine the nature of the distribution of the data. Thirdly, participants' beliefs in causes of cancer, efficacy of medical treatments and ACTs, satisfaction with health care professionals, encouragement to use ACTs, and will to live were evaluated using measures of central tendency and dispersion. Lastly, comparisons were made, using parametric and non-parametric statistics, between participants who were using ACTs in conjunction with medical treatments and participants who were only using conventional treatment. These two groups of participants were compared with regard to beliefs, treatment practices, preferred treatment decision role, quality of life and demographic variables.

Demographic Statistics

Potential subjects.

Data collection took place from January 1996 to June 1996, with a total of 64 women with breast cancer being identified by clinic nurses as potential subjects who met the sampling criteria. A total of 52 women agreed to participate in the study, indicating a response rate of 81.2 percent (n = 12 refused). Table 2 lists the women's reasons for not participating in the study.

Table 2 Frequency and Percent Distribution of Reasons for Non-Participation

Reason for Refusal	Frequency (%)
No interest in participating	3 (25.0)
Residence in rural Manitoba	4 (33.3)
Holidays	2 (16.6)
Disease-related complications	3 (25.0)

n = 12

Data collection occurred in three outpatient oncology clinics in Winnipeg: Victoria General Hospital Outpatient Oncology Unit, The Manitoba Cancer Treatment and Research Foundation (MCTRF) Outpatient Oncology Unit at St. Boniface General Hospital, and MCTRF Outpatient Oncology Unit at Health Sciences Centre (Table 3). Subjects from Victoria General Hospital formed a slightly higher percentage of the total sample in comparison from the two MCTRF outpatient oncology units because of earlier access to the facility by the researcher in January 1996. Data collection at the MCTRF outpatient oncology units did not begin until February 1996.

Table 3 **Demographics of Sample According to Hospital**

Hospital	Frequency
Victoria General Hospital	23 (44.2)
Health Sciences Centre (MCTRF)	14 (26.9)
St. Boniface General Hospital (MCTRF)	15 (28.8)

Total N = 52

Demographic characteristics of the sample.

Sociodemographic characteristics of the sample are presented in Table 4. The majority of the sample was married (75%) and between the ages of 41 years and 65 years (78.9%). The majority of participants had received a high school diploma, with 55.9 percent of the sample having pursued post-secondary education. Participants were widely distributed amongst the occupational categories of "clerical", "professional/management", "homemaker" and "other", the latter category including retail, labourers and self-employed individuals. Just over 11 percent of the participants were retired. A large percentage of participants (59.6%) indicated their family income to be greater than $40,000 per year.

Over a third of the sample reported their ethnic origin as European (36.5%), with another 25 percent of the sample considering their ethnic origin to be from the British Isles. Just over 20 percent (21.2%) of the sample declined to classify themselves as having an ethnic group of origin, reporting their ethnic background to be "Canadian". With regard to religious affiliation, 40 percent of the sample was Catholic and 30 percent was Protestant. Over eighty percent of subjects lived within Winnipeg.

Table 4 **Sociodemographic Characteristics of the Sample**

Sociodemographic Variable	N	Percentage	Sociodemographic Variables	N	Percentage
Marital Status *			Family Income **		
Married	39	75.0	below $10,000	2	3.8
Divorced	2	3.8	$11,000-20,000	2	3.8
Never Married	6	11.5	$21,000-30,000	4	7.7
Widowed	2	3.8	$31,000-40,000	10	19.2
Common-law	2	3.8	$41,000-50,000	12	23.1
			over $50,000	19	36.5
Age *			Ethnic Background		
20-30 yrs	0	0.0	European	19	36.5
31-40 yrs	5	3.6	British Isles	13	25.0
41-50 yrs	21	40.4	Asian	1	1.9
51-65 yrs	20	38.5	French	6	11.5
65yrs and over	5	9.6	Aboriginal	2	3.8
			Other	11	21.2
Education			Religion *		
grade 8 or less	2	3.8	Catholic	21	40.4
some high school	5	9.6	Protestant	16	30.8
high school diploma	16	30.8	Jewish	2	3.8
some college	11	21.2	None	3	5.8
college degree	11	21.2	Other	9	17.3
graduate degree	7	13.5			
Occupation			Residency		
clerical	12	23.1	urban	43	82.7
retired	6	11.5	rural	9	17.3
management/ professional	22	42.3			
homemaker	7	13.5			
other	5	9.5			

Total N = 52

*** one missing value**
**** two missing values**

Participants' medical charts were reviewed by the researcher to determine participants' date of diagnosis, conventional treatment protocol history, and staging of disease. The TNM staging criteria (UICC, 1987) was used when possible to determine participants' stage of disease (Stage 1 to 4). However, the MCTRF facilities were not consistent in applying the TNM staging criteria for all participants. As a result, selected participants' stage of disease was determined in consultation with the facilities' oncologists.

Twenty-six women were categorized with either Stage 1 or 2 disease, indicating local malignant involvement (Table 5). The remaining twenty-six participants' were categorized as having more advanced breast cancer (Stage 3 or 4). Over thirty-four percent of the women had experienced a recurrence of cancer, either local chest wall recurrence or distant metastases. The sample ranged between 2 months to over 22 years since time of diagnosis. Forty percent of participants had been diagnosed one year ago or less at the time of the interview, 21.2 percent had been diagnosed with breast cancer between one and two years ago, and the final 38.4 percent were diagnosed more than two years ago. A large percentage (28.3%) of the women interviewed reported their original date of diagnosis to be over five years ago.

The majority of women (92.3%) had undergone either a lumpectomy or mastectomy following their diagnosis. Four women who did not receive surgery had been diagnosed with inflammatory breast cancer, which was clinically unamendable to surgery. In addition to surgery, most women participating in the study had received chemotherapy, with 80.8 percent reporting the use of antineoplastic agents at some point in their cancer trajectory. An additional 44.2 percent of participants reported radiotherapy as adjuvant treatment for their breast cancer. Hormone therapy, specifically tamoxifen or Megace, was also used by 50.0 percent of participants. Thus, the medical treatment protocols used by participants included a mixture of surgery, chemotherapy, radiotherapy and hormone therapy, depending on the participants' stage of cancer, disease profile, and demographic characteristics.

Table 5 Disease and Treatment Profile of Participants

Characteristic	Frequency	Percent
Stage of Disease		
Stage 1	6	11.5%
Stage 2	20	38.5%
Stage 3	4	7.7%
Stage 4	22	42.3%
Time Since Diagnosis		
0 to 6 months	13	25.0%
7 to 12 months	8	15.4%
13 to 24 months	11	21.2%
25 to 60 months	5	9.6%
61+ months	15	28.8%
Recurrence		
Yes	18	34.6%
No	34	61.5%
Surgery		
Yes	48	92.3%
No	4	7.7%
Chemotherapy		
Yes	42	80.8%
No	10	19.2%
Radiotherapy		
Yes	29	55.8%
No	23	44.2%
Hormone Therapy		
Yes	26	50.0%
No	26	50.0%

N = 52

Data was also collected related to the characteristics of the face-to-face administration of the study's instruments. The majority (80.7%) of interviews occurred in participants' homes, with a small number (5.8%) choosing to be interviewed in either their workplace or in a restaurant. Just over thirteen percent of participants requested to be interviewed in the clinical setting following recruitment by the researcher. Attempts were made by the researcher to ensure privacy in the clinical setting by conducting interviews in a quiet, enclosed space. Participants' rationale for requesting an interview immediately following recruitment included time constraints, living in a rural area, and distraction from the time-consuming and tedious administration of chemotherapy. The decision to administer the questionnaires to three women during their chemotherapy session was made in consultation with clinic nurses, who considered the effect of anti-nauseant medication and chemotherapy agents on participants' cognitive ability. No limitations in cognitive ability by the three participants was observed by the researcher.

The length of the meetings between participants and the researcher ranged from 45 minutes to three hours in length. The majority of participants used the interview as an opportunity to share their cancer experience and to ask questions regarding ACTs. Several participants commented on the therapeutic benefits of sharing their story with a health care professional they considered "outside" of their circle of care providers. In two instances, the participant's spouse was present during the interview.

Internal Consistency of the BTPS-BC

Cronbach's standardized alpha coefficients for the seven scales ranged from 0.42 to 0.91 (Table 6). Four of the scales, "Reasons for using ACTS", "Efficacy of

ACTs", "Satisfaction with Health Care Professionals", and "Will to Live" met the pre-set criteria of .70. Two of the scales "Causes of Cancer" and "Encouragement to use ACTs" approached the criterion value of .70, with values of .66 and .69 respectively. The "Efficacy of Medical Treatments" scale performed poorly achieving a standardized Cronbach's alpha of .42.

Table 6 Internal Consistencies of the Scales on the BTPS-BC

Scales	Cronbach's Standardized Alpha	Inter-item Correlation	Item-to-total Correlation
Reasons for using ACTs	.80	100.0%	83.3%
Causes of Cancer	.66	0%	43.8%
Efficacy of Medical Treatments	.42	16.6%	50.0%
Efficacy of ACTs	.79	64.3%	57.1%
Satisfaction with Health Care Professionals	.91	80.0%	60.0%
Encouragement to use ACTs	.69	25.0%	50.0%
Will to Live	.91	91.6%	83.3%

"Reasons for Using ACTs" Scale.

Item means on the "Reasons for using ACTs" scale ranged from 2.09 to 3.63, with a standard deviation ranging from 1.16 to 1.55. Five of the six items (83.3%) achieving item-to-total correlations between 0.39 and 0.60. Item C obtained an item-to-total correlation of 0.76. All items scored 50 percent or above the 0.30 to 0.70 criterion for inter-item correlations, indicating that the items were internally consistent.

"Causes of Cancer" Scale.

"Causes of Cancer" scale item means ranged from 1.40 to 3.94 with a standard deviation ranging from 0.57 to 1.44. Seven items (A, C, E, G, K, M and O) achieved item-to-total correlations between 0.30 and 0.46. All other items scored below 0.30, suggesting these items were not parallel concepts. No items met the pre-specified criterion level of 50 percent of inter-item correlations being between 0.30 and 0.70. Thus, items on the "Causes of Cancer" scale were poorly correlated with each other, suggesting each item represented a distinct cause of cancer.

"Efficacy of Medical Treatments".

Item means on the "Efficacy of Medical Treatments" scale ranged from 1.52 to 4.21 with a standard deviation range of 0.72 to 1.65. Six items (A, B, C, D, I and L) on the scale obtained item-to-total correlations between 0.30 and 0.50. Two items (C and I) obtained 50 percent of inter-item correlations within the pre-set criterion values (0.28 to 0.47). This finding suggested the items on the "Efficacy of Medical Treatments" were poorly related to one another and may represent independent concepts.

"Efficacy of ACTs" Scale.

Item means on the "Efficacy of ACTs" ranged from 1.69 to 4.00, with a standard deviation of 0.64 to 1.35. Items on the "Efficacy of ACTs" scale demonstrated reasonable internal consistency, with 8 out of 14 items (57.1%) achieving item-to-total correlations between 0.40 to 0.70. Items I, J and N scored below 0.40, indicative of items which are not parallel to other scale items. Items D, K and L scored item-to-total correlations greater than 0.70 (0.75 to 0.77) which may be suggestive of redundancy. Over half of the items (9/14) achieved 50 percent of inter-item correlations between 0.28 and 0.70. Items A, B, D, E, F, G, K, L, and M achieved the pre-set criterion for inter-item correlations.

"Satisfaction with Health Care Professionals" Scale.

Item means on the "Satisfaction with Health Care Professionals" scale ranged from 2.67 to 4.17, with a standard deviation range of 0.73 to 1.47. Nine of the fifteen items (60.0%) achieved item-to-total correlations between 0.40 and 0.72. Five items (B, D, E, K, and L) obtained item-to-total correlations greater than 0.70, indicating possible redundancy. Items C and O scored less than 0.40 on item-to-total correlations, suggesting these items may not represent concepts parallel to other items on the scale. The majority of the items (86.6%) achieved inter-item correlations between 0.29 and 0.70 at the pre-set 50 percent criterion level. Items C and O scored below 50 percent, indicating that items related to women's comprehension of information provided by health care professionals were poorly correlated with items exploring the demeanour and skill of health care professionals.

"Encouragement to use ACTs" Scale.

On the "Encouragement to use ACTs" scale, item means ranged from 1.46 to 3.98, with a standard deviation of 0.94 to 1.59. Exactly 50 percent of the items achieved item-to-total correlations between 0.40 and 0.70. Items A, B, C, and D achieved less than 0.40 on item-to-total correlation. Two items (E and H) scored greater or equal to 50% of inter-item correlations between 0.30 and 0.70. Thus, the majority of scale items did not correlate well with one another.

"Will to Live" Scale.

Item means on the last scale, "Will to Live", ranged from 3.58 to 4.78, with a standard deviation of 0.54 to 1.55. Ten out of twelve items achieved an item-to-total correlation between 0.51 and 0.71. Items B and G failed to meet the pre-determined criteria for item-to-total correlations, suggesting these items may not represent concepts parallel to the other items on the scale. Eleven out of the twelve items achieved 50 percent of inter-item correlations between 0.30 and 0.70. Item L failed to achieve the percent criterion level recommended by Nunnally (1978), suggesting this item was poorly correlated with other scale items.

Summary.

In summary, testing of the internal consistency of the seven scales comprising the BTPS-BC was conducted. Four scales ("Reasons to use ACTs", "Efficacy of ACTs", "Satisfaction with Health Care Professionals" and "Will to Live") achieved the recommended reliability criteria and two scales ("Causes of Cancer" and "Encouragement to use ACTs") approached the recommended internal consistency reliability value of 0.70 for an immature scale (Nunnally, 1978).

Internal Validity Estimates and Revised Internal Consistencies of Scales

Similar to the methodology used by Yates (1991), exploratory and confirmatory factor analysis was conducted on the seven scales to determine the possible subdimensions existing in each scale, to assist in the elimination of extraneous items, and determine the factor structure of scales when used with a sample of Canadian women with breast cancer. In some instances, the original factor structure reported by Yates (1991) were consistent with internal factor structures found with this study's sample. However, in five instances, revisions to scales were undertaken to more appropriately reflect the scale dimensions meaningful to this sample of women with breast cancer. Reliability estimates for the revised scale and subscales were used to confirm the internal consistency of the restructured scales.

"Causes of Cancer" Scale.

Examination of the scree plot for the items comprising the "Causes of Cancer" scale suggested that between 1 and 4 factors were responsible for the pattern of correlations found within the 16 items. As well, three factors had eigenvalues greater than 1.0. A qualitative analyses of the one to four factor solutions further suggested that two main factors, each containing five to six items, were present (Table 7). The two factors were defined as "External/Uncontrollable Causes of Cancer" and "Internal/Controllable Causes of Cancer". Together, these two factors accounted for 62.2 percent of the total variance.

Table 7 Factor Analysis of the "Causes of Cancer" Scale

Item #	Factors and Associated Items	Factor Loading
	Factor 1 - External/Uncontrollable Causes of Cancer	
C	- My cancer was caused by pollution	.72
O	- My cancer was caused by multiple factors	.65
M	- My cancer was the result of exposure to insecticides	.49
P	- The cause of my cancer is not known	.40
I	- My cancer was caused by excessive sunlight	.37
H	- My cancer was the result of a disturbance in my body	.29
D	- My cancer was caused by smoking	.29
N	- My cancer was a result of genetic factors	.26
	Factor 2 - Internal/Controllable Causes of Cancer	
B	- I could have prevented my cancer	.66
G	- My cancer was caused by eating the wrong foods	.52
E	- My cancer was caused by a build-up of toxins in the body	.50
K	- My cancer was caused by my lifestyle	.49
A	- My cancer was caused by a weakness in the immune system	.40
F	- My cancer was caused by stress	.37
J	- My cancer was caused by a microorganism	.31
L	- My cancer was caused by drinking alcohol	.21

Item factor loadings on these two factors ranged from 0.21 to 0.72, with items I and F loading below the preset criteria of 0.40. Although items I and F had lower factor loadings, these items did not achieve high loadings on the alternative factor (-.04 and -.02 respectively) and were thus included on the subscales. As well, these items were retained because of literature and clinical experience which supported these items as being relevant beliefs about causes of cancer for some people with cancer (National Breast Cancer Forum, 1994). Items H, D, N, J and L also failed to meet the pre-set criteria of .40 set by the researcher for factor loadings. Item H "My cancer was caused by a disturbance in the body" was interpreted with difficulty by participants who required clarification from the researcher regarding what type of disturbance was implied by the item. Future testing of the scale may require the elimination or restructuring of this item. Qualitative analysis of field notes taken during participant interviews revealed Items D "My cancer was caused by smoking" and L "My cancer was caused by drinking alcohol" were causes of cancer that participants believed were unrelated to the development of breast cancer. As well, item J loaded on factor two and failed to conceptually fit the concept of internal causes of cancer represented by the factor. Interestingly, item N "My cancer was caused by genetic factors" fell below the prerequisite factor loading value of 0.40, suggesting this item may represent a unique factor not included in the two factor solution for this scale. This item may index an internal, uncontrollable cause of cancer that was perceived very differently from the other items. Future testing of the scale may determine the relevance of item N to the "Causes of Cancer" scale.

Overall, the factor analysis of the "Causes of Cancer" scale resulted in the development of two distinct subscales. The "Internal/Controllable Causes of Cancer" subscale was comprised of six items (A, B, E, F, G, and K) that explored beliefs about causes of cancer that are controllable by an individual or occur within the body. A Cronbach's standardized alpha coefficient of 0.62 was obtained for this subscale, with half the items (3/6) achieving item-to-total correlations greater than 0.36 (Table 13). Two of the six items achieved 50 percent of inter-item correlations between 0.30 and 0.70.

The "External/Uncontrollable Causes of Cancer" subscale consisted of five items (C, O, M, P and I) which explored beliefs about causes of cancer that are environmental and/or unknown, limiting the amount of control an individual has regarding exposure or prevention. A Cronbach's standardized alpha coefficient of .62 was obtained for this subscale, with 4 out of 5 items obtaining item-to-total correlations greater than 0.35 (Table 13). Two of the five items achieved 50 percent of inter-item correlations between 0.30 and 0.47. The two subscales were used in subsequent analysis to compare the beliefs about causes of cancer by participants using ACTs versus participants who used only conventional medical treatments.

"Efficacy of Medical Treatment" Scale.

The scree plot of the eigenvalues of the "Efficacy of Medical Treatment" scale items suggested that between 1 and 4 factors were responsible for the underlying pattern of correlations found within the 12 items. Analysis of the eigenvalues revealed two factors with eigenvalues greater than 1.0. Based on Yates' (1991) analysis, a confirmatory two factor solution was tested and found to be appropriate (Table 8). Factor 1, "Mechanism of Medical Treatment", contained five items related to the process through which medical treatments effect the body, with item factor loadings ranging from 0.42 to 0.67. Factor Two "Outcome of Medical Treatment" contained five items with factor loadings that met the preset criteria of 0.40. These items referred to effects of medical treatments on cancer, including cure, remission, and prevention of metastases. Together, the two factors explained 0.89 percent of the total variance.

Table 8 Factor Analysis of the "Efficacy of Medical Treatments" Scale

Item #	Factors and Associated Items	Factor Loading
	Factor 1 - Mechanism of Medical Treatment	
J	- Medical treatments strengthen the body's natural reserves	.67
I	- Medical treatments assist the body's natural forces to heal	.66
L	- Medical treatments reduce the chance that alternative/complementary therapies will work	.56
G	- It is easy to understand how medical treatments work	.46
F	- Medical treatments have side effects	.42
H	- It is the patient's fault if medical treatments don't work	.14
	Factor 2 - Outcome of Medical Treatments	
C	- Medical treatments could cause a remission of my cancer	.64
A	- Medical treatments can cure my cancer	.56
B	- Medical treatments prevent the spread of my cancer	.46
D	- Medical treatments assist other treatments to work	.46
K	- Medical treatments are more important than alternative/complementary therapies	.40
E	- Medical treatments relieve my symptoms	-.08

The factor loading for item H "It is the patient's fault if medical treatments don't work" failed to meet the pre-specified criteria of greater than or equal to 0.40. As previously noted by Yates (1991), this item did not fit the concept of efficacy of treatments and was therefore excluded from the scale. Item E "Medical treatments relieve my symptoms" also loaded on both factors, suggesting that this item may not be relevant to the efficacy of medical treatments for women with breast cancer. Many participants reported the relief of symptoms was not relevant because of the lack of physiological changes associated with the development of breast cancer. Future testing of the scale with a breast cancer population may result in elimination of this item. Item D, "Medical treatments assist other treatments to work", loaded on factor two with a value of 0.46 and factor one with a value of 0.40. Despite the fact that this item "double-loaded" on two factors, it was included in the "Outcome of Medical Treatments" subscale because of the conceptual validity of including this item on a subscale exploring the process of medical treatments.

As a result of the factor analysis of the "Efficacy of Medical Treatments" scale, two subscales were developed which explored beliefs about the effectiveness of conventional medical therapy. The "Mechanism of Medical Treatment" subscale was composed of five items (J, I, L, G and F) and had a Cronbach's standardized alpha of .66. All items achieved item-to-total correlations greater than 0.31 (Table 13). Two of the five items obtained 50 percent of inter-item correlations between .30 and .70. A Cronbach's standardized alpha of 0.65 was achieved for the "Outcome of Medical Treatment" subscale, composed of five items (C, A, B, D, and K). Three of the five items on the subscale achieved item-to-total correlations between 0.37 and 0.57, with 3 of the 5 items obtaining 50 percent of inter-item correlations between 0.30 and 0.70 (Table 13). Together, the two subscales were used to examine participants' beliefs regarding the effectiveness of conventional medical treatments and the influence of these beliefs on ACT use.

"Efficacy of Alternative/Complementary Therapies" Scale.

Comments were made by participants regarding the similarities of the items on the "Efficacy of Alternative/Complementary Therapies" and "Reasons for using Alternative/Complementary Therapies" scales. For example, item C ("I believe ACTs will improve my quality of life") on the "Reasons for using Alternative/ Complementary Therapies" was conceptually parallel to items on the "Efficacy of Alternative/Complementary Therapies" scale which explored the mechanism of ACTs.

As a consequence of the apparent similarity of meaning of the items on the scales, the items were combined to form the "Efficacy and Rationale of ACT Use" scale. A Cronbach's alpha of 0.88 was found for the combined scale, with 11 of the 18 items meeting the criteria of between 0.40 and 0.70 for item-to-total correlations. More than 50 percent of the items met the pre-set criteria for inter-item correlations, confirming the similarities of the items on the "Efficacy and Rational of ACT Use" scale. As a result, an exploratory factor analysis was conducted on all items composing the two scales.

A scree plot of the eigenvalues for the revised "Efficacy and Rationale of ACT Use" scale revealed between 2 to 5 factors were responsible for the underlying patterns of correlations. Three factors were found to have eigenvalues greater than 1.0. A qualitative analysis of the exploratory factor solutions suggested that conceptually, a two factor solution was most appropriate in interpreting the underlying dimensions present on the scales (Table 9). Factor 1 "Mechanisms of ACTs" was comprised of ten items which were related to the mechanisms through which ACTs function, with item factor loadings ranging from 0.48 to 0.82. Factor 2 "Outcome of ACTs" contained eight items which conceptually explained the physiological results of ACTs. Factor loadings on this factor ranged from 0.35 to 0.84. Seventy-two percent of the total variance was explained by the two factors.

Table 9 Factor Analysis of the Revised "Efficacy and Rationale of ACT Use" Scale

Item # and Scale	Factors and Associated Items	Factor Loading
	Factor 1 - Mechanism of Alternative/Complementary Therapies	
K - Efficacy	- ACTs assist the body's natural forces to heal	.82
L - Efficacy	- ACTs strengthen the body's natural reserves	.81
A - Efficacy	- ACTs are helpful	.81
B - Efficacy	- It is wise to use ACTs	.78
C - Reasons	- I believe ACTs will improve my quality of life	.73
F - Reasons	- Alternative/complementary practices are part of my daily life already	.70
D - Reasons	- ACTs help me manage the side effects of medical treatment(s)	.65
F - Efficacy	- ACTs will assist other treatments to work	.64
E - Reasons	- I feel ACTs increase my control over my treatment choices	.55
B - Reasons	- I don't know if ACTs can cure my cancer but I will try any treatment	.48
	Factor 2 - Outcome of Alternative/Complementary Therapies	
D - Efficacy	- ACTs will prevent the spread of my cancer	.84
C - Efficacy	- ACTs will cure my cancer	.77
E - Efficacy	- ACTs could cause a remission of my cancer	.70
M - Efficacy	- ACTs are more important than medical treatments	.59
A - Reasons	- I believe ACTs can cure my cancer	.58
J - Efficacy	- It is the patient's fault if ACTs don't work	.43
H - Efficacy	- ACTs have side effects	.35
G - Efficacy	- ACTS will relieve my symptoms	.35
I - Efficacy	- It is easy to understand how ACTs work	.12
N - Efficacy	- ACTs reduce the chances that medical treatment will work	-.24

Items I and N from the "Efficacy of ACTs" scale obtained factor loadings of 0.12 and -0.24 respectively on Factor 2. Also, these items performed poorly with regard to inter-item correlations on the "Efficacy and Rationale of ACT Use" scale (5.5% and 0% respectively). As a result of the failure to meet the criteria of greater than or equal to 0.40 and the lack of communality with other scale items, items I and N were excluded from the "Outcome of ACTs" subscale. As well, item A from the

"Reasons for using ACTs" scale was excluded from the subscale because of the redundancy of the item with the statement "ACTs will cure my cancer" from the "Efficacy of ACTs" scale. As a result, seven items comprised the "Outcome of ACTs" subscale (D, C, E, M, J, H and G - Efficacy).

Overall, the Cronbach's standardized alpha for the "Mechanism of ACTs" subscale was .91, with seven of the ten items obtaining item-to-total correlations between 0.54 and 0.73 (Table 13). All items met the pre-set criteria of 50 percent of items achieving inter-item correlations between 0.30 and 0.70. The "Outcome of ACTs" subscale resulted in a Cronbach's standardized alpha of 0.80, with five of the seven items meeting the item-to-total correlation criterion (Table 13). As well, all items met the inter-item correlation criterion. Together, the two subscales, "Mechanisms of ACTs" and "Outcome of ACTs" were used in subsequent analyses to explore the beliefs about ACTs by women using these types of therapies versus women who have used only conventional medical treatment.

"Satisfaction with Health Care Professionals" Scale.

The scree plot for the "Satisfaction with Health Care Professionals" scale items suggested between 2 and 4 factors were responsible for the correlations found among the 15 items. Analysis of the eigenvalues revealed two factors greater than 1.0. Qualitative analysis of the two and four factor solutions led to the consensus that there were two main factors present within the scale. The two factors explained 81.1 percent of the total variance (Table 10).

Table 10 Factor Analysis of the "Satisfaction with Health Care Professionals" Scale

Item #	Factors and Associated Items	Factor Loading
	Factor 1 - Caring Behaviours of Health Care Professionals	
B	- Conventional health care professionals are very sympathetic people	.89
D	- Conventional health care professionals have a good manner	.88
E	- Conventional health care professionals provide emotional support	.88
L	- Conventional health care professionals inspire confidence	.84
H	- Conventional health care professionals care more about the disease than the person	.78
K	- Conventional health care professionals sometimes make you feel angry	.74
F	- Conventional health care professionals don't spend enough time with their patients	.70
A	- Conventional health care professionals are hard to talk to	.67
N	- Conventional health care professionals don't encourage their patients to ask questions	.67
I	- Conventional health care professionals give realistic hope	.66
M	- Conventional health care professionals are up-to-date in their knowledge about my disease	.50
G	- Conventional health care professionals are well trained	.47
J	- You can trust them to tell you the truth	.44
	Factor 2 - Understanding Health Care Professionals	
C	- Conventional health care professionals use simple explanations	.80
O	- I can understand what they are telling me	.77

Factor One, "Caring Behaviours of Health Care Professionals", contained 13 items related to the interpersonal skills and professionalism of conventional health care providers. The thirteen items loading on Factor One met the pre-set criteria of greater than or equal to .40, with factor loadings ranging from 0.44 to 0.89. The Cronbach's standardized alpha coefficient for this subscale was 0.92 (Table 13). Seven of the thirteen items met the criterion for item-to-total correlations. All items achieved 50 percent of inter-item correlations between 0.30 and 0.70. The subscale was used in the analysis to explore the level of satisfaction with health care professionals felt by participants using ACTs versus participants who were using only medical treatments.

Factor Two, "Understanding Health Care Professionals", was comprised of only two items which described participants' comprehension of the information provided by health care professionals. This latter factor was considered to be reflective of participants' understanding of the disease and treatment information provided by health care professionals. Both items met the pre-specified criterion of greater than or equal to .40. A Kendall Tau B Correlation Coefficient of 0.52 was obtained for the subscale, which reflects the small number of items included on the subscale. Despite the limited reliability of the "Understanding Health Care Professionals" subscale, the dimension is an important variable which may influence women with breast cancer decision to explore alternative or complementary treatment options (Fletcher, 1992; National Forum on Breast Cancer, 1994). Thus, the "Understanding Health Care Professional" subscale was used in subsequent analyses in the study.

"Encouragement to use Alternative/Complementary Therapies" Scale.

A review of the scree plot for the "Encouragement to use Alternative/Complementary Therapies" scale revealed that between 1 and 4 factors were responsible for the patterns of correlations among the scale items (eigenvalues >1.0). A confirmatory one factor solution was used to identify extraneous items because of the limited number of items contained by the scale (i.e., eight items). The one factor solution accounted for 73.0 percent of the total variance (Table 11). However, the results of the factor analysis should be considered with caution because of the large number of missing values for items E, F, G, and H, which were not applicable to participants who considered themselves to be nonusers of ACTs. As well, several participants (N=8) responded "strongly disagree" to item G, "My doctor has supported me in using alternative/complementary therapies", because they had not informed their physician about their use of ACTs. Future studies exploring the beliefs and practices of women with breast cancer will need to consider these limitations in the design of the scale.

Table 11 Factor Analysis of the "Encouragement to use ACTs" Scale

Item #	Factors and Associated Items	Factor Loading
	Factor 1 - Support for using ACTs	
E	- My family have supported me in using alternative/complementary therapies	.75
G	- My doctor has supported me in using alternative/complementary therapies	.69
H	- Other health care professionals have supported me in using alternative/complementary therapies	.68
F	- My friends have supported me in using alternative/complementary therapies	.60
D	- Other health care professionals have tried to convince me to use alternative/complementary therapies	.40
B	- My friends have tried to convince me to use alternative/complementary therapies	.31
A	- My family has tried to convince me to use alternative/complementary therapies	.18
C	- My doctor has tried to convince me to use alternative/complementary therapies	.08

Item factor loadings for items E, G, H and F met the preset criteria of 0.40, with item factor loadings ranging from 0.60 to 0.75. Items A, B, and C fell below 0.40, suggesting these items are extraneous to the conceptual domain represented by the scale. However, item D, "Other health care professionals have tried to convince me to use alternative/complementary therapies", had a factor loading of 0.40, meeting the pre-specified criteria. In spite of this finding, item D failed to fit conceptually with the concept of "support" encompassed by items E, F, G and H. As a result, this item was excluded from the resulting 4-item scale of "Support to use ACTs".

A Cronbach's standardized alpha coefficient of 0.76 for the "Support to use ACTs" subscale was obtained, with all items meeting the pre-set criterion of between 0.40 and 0.70 for item-to-total correlations (Table 13). All inter-item correlations achieved the 50 percent criterion of correlations between 0.30 and 0.70. The "Support to Use ACTs" subscale was used in subsequent analyses to describe the level of support received by participants using ACTs in conjuction with medical treatments.

"Will to Live" Scale.

The scree plot of the eigenvalues of the 12 items comprising the "Will to Live" scale suggested between 1 and 3 factors were accountable for the pattern of correlations found within the scale. Further investigation of the eigenvalues revealed three factors with eigenvalues greater than 1.0. Qualitative analysis of the one, two and three factor solutions was used to determine the final factor solution. Table 12 illustrates the final two factors defined within the "Will to Live" scale, each containing between five and seven items. The two factor solution accounted for 83.2 percent of the total variance.

Table 12 **Factor Analysis of the "Will to Live" Scale**

Item #	Factors and Associated Items	Factor Loading
	Factor 1 - Immediate Perspective on the Will to Live	
A	- It's worth having any treatment even if the chances they will work may not be high	.77
B	- I don't care how uncomfortable a treatment is, I will have it if it improves my chances	.76
E	- I desperately want to live	.73
C	- I will hang on to life at any cost	.72
D	- I am prepared to have any treatment to get better	.68
F	- I have a lot to live for	.64
L	- I really don't care anymore whether I live or die	.57
	Factor 2 - Future Perspective on the Will to Live	
G	- I'm going to beat cancer regardless of what happens	.79
I	- I am hoping my treatments will work a cure	.76
H	- I am determined to beat cancer	.71
J	- If my current treatment does not work I will find something that will	.69
K	- I am optimistic and hopeful	.64

Item factor loadings in the "Immediate Perspective on the Will to Live" factor and "Future Perspective on the Will to Live" factor ranged from 0.57 to 0.79. All item factor loadings met the pre-specified criterion of greater than or equal to 0.40. As a result of the conceptual similarities of the items on the two subscales, a decision was made to maintain the "Will to Live" scale as a 12-item scale in subsequent analyses comparing participants using ACTs versus participants using only conventional treatments.

Table 13 Internal Consistencies of the Revised Subscales of the BTPS-BC

Subscales	Cronbach's Standardized Alpha	Inter-item Correlation	Item-to-total Correlation
External/Uncontrollable Causes of Cancer	.62	40.0%	80.0%
Internal/Controllable Causes of Cancer	.62	33.3%	50.0%
Mechanism of Medical Treatment	.66	40.0%	100.0%
Outcome of Medical Treatment	.65	60.0%	60.0%
Mechanism of Alternative/ Complementary Therapies	.91	100.0%	70.0%
Outcome of Alternative/ Complementary Therapies	.80	100.0%	71.4%
Caring Behaviours of Health Care Professionals	.92	100.0%	53.8%
Understanding Health Care Professionals	.52 (Kendall Tau B)	-	-
Support to use ACTs	.76	100.0%	100.0%

Conclusion.

Factor analyses of the seven scales were used to eliminate extraneous variables and develop meaningful subscales which measured beliefs and attitudes of participants regarding cause of cancer, treatment, satisfaction with health care provider(s), encouragement to use ACTs, and the will to live. In total, nine new scales were created from the seven original scales. Interpretable subdimensions were identified for all scales. Twelve items did not meet the pre-set factor analysis criteria or were not interpretable. These items were deleted from the scales for subsequent analyses.

Rates of Usage of Alternative/Complementary Practitioners

The rates of usage of both medical practitioners and alternative/complementary therapists by participants are presented in Table 14. Women were asked to respond "yes" or "no" to whether they had consulted six types of alternative therapists and three types of medical practitioners at any point in their disease trajectories. An open-ended question "Is there anyone else you have consulted about your breast cancer" was also asked to explore other options not included on the BTPS-BC.

Table 14 **Frequency and Percent Distribution of Medical and Alternative/ Complementary Practitioners Seen**

Practitioner(s) Seen	Frequency (%)
Acupuncturist	1 (1.9)
Chiropractor	5 (9.6)
MD who offers ACTs	-
Homeopath	1 (1.9)
Medical Oncologist	51 (98.1)
Naturopath	4 (7.7)
Nutritionist	6 (11.5)
Radiation Oncologist	37 (71.2)
Spiritual/Faith Healer	19 (36.5)
Surgeon	52 (100.0)

Total N = 52

All participants in the study had consulted a surgeon following the diagnosis of breast cancer to discuss breast removal options. A medical oncologist was also seen by the majority of the sample, with 98.1 percent reporting at least one visit to a doctor specializing in cancer care. Radiation oncologists were used by approximately 70 percent of participants, either in consultation with their medical oncologist or for radiation treatment.

With regard to alternative/complementary therapists, the highest response rate for usage was reported for spiritual/faith healers. Approximately 35 percent of participants (n=19) reported consulting an individual regarding spiritual or faith issues related to the diagnosis, prognosis and treatment of breast cancer. Six women (11.5%) had visited a nutritionist regarding prevention of breast cancer or management of medical treatment side effects (i.e., nausea, weight loss). A chiropractor was visited by five women for muscular-skeletal problems specific to breast surgery, pain management and stress reduction. As well, five women reported attending either a naturopath or homeopath regarding ACTs. Only one woman reported consulted an acupuncturist regarding health concerns related to her breast cancer. No participants reported visiting a medical doctor who offered ACTs.

Table 15 lists other alternative/complementary therapists not indexed by the BTPS-BC but consulted by participants in the study.

Table 15 **Frequency and Percent Distribution of Additional Alternative/ Complementary Practitioners Seen**

Practitioner(s) Seen	Frequency (%)
Massage Therapist	11 (21.2)
Counsellor	4 (7.7)
Herbalist	3 (5.8)
Reflexologist	3 (5.8)
Support Group	2 (3.8)
Bodyworker	3 (5.8)
Other (e.g., Reiki Master)	4 (7.6)

Total N = 52

Overall, twenty-nine women (55.8%) reported using an alternative/ complementary therapist at least once for advice on their disease and/or cancer treatment. Forty-four percent (n=13) of participants who reported visiting an alternative/complementary practitioner(s) had seen only one therapist regarding their disease. Fifteen women (65.5%) who reported visiting an alternative/complementary practitioner had seen more than one therapists, with seven alternative/complementary therapists being the maximum number of practitioners seen by one individual. Spiritual/faith healers, massage therapists and nutritionists were the three most frequently consulted alternative/complementary therapists.

Rates of Usage of Alternative/Complementary Therapies

Table 16 lists the frequency of reported use of seven common ACTs by participants. The women were asked how frequently they had used or were using each ACT. Response options included "Never", "Rarely", "Occasionally" and "Frequently".

Table 16 **Frequency and Percent Distribution of Reported use of Alternative/ Complementary Therapies**

Alternative/Complementary Therapies	Never %	Rarely %	Occasionally %	Frequently %
Detoxification	43 (82.7)	-	3 (5.8)	6 (11.5)
Faith Healing	24 (46.2)	3 (5.8)	11 (21.2)	14 (26.9)
Herbal Remedies	26 (50.0)	4 (7.7)	7 (13.5)	15 (28.8)
Immune Therapies	40 (76.9)	-	2 (3.8)	10 (19.2)
Meditation/Relaxation Therapies	19 (36.5)	3 (5.8)	16 (30.8)	14 (26.9)
Special Foods/Diets	38 (73.1)	3 (5.8)	4 (7.7)	7 (13.5)
Vitamin or Tonics	22 (42.3)	1 (1.9)	6 (11.5)	23 (44.2)

Total N = 52

The three most frequently reported ACTs, in descending order of frequency, were meditation/relaxation therapies, vitamins/tonics and faith healing. Over sixty percent of participants reported using some form of meditation or relaxation therapy during their disease trajectory. Thirty women reported using meditation or relaxation techniques "occasionally" or "frequently". Approximately 57 percent of women reported using vitamins or tonics to some extent following diagnosis with breast cancer. The use of vitamin therapy had the highest degree of use, with 23 women stating they had "frequently" used vitamins. Just over 53 percent of participants described themselves as users of faith healing or spiritual interventions which were directed towards the effects and outcome of their disease.

Detoxification therapies were used the least by participants, with only 17.3 percent of the sample reporting the use of ACTs for cleansing purposes. Only nine women reported using detoxification therapies either "occasionally" or "frequently". Immune therapies and special foods or diets were also used infrequently by participants, with 23.1 and 26.9 percent of the sample respectively reporting use of these types of ACTs.

An open-ended question "Is there any other alternative/ complementary therapies you have used for your breast cancer?" was also asked to ensure ACTs used by participants that were not listed on the BTPS-BC were assessed (Table 17). Massage therapy, shark cartilage and support groups were the three most frequently reported ACTs used by participants, in descending order of frequency. Future testing of the questionnaire with a breast cancer population may warrant inclusion of these additional ACTs on the "Types of ACTs Used" scale.

Table 17 **Frequency and Percent Distribution of Reported use of Additional Alternative/Complementary Therapies**

Alternative/Complementary Therapies	**Frequency (%)**
Massage therapy	10 (19.2)
Shark cartilage	4 (7.7)
Support Group	4 (7.7)
Aromatherapy	2 (3.8)
Bodywork	2 (3.8)
Laying on of hands	2 (3.8)
Music therapy	2 (3.8)
Reflexology	2 (3.8)
Yoga	2 (3.8)
Aboriginal healing	2 (3.8)
Other (e.g., Ozone therapy)	4 (7.6)

Total N = 52

Rates of Intention to see Medical and Alternative/Complementary Practitioners

Participants were also questioned about their intention to visit both medical and alternative/complementary therapists. Women participating in the study were asked "Do you intend to see any of the following practitioners about your illness in the future", using a response range from "Definitely" to "Never". The response categories was condensed for analysis purposes, resulting in three categories (i.e., "Definitely/ Probably", "Uncertain" and "Probably Not/Never") (Table 18).

Table 18 **Rate of Intention to see Medical and Alternative/Complementary Practitioners**

Practitioner(s)	Probably Not/Never (%)	Uncertain (%)	Definitely/Probably (%)
Acupuncturist	31 (59.7)	11 (21.2)	10 (19.2)
Chiropractor	36 (69.3)	5 (9.6)	11 (21.1)
Doctor who offers ACTs	18 (35.3)	7 (13.7)	26 (51.0)
Homeopath	24 (47.1)	10 (19.6)	17 (33.3)
Medical Oncologist	-	-	52 (100.0)
Naturopath	22 (42.4)	10 (19.2)	20 (38.5)
Nutritionist	27 (51.9)	3 (5.8)	22 (55.8)
Radiation Oncologist	2 (3.8)	3 (5.8)	47 (90.4)
Spiritual/Faith Healer	25 (48.1)	1 (2.0)	25 (49.0)
Surgeon	5 (9.6)	1 (1.9)	46 (88.5)

Total = 52

All participants reported the intention of attending a medical oncologist in the future. Similarly, a high percentage of participants (90.4 and 88.5 percent respectively) expressed the intention to see a radiation oncologist and surgeon in the future. With regard to alternative/complementary therapists, 55.8 percent of the women expressed a desire to visit a nutritionist, followed by 51.0 percent of participants reporting the intention to see a medical doctor who offers ACTs. The third highest ranked alternative/complementary practitioner, in terms of intention to visit, was a spiritual/faith healer, with 49.0 percent of the sample reporting the desire to consult a practitioner for spiritual advice and/or healing.

The three alternative/complementary therapists that received the lowest rating regarding intention to visit were acupuncturist, chiropractor and homeopath. Only 19 percent of the women reported an intention to visit an acupuncturist regarding some aspect of their disease. Twenty-one percent of participants expected they would consult a chiropractor in the future. As well, only thirty-three percent of women reported a positive intention to visit a homeopath in the future.

Confusion was expressed by some participants regarding selected alternative/complementary therapists, with approximately 20 percent of the sample being uncertain whether they would visit an acupuncturist, homeopath or naturopath in the future. This result may be reflective of the lack of knowledge by participants about the theory and practice of these selected therapists.

Participants were also asked an open-ended question regarding their intention to see an alternative/complementary therapist(s) not listed on the BTPS-BC. Table 19 lists additional practitioners offering ACTs that were mentioned by participants as therapists they intend to see in the future. The most frequently mentioned alternative/complementary therapists were counsellors, practitioners offering traditional chinese medicine, massage therapists and Tai Chi instructors.

Table 19 **Frequency of Intention to see Additional Alternative/ Complementary Practitioner**

Alternative/Complementary Practitioners	Frequency (%)
Counsellor	4 (7.7)
Massage therapist	4 (7.7)
Traditional Chinese Medicine Practitioner	3 (5.8)
Tai Chi instructor	3 (5.8)
Yoga instructor	2 (3.8)
Aboriginal healer	2 (3.8)
Other (e.g., Reflexologist)	3 (5.8)

Total N = 52

Intention to use Alternative/Complementary Therapies

Participants were asked to comment on their intention to use seven common ACTs, using a response range from "Definitely" to "Never". For analysis purposes, the response range was condensed into three groups; "Definitely/Probably", "Uncertain", and "Probably Not/Never". Table 20 displays the rates of intention to use ACTs.

Table 20 **Rates of Intention to use Alternative/Complementary Therapies**

Alternative/Complementary Therapies	Probably Not/Never (%)	Uncertain (%)	Probably/Definitely (%)
Detoxification	29 (56.7)	4 (7.7)	19 (36.5)
Faith healing	25 (49.1)	3 (5.9)	23 (45.1)
Herbal remedies	15 (28.9)	7 (13.5)	30 (57.6)
Immune therapies	28 (63.8)	6 (11.5)	18 (34.6)
Meditation/relaxation therapies	18 (34.6)	2 (3.8)	32 (61.5)
Special foods/diets	29 (55.8)	6 (11.5)	17 (32.9)
Vitamins or Tonics	13 (25.0)	3 (5.8)	36 (69.2)

Total N = 52

The three ACTs participants reported most likely to use were vitamins or tonics, meditation/relaxation therapies, and herbal remedies. Almost 70 percent of the sample reported an intention to try vitamins or tonics in the future. Over 60 percent of participants responded "Probably" or "Definitely" about their intent to use a relaxation or meditation technique for their breast cancer. With regard to herbal remedies, 57.6 percent of the women reported that they planned to try a herbal-based supplement in the future for the treatment or prevention of breast cancer.

The three ACTs that participants were least likely to report a positive intention to use in the future were special foods/diets, immune therapies, and detoxification therapies. Only 17 women reported the intention to change their diet or food consumption in response to their diagnosis of breast cancer. Similarly, 18 women reported a positive intention to use therapies to boost immune system functioning. Nineteen participants expressed the desire to undertake detoxification therapies for their breast cancer. The greatest uncertainty about ACTs was expressed for herbal remedies, special foods/diets, and immune therapies, with between 11.5 to 13.5 percent of respondents being unsure of their future intention to use these types of ACTs.

Distribution of Responses to the "Cause of Cancer" Scale

Assessment of participants' responses to the 16 items on the "Beliefs about Cause of Cancer" resulted in item means that ranged from 1.40 to 3.9, with a standard deviation of .57 to 1.44. Participants were asked "How much do you agree with the following statements about your cancer?" using a 5-point Likert-type response scale of "Strongly Agree" to "Strongly Disagree" (1 to 5). The responses on the index were reverse coded to facilitate interpretation (5 to 1), so that a higher score on the scale would indicate agreement with beliefs about causes of cancer.

The five highest ranked beliefs about causes of cancer were in descending order: 1) the cause of my cancer is not known; 2) my cancer was caused by multiple factors; 3) my cancer was caused by stress; 4) my cancer was caused by a weakness in the immune system; and 5) my cancer was the result of a disturbance in my body/my cancer was caused by pollution (tied).

The five lowest ranked beliefs about cause of cancer by women with breast cancer were: 1) my cancer was caused by excessive sunlight; 2) my cancer was caused by drinking alcohol; 3) my cancer was caused by smoking; 4) I could have prevented my cancer; and 5) my cancer was caused by my lifestyle (Table 21).

Table 21 **Item Means of "Cause of Cancer" Scale**

Highest Ranked Beliefs	Mean	Lowest Ranked Beliefs	Mean
- The cause of my cancer is not known	3.9	- My cancer was caused by excessive sunlight	1.4
- My cancer was caused by multiple factors	3.8	- My cancer was caused by drinking alcohol	1.6
- My cancer was caused by stress	3.5	- My cancer was caused by smoking	1.6
- My cancer was caused by a weakness in the immune system	3.3	- I could have prevented my cancer	2.1
- My cancer was the result of a disturbance in my body	3.1	- My cancer was caused by my lifestyle	2.1
- My cancer was caused by pollution	3.1		

Participants were also asked about other causes of cancer they believed were related to the development of their breast cancer that were not included on the scale. Table 22 lists these causes of cancer and respective frequencies. The two most frequently mentioned causes of cancer were hormone therapy (i.e., estrogen replacement, birth control pill) and injury to breast. Inclusions of these causes of cancer on the scale may be warranted in future research.

Table 22 **Frequency and Percent Distribution of Additional Causes of Cancer**

Alternative/Complementary Practitioners	Frequency (%)
Hormone Therapy	8 (15.4)
Injury to Breast	5 (9.6)
Personality Type	2 (3.7)
Other (e.g., Satan)	15 (28.8)

Total N = 52

"Internal/Controllable Causes of Cancer" Subscale.

The item means on the "Internal/Controllable Causes of Cancer" subscale ranged from 2.1 to 3.5, with a standard deviation of 1.04 to 1.32 (Table 23). An index was created, with each participant's response score on the six items added to give a total score for the subscale, with a potential range of 6 to 30. However, to facilitate interpretation and statistical analysis, the total score for the subscale was divided by the number of items on the scale to create an index of mean total score, with a potential range of 1 to 5. Similar to Yates' (1991) analysis, participants whose score was less than 3.0 were categorized as being in disagreement with beliefs about "internal/controllable" causes of cancer. Individuals whose score was 3.0 were categorized as uncertain, while participants who scored greater than 3.0 were considered to agree with beliefs about "internal/controllable" causes of cancer.

Table 23 Item Means of "Internal/Controllable Causes of Cancer" Subscale

Items	Mean
- My cancer was caused by stress	3.5
- My cancer was caused by a weakness in the immune system	3.3
- My cancer was caused by eating the wrong foods	2.5
- My cancer caused by a build up of toxins in the body	2.5
- I could have prevented my cancer	2.1
- My cancer was caused by my lifestyle	2.1

The distribution of mean total scores for the "Internal/Controllable Causes of Cancer" subscale are listed on Table 24. The actual range of mean total scores was 1.3 to 4.0. The overall mean total score for the subscale was 2.65 (SD = 0.67). The majority of participants (60.8%) disagreed with statements about "internal/controllable" causes of cancer. Only 15 women scored greater than 3 on the total mean score, indicating positive beliefs about causes of cancer being from an internal source and/or controllable.

Table 24 Frequency and Percent Distribution of Total Mean Scores of the "Internal/Controllable Causes of Cancer" Subscale

Category	Frequency (%)
Positive Beliefs (>3)	15 (29.4)
Uncertain (=3)	5 (9.8)
Negative Beliefs (<3)	31 (60.8)

Total N = 51

"External/Uncontrollable Causes of Cancer" Subscale.

Item means for the "External/Controllable Causes of Cancer" subscale ranged from 1.4 to 3.9, with a standard deviation of 0.56 to 1.32 (Table 25). A total mean score for the subscale was created by adding participants' responses for the five items, resulting in a potential total score range of 5 to 25. However, participants' total scores for the subscale were divided by the number of items on the scale for ease of interpretation and statistical analysis. The resulting potential range of mean total scores was 1 to 5. Participants who scored less than 3.0 were considered to hold negative beliefs about external/uncontrollable cause of cancer. Individuals who scored 3.0 were categorized as being unsure of their beliefs about cause of cancer that arise from external sources or are considered uncontrollable. Participants whose mean total score was greater than 3.0 were categorized as agreeing with beliefs about external/ uncontrollable causes of cancer.

Table 25 Item Means of "External/Uncontrollable Causes of Cancer" Subscale

Items	Mean
- The cause of my cancer is not known	3.9
- My cancer was caused by multiple factors	3.8
- My cancer was caused by pollution	3.1
- My cancer was the result of exposure to insecticides	2.7
- My cancer was caused by excessive sunlight	1.4

The distribution of categories of mean total scores on the "External/ Uncontrollable Cause of Cancer" subscale is listed on Table 26. The actual range of mean total scores was 1.2 to 4.4. The overall mean total score for the subscale was 3.0 (SD = 0.73). Exactly half of the participants held negative beliefs about external/ uncontrollable causes of cancer. Forty-two percent of participants, in contrast, held positive beliefs about causes of cancer considered external or uncontrollable.

Table 26 Frequency and Percent Distribution of Mean Total Scores of the "External/Uncontrollable Causes of Cancer" Subscale

Category	Frequency (%)
Positive (>3)	22 (42.3)
Uncertain (=3)	4 (7.7)
Negative (<3)	26 (50.0)

Total = 52

<u>Distribution of Responses to the "Mechanism of Medical Treatments" Subscale</u>

Participants were asked "How much do you agree with the following statements about the medical treatments for cancer?" using a 5-point Likert-type scale ranging from "Strongly Agree" to "Strongly Disagree" (1 to 5). To facilitate interpretation of the results, items G, I, and J were reverse coded (5 to 1) so that a high score on the subscale would indicate a positive perception of medical treatments and a low score would indicate a negative perception.

Each participant's response score for the five items comprising the subscale were added to provide a total score, with a potential range of 5 to 25. However, to facilitate interpretation and analysis, the total score for the subscale was divided by 5 to provide a mean total score, with a range of 1 to 5. Participants who scored less than 3.0 were categorized as having negative beliefs about the mechanism of medical treatments. Women who scored a mean total score of 3.0 were considered to be uncertain about beliefs regarding the mechanism of medical treatments. Participants whose mean total score was greater than 3.0 were categorized as having positive beliefs about the mechanism of medical treatments.

Item means for the "Mechanism of Medical Treatments" subscale ranged from 1.5 to 3.8, with a standard deviation of 0.8 to 1.3 (Table 27). The actual range of mean total scores was 1.2 to 4.6. The overall mean total score for the subscale was 3.1 (SD = 0.70). Half of the participants (51.0%) held positive beliefs about the mechanism of medical treatments, with approximately 40 percent expressing a negative attitude toward the processes through which medical treatments function within the body (Table 28).

Table 27 **Item Means of "Mechanism of Medical Treatments" Subscale**

Items	Item Means
- Medical treatments reduce the chance that alternative/complementary therapies will work	3.8
- Medical treatments assist the body's natural forces to heal	3.6
- It is easy to understand how medical treatments work	3.5
- Medical treatments strengthen the body's natural reserves	3.1
- Medical treatments have side effects	1.5

Table 28 **Frequency and Percent Distribution of Mean Total Scores of the "Mechanism of Medical Treatments" Subscale**

Category	Frequency (%)
Positive (>3)	26 (51.0)
Uncertain (=3)	5 (9.8)
Negative (<3)	20 (39.2)

Total N = 51

Distribution of Responses to the "Outcome of Medical Treatments" Subscale

Similar to the "Mechanism of Medical Treatments" subscale, participants were asked to answer how strongly they agreed with five statements about the outcome of medical treatments. A 5-point Likert-type response scale, ranging from "Strongly Agree" to "Strongly Disagree" (1 to 5) was used to measure participant's beliefs. For ease of interpretation and statistical analysis, all items on the subscale were reverse coded (5 to 1), resulting in a high score on the scale being indicative of positive beliefs about the outcome of medical treatments.

Table 29 illustrates the item means for the "Outcome of Medical Treatments" subscale, which ranged from 3.4 to 4.3 (SD = 0.72 - 1.29). A total score for the subscale was developed by adding participants' responses to all five items, with a potential range of 5 to 25. As in previous scales, a mean total score was developed by dividing the total score by the number of items on the subscale, resulting in a potential range of mean total scores of 1 to 5. Mean total scores under 3.0 were categorized as negative beliefs about the beneficial outcomes of medical treatment. Participants whose mean total score was above 3.0 were considered to hold positive beliefs about the results of conventional medical therapies. A mean total score of 3.0 was considered indicative of uncertainty about the outcome of medical treatments.

Table 29 **Item Means of "Outcome of Medical Treatments" Subscale**

Items	Item Means
- Medical treatments prevent the spread of my cancer	4.3
- Medical treatments could cause a remission of my cancer	4.2
- Medical treatments are more important than alternative/complementary therapies	4.1
- Medical treatments assist other treatments to work	4.1
- Medical treatments can cure my cancer	3.4

The range of mean total scores was 2.0 to 5.0, with over 90 percent of participants reporting a positive belief in the outcome of medical treatments (Table 30). Only three women had a mean total score below 3.0, indicating negative beliefs in the beneficial outcomes of medical treatments. Only one participant scored exactly 3.0, indicating limited uncertainty in the sample about the outcome of medical therapies. The overall mean total score for the subscale was 4.0 (SD = 0.60).

Table 30 **Frequency and Percent Distribution of Mean Total Scores of the "Outcome of Medical Treatments" Subscale**

Category	Frequency (%)
Positive (>3)	49 (94.2)
Uncertain (=3)	1 (1.9)
Negative (<3)	2 (3.8)

Total N = 52

Distribution of Responses to the "Mechanism of Alternative/Complementary Therapies" Subscale

Participants were asked "How much do you agree with the following statements about alternative/complementary therapies?" using a 5-point Likert-type scale ranging from "Strongly Agree" to "Strongly Disagree" (1 to 5). To improve comprehension of the responses, the index was reverse coded (5 to 1), with a higher score being indicative of a positive attitude towards mechanisms of ACTs. Item means on the subscale ranged from 2.1 to 4.0, with a standard deviation of .88 to 1.60 (Table 31).

Table 31 Item Means of "Mechanism of Alternative/Complementary Therapies" Subscale

Items	Item Means
- ACTs are helpful	4.0
- ACTs assist the body's natural forces to heal	4.0
- ACTs strengthen the body's natural reserves	4.0
- ACTs will assist other treatments to work	3.8
- It is wise to use ACTs	3.8
- I believe ACTs will improve my quality of life	3.6
- ACTs help me manage the side effects of medical treatment(s)	3.6
- I don't know if ACTs can cure my cancer but I will try any treatment	3.5
- I feel ACTs increase my control over my treatment choices	3.4
- Alternative/complementary practices are part of my daily life already	2.1

A total score was created by adding participants' response score for the ten items comprising the subscale, resulting in a potential total score range of 10 to 50. A mean total score was developed for participants by dividing the total score by the number of items of the scale, leading to a potential range of 1 to 5. Participants were categorized as having negative beliefs about the mechanisms through which ACTs function if their mean total score was less than 3.0. Women whose mean total score was 3.0 were categorized as uncertain. A mean total score greater than 3.0 was indicative of positive beliefs about the mechanism of ACTs.

The distribution of mean total scores for the "Mechanism of Alternative/ Complementary Therapies" subscale is listed on Table 32. The actual range of mean total scores was 1.5 to 5.0. The overall mean total score was 3.6 (SD = 0.87). The majority of participants (76.5%) agreed with the subscale items. Only 21.6 percent of the sample disagreed with the processes through which ACTs function within the body and the usefulness of ACTs.

Table 32 **Frequency and Percent Distribution of Mean Total Scores of the "Mechanism of Alternative/Complementary Therapies" Subscale**

Category	Frequency (%)
Positive (>3)	39 (76.5)
Uncertain (=3)	1 (2.0)
Negative (<3)	11 (21.6)

Total N = 51

Distribution of Responses to the "Outcome of Alternative/Complementary Therapies" Subscale

A response range from "Strongly Agree" to "Strongly Disagree" (1 to 5) was used by participants to answer the question "How much do you agree with the following statements about alternative/complementary therapies?". To facilitate interpretation of data, all items, except for item H, were reverse coded (5 to 1), resulting in a high score on the scale being indicative of positive beliefs in the outcome of ACTs. Item means on the subscale ranged from 1.7 to 3.2 (SD = 0.16 - 0.64) (Table 33).

Table 33 **Item Means of "Outcome of Alternative/Complementary Therapies" Subscale**

Items	Item Means
- ACTs could cause a remission of my cancer	3.2
- ACTs will relieve my symptoms	3.1
- ACTs will prevent the spread of my cancer	3.0
- ACTs have side effects	2.7
- ACTs will cure my cancer	2.5
- It is the patient's fault if ACTs don't work	1.9
- ACTs are more important than medical treatments	1.7

A response index was created with each participant's response score on the seven items added to give a total score for the subscale, with a potential range of 7 to 35. However, to facilitate statistical analysis and interpretation of the data, a mean total score was created by dividing the mean score by the number of items on the subscale, resulting in a potential range of 1 to 5. Participants were categorized into "negative", "uncertain", and "positive" grouping using previously delineated scoring ranges (i.e., < 3.0, = 3.0, and > 3.0).

The distribution of mean total scores for the "Outcome of Alternative/ Complementary Therapies" subscale is listed on Table 34. The actual range of mean total scores was 1.0 to 3.7. The majority of participants (62.7%) held negative beliefs about the outcome of ACTs. Eleven women held positive beliefs about the beneficial outcome of ACTs. Interestingly, 15.7 percent of the sample were uncertain about the subscale items exploring the outcomes of ACTs. The overall mean total score for the "Outcome of Alternative/Complementary Therapies" subscale was 2.8 (SD = 0.99).

Table 34 **Frequency and Percent Distribution of Mean Total Scores of the "Outcome of Alternative/Complementary Therapies" Subscale**

Category	Frequency (%)
Positive (>3)	11 (21.6)
Uncertain (=3)	8 (15.7)
Negative (<3)	32 (62.7)

Total N = 52

Distribution of Responses to the "Care Behaviours of Health Care Professionals" Subscale

Participants were asked to answer the question "How much do you agree with the following statements about your conventional health care professional(s)?", using a response range "Strongly Agree" to "Strongly Disagree" (1 to 5). To facilitate interpretation of the results, item responses were reverse coded (5 to 1) so that a high score on the scale indicated satisfaction with the care behaviours of health care providers. Exceptions were made for items A, F, H, K and N, whose response range remained from 1 to 5. The item means for the 13 items comprising the scale ranged from 3.0 to 4.2, with a standard deviation of 0.73 to 1.47 (Table 35).

Table 35 Item Means of "Care Behaviours of Health Care Professionals" Subscale

Items	Item Means
- Conventional health care professionals are well trained	4.2
- Conventional health care professionals are up-to-date in their knowledge about my disease	4.1
- You can trust them to tell you the truth	4.1
- Conventional health care professionals are very sympathetic people	3.9
- Conventional health care professionals inspire confidence	3.8
- Conventional health care professionals have a good manner	3.8
- Conventional health care professionals give realistic hope	3.6
- Conventional health care professionals provide emotional support	3.5
- Conventional health care professionals care more about the disease than the person	3.3
- Conventional health care professionals don't encourage their patients to ask questions	3.3
- Conventional health care professionals are hard to talk to	3.2
- Conventional health care professionals don't spend enough time with their patients	3.2
- Conventional health care professionals sometimes make you feel angry	3.0

A total score was created by adding participant's responses to the 13 items comprising the subscale, with a potential range of 13 to 65. A mean total score was developed by dividing the total score by the number of items on the subscale, resulting in a potential mean total score range of 1 to 5. Participants whose mean total score was less than 3.0 were classified as being dissatisfied with their health care professional(s). Individuals who scored greater than 3.0 were categorized as being satisfied with the care and demeanour of their health care professional(s). A score of 3.0 represented uncertainty about the ability to understand the information provided by health care professionals.

The actual range of mean total scores was 1.7 to 4.7. The overall mean total score was 3.5 (SD = 0.74). Twenty-two percent of the sample were categorized as being dissatisfied with their health care professional(s), scoring a mean total score less than 3.0 (Table 36). However, the majority of participants (78.0%) reported being satisfied with the caring behaviour of their health care provider(s).

Table 36 **Frequency and Percent Distribution of Mean Total Scores of the "Care Behaviours of Health Care Professional(s)" Subscale**

Category	Frequency (%)
Satisfied (>3)	39 (78.0)
Uncertain (=3)	–
Dissatisfied (<3)	11 (22.0)

Total N = 50

Distribution of Responses to the "Understanding Health Care Professionals" Subscale

Participants were asked to answer the question "How much do you agree with the following statements about your conventional health care professional(s)?", using a response range "Strongly Agree" to "Strongly Disagree" (1 to 5). To facilitate interpretation of the results, item responses were reverse coded (5 to 1) so that a high score on the scale indicated a high level of understanding of the information and explanations provided by health care providers. The item means were 3.8 and 3.9, with a standard deviation of .91 and 1.1 repectively (Table 37).

Table 37 Item Means of "Understanding Health Care Professionals" Subscale

Items	Item Means
- Conventional health care professionals use simple explanations	3.8
- I can undestand what they are telling me	3.9

A total score was created by adding participant's responses to the two items comprising the subscale, with a potential range of 2 to 10. A mean total score was developed by dividing the total score by the number of items on the subscale, resulting in a potential mean total score range of 1 to 5. Participants whose mean total score was less than 3.0 were classified as being unable to understand their health care professional(s). Individuals who scored greater than 3.0 as being able to understand health care professional(s). A score of 3.0 was considered to represent uncertainty.

The actual range of mean total scores was 1.5 to 5. The overall mean total score was 3.8 (SD = 0.90). The majority of the sample (80.8%) were categorized as being able to understand their health care professional(s), scoring a mean total score greater than 3.0 (Table 38).

Table 38 **Frequency and Percent Distribution of Mean Total Scores of the "Understanding Health Care Professional(s)" Subscale**

Category	Frequency (%)
Understand (>3)	42 (80.8)
Uncertain (=3)	3 (5.8)
Do not Understand (<3)	7 (13.5)

Total N = 52

Distribution of Responses to the "Support to use ACTS" Subscale

Participants were asked "How much do you agree with the following statements about the encouragement you received to use alternative/complementary therapies in the treatment of you illness". A response range of "Strongly Agree" to "Strongly Disagree" (1 to 5) was used. However, to facilitate interpretation of the data, the four items on the subscale were reverse coded (5 to 1) so that a high score reflected support for the use of ACTs. Item means on the subscale ranged from 2.2 to 4.0 (SD = 1.35 - 1.56) (Table 39).

Table 39 **Item Means of "Support to use ACTs" Subscale**

Items	Item Means
- My family have supported me in using alternative/complementary therapies	4.0
- My friends have supported me in using alternative/complementary therapies	4.0
- Other health care professionals have supported me in using alternative/complementary therapies	2.7
- My doctor has supported me in using alternative/complementary therapies	2.2

The participants' responses to the four subscale items were added so that a total score with a potential of 4 to 20 was developed. A mean total score was created by dividing the total score by the number of items on the subscale, resulting in a potential mean total score range of 1 to 5. Participants with a mean total score less than 3.0 were categorized as not receiving support to use ACTS. Individuals whose mean total score was greater than 3.0 were categorized as receiving support to use ACTs. A mean score of 3.0 was considered to reflect uncertainty about the level of support received by participants to use ACTs.

The range of mean total scores was 1.0 to 5.0. The overall mean total score for the "Support to use ACTs" subscale was 3.2 (SD = 1.1). Fifty-six percent of participants who responded to the subscale (i.e., considered themselves users of ACTs) perceived that they had received support from others regarding the use of ACTs (Table 40). Thirty-four percent of users of ACTs did not receive support for their use of ACTs. Only five women were uncertain if they had received support from their family, friends and health care providers. These women may have been unsure if people important to them were aware of their use of ACTs.

Table 40 **Frequency and Percent Distribution of Mean Total Scores of the "Support to use ACTs" Subscale**

Category	Frequency (%)
Support (>3)	20 (52.6)
Uncertain about Support (=3)	5 (13.2)
Lack of Support (<3)	13 (34.2)

Total N = 38

Distribution of Responses to the "Will to Live" Scale

On the "Will to Live" Scale, women with breast cancer were asked, "How much do you agree with the following statements about your will to live?", using a response range from "Strongly Agree" to "Strongly Disagree" (1 to 5). To facilitate interpretation of the data, all items, except item L, were reverse coded so that a high score on the scale would be indicative of a strong will to live. The item means on the scale ranged from 3.6 to 4.8, with a standard deviation of .54 to 1.55 (Table 41).

Table 41 Item Means of the "Will to Live" Subscale

Items	Item Means
- I have a lot to live for	4.8
- I really don't care anymore whether I live or die	4.8
- I am optimistic and hopeful	4.7
- I desperately want to live	4.7
- I am hoping my treatments will work a cure	4.6
- I am determined to beat cancer	4.3
- I'm going to beat cancer regardless of what happens	4.1
- It's worth having any treatment even if the chances they will work may not be high	4.1
- I don't care how uncomfortable a treatment is, I will have it if it improves my chances	4.1
- If my current treatment does not work I will find something that will	4.0
- I am prepared to have any treatment to get better	3.9
- I will hang on to life at any cost	3.6

A total score was created by adding participants' responses to the items composing the scale, resulting in a potential range of 12 to 60. A mean total score was developed by dividing the total score by the number of items on the scale, with a potential score range of 1 to 5. Participants who score less than 3.0 were considered to have a low will to live. Individuals who scored greater than 3.0 were categorized as having a strong will to live. A mean total score of 3.0 was indicative of a moderate will to live.

The range of mean total scores on the "Will to Live" scale was 2.3 to 5.0. Only four participants reported a mean total score below 3.0 (Table 42). The majority of respondents (92.2%) scored a mean total score greater than 3.0, indicating a positive will to live. The mean total score for the sample was 4.3 (SD = 0.75).

Table 42 **Frequency and Percent Distribution of Mean Total Scores of the "Will to Live" Subscale**

Category	Frequency (%)
Strong Will to Live (>3)	47 (92.2)
Moderate Will to Live (=3)	–
Weak Will to Live (<3)	4 (7.8)

Total N = 51

Distribution of Responses to the Decisional Preference Card-Sort

Participants were asked to sort through five cards reflecting three types of control over decision making (i.e., active, collaborative, and passive). Using methodology recommended by Degner and Sloan (1992), participants were categorized into the three groupings based on the first card selected, reflecting their most preferred role in treatment decision making. Individuals who chose card A or B were categorized as preferring an active role in making decisions about treatment with their physician(s). Women who selected card C were considered to prefer a collaborative role, where the doctor and the woman together would reach a decision regarding cancer treatment. Participants who chose card D or E as their first choice were categorized as preferring a passive role in treatment decision making.

Table 43 displays the distribution of the sample in regard to preferred treatment decision making role. The majority of women (62.7%) preferred to play a collaborative role with their physician in making treatment decisions. Ten women (19.6%) preferred an active role in making treatment decisions, and only nine women were found to prefer a passive decisional role.

Table 43 Frequency and Percent Distribution of Preferred Decisional Role

Category	**Frequency (%)**
Active Role	10 (19.6)
Collaborative Role	42 (62.7)
Passive Role	9 (17.6)

Total N = 51

An ordinal score, ranging from 1 to 11, was also applied to participants' responses to the decisional preference card-sort. This range represented the "valid" responses to the card-sort, according to the hypothetical psychological dimension underlying treatment decision making (Coombs, 1976). The responses of twenty-four participants, or 47.1 percent, unfolded onto the psychological dimension of active, collaborative or passive decisional control. This result failed to meet the criterion of 50% + 1 of observations falling directly on the dimension (Coombs, 1976). The distribution of the valid responses are listed on Table 44. As a consequence of this finding, subsequent analysis of the relationship between ACT use and preferred decisional role warrants cautious interpretation.

Table 44 Frequency and Percent Distribution of Ordinal Scoring of Preferred Decisional Role

Ordinal Score	Frequency (%)
1 (ABCDE)	1 (4.0)
2 (BACDE)	2 (8.0)
3 (BCADE)	4 (16.0)
4 (BCDAE)	-
5 (CBDAE)	4 (16.0)
6 (CDBAE)	3 (12.0)
7 (CDBEA)	3 (12.0)
8 (CDEBA)	4 (16.0)
9 (DCEBA)	3 (12.0)
10 (DECBA)	-
11 (EDCBA)	1 (4.0)

Total N = 24

Participants were also presented with all five cards at one time and asked to select the card which best described the role in treatment decision-making they actually performed. Individuals who selected cards "A" or "B" were considered to have obtained an active role in the treatment decision-making process. Participants who selected card "C" believed they had played a collaborative role with their physician in making treatment decisions. Participants who chose cards "D" or "E" were categorized as having played a passive role in treatment decision-making. Table 45 describes the distribution of actual decision-making roles played by participants. A passive role in treatment decision-making was reported most frequently by participants (45.1%). Only thirteen women (25.5%) played an active role in treatment decisions, with 15 women reporting a collaborative role as being the actual role they played in making treatment decisions.

Table 45 Frequency and Percent Distribution of Actual Decisional Role

Category	Frequency (%)
Active Role	13 (25.5)
Collaborative Role	15 (29.4)
Passive Role	23 (45.1)

Total N = 51

Participants' preferred role in treatment decision-making was compared to the actual role they played in making decisions about treatment with their physician(s). Individuals were categorized as either receiving the decisional role they preferred, playing a more active role in decision-making than they would have preferred, or receiving a role in treatment decisions that was less active than they would have preferred. Table 46 lists the distribution of congruency between actual and preferred decisional role.

Table 46 **Frequency and Percent Distribution of Congruency between Actual and Preferred Decisional Role**

Category	Frequency (%)
Played Less Active Role	18 (35.3)
Congruent	21 (41.2)
Played More Active Role	12 (23.5)

Total N = 51

Approximately forty-one percent of women received the role in treatment decisions that they preferred to perform. Over 35 percent performed a role in making treatment decisions that was less active than the role they would have preferred. Only 23.5 percent of participants believed they had been given a role in treatment decisions that was more active than the role they would have liked to have performed.

Distribution of Responses and Internal Reliability of the EORTC QLQ-C30 (version 2)

Participants were asked to complete the EORTC QLQ-C30 (version 2) quality of life survey, which examined physical, emotional, cognitive, role and social functioning, symptom distress, and overall quality of life. Participants' total scores on the subscales were linearly transformed to a 0 to 100 scale. A higher score represented a higher level of functioning and quality of life. A higher score on the symptom distress scales and items reflected a higher level of symptomatology. Table 43 lists the mean score and Cronbach's standardized alpha coefficient for the functioning subscales. The means scores ranged from 72.0 to 80.0, with a standard deviation of 18.5 to 31.9. Item means and reliability estimates are also listed on Table 47 for the symptom distress subscales and items. Mean scores ranged from 6.7 to 32.3, with a standard deviation ranging from 14.5 to 30.9.

Table 47 Mean Total Scores of EORTC QLQ-C30 (version 2) Subscales and Symptom Items

Subscale	Mean Score	SD	Cronbach's alpha coefficient
Physical Functioning	80.0	27.4	.77
Cognitive Functioning	82.7	20.5	.25
Role Functioning	74.0	31.9	.64
Emotional Functioning	76.0	18.5	.67
Social Functioning	80.4	27.2	.64
Global Quality of Life	72.0	20.3	.69
Fatigue	32.3	25.4	.86
Nausea and Vomiting	6.7	14.5	.28
Pain	18.9	26.8	.46
Dyspnea	18.6	26.7	*
Sleep Disturbance	32.1	30.9	*
Appetite Loss	9.6	20.2	*
Constipation	15.4	29.1	*
Diarrhea	13.5	27.4	*
Financial Impact	14.7	26.7	*

Total N = 52 *** single item scales, no Cronbach's alpha coefficient calculated**

The reliability coefficients for the subscales ranged from .25 to .77. With the exception of the Cognitive Functioning, Pain and Nausea and Vomiting subscales, the reliability estimates approached the .70 criteria used from an immature scale (Nunnally, 1978).

Description of Users of Alternative/Complementary Therapies

Participants who considered themselves to be users of ACTs were identified by their responses to the question "How strictly do you adhere to any alternative/complementary regime used for your cancer?". The response range included "Completely", "Almost Completely", "Only Partially" and "Not Applicable - have not used ACTs". This method of categorization was used to group participants because it allowed subjects to distinguish whether they considered the therapies they had used for their breast cancer to be alternative or complementary to medical treatment.

Table 48 provides a description of the sample in regard to adherence to ACTs. Thirty percent of participants reported complete adherence to an alternative or complementary treatment regime. Eleven women felt that when using an ACTs, they almost completely adhered to the protocol. Fifteen percent of the sample categorized themselves as only partial users of ACTs. The remaining 32.7 percent of participants believed they had never tried an intervention that was alternative or complementary to their medical therapy.

Table 48 **Frequency and Percent Distribution of Adherence to Alternative/ Complementary Therapy Regime**

Category	Frequency (%)
Completely Adhere	16 (30.8)
Almost Completely	11 (21.2)
Only Partially	8 (15.4)
Not Applicable	17 (32.7)

Total N = 52

Closer examination of the women who considered themselves to be "non-users" of ACTs revealed some participants (N=13) who had reported the use of selected ACTs or alternative/complementary practitioner on the BTPS-BC. From field notes taken during subject interviews, these individuals did not believe their previous use of interventions, which were classified as alternative/complementary on the BTPS-BC, was truly characteristic of ACT use. For example, some women had used spiritual therapies which they considered to be part of their lifestyle or religious practices rather than an ACTs. As well, some women had explored ACTs at some point in their disease trajectory but had terminated the regime after a brief period of time. These individuals did not consider themselves to be users of ACTs.

To ensure that participants in the "Not applicable" category who reported some use of ACTs were not significantly different in terms of beliefs and attitudes from individual who denied the use of any ACT or alternative/complementary therapist, a comparison between the two groups was conducted. Only four women were found who had not used any ACT or consulted a practitioner providing ACTs. Using non-parametric statistics, no significant differences were found between the two groups with regard to demographic characteristics, beliefs about cause of cancer, medical treatment and ACTs, satisfaction with health care professionals, and will to live, quality of life, and preferred treatment decision role ($p<.05$). Therefore, the combining of participants who classified themselves as "non-users" of ACTs but had used ACTs and participants who have never used ACTs into one group was appropriate and acceptable. For subsequent analyses, participants scoring in the first three categories were considered users of ACTs. Overall, 67.3 percent of participants were considered to have used ACTs at some point, and to some extent, during their disease trajectory.

Cost of Alternative/Complementary Therapies and Practitioners

Participants were asked to estimate the amount of money they had spent on prescribed medication, visits to alternative/complementary therapists, a special diet related to their cancer, or other pills, vitamins or tonics not prescribed by their physician. Table 49 outlines the amount of money spent on cancer treatments, ranging from $0 to $2,500.

Table 49 **Frequency and Percent Distribution of Amount Spent per Month on ACTs and Practitioner**

Category	Frequency (%)
Prescribed Medication	
$0/month	21 (42.9)
$1-50/month	15 (30.6)
$51-200/month	13 (26.5)
$201-3,000/month	-
Visits to Alternative/Complementary Practitioner	
$0/month	38 (73.1)
$1-50/month	5 (9.6)
$51-200/month	7 (13.5)
$201-3,000/month	2 (3.8)
Special Diet	
$0/month	51 (98.1)
$1-50/month	-
$51-200/month	-
$201-3,000/month	1 (1.9)
Pills, Vitamins, Tonics, etc.	
$0/month	22 (42.3)
$1-50/month	23 (44.2)
$51-200/month	6 (11.5)
$201-3,000/month	1 (1.9)

Total N = 52

The average amount of money spent per month by participants on medication prescribed by their doctor was $79.15 (SD = 152.73). In comparison, the average amount spent on non-prescription ACTs per month was $ 23.27 (SD = 43.02). With regard to how much money participants spent on visiting alternative/complementary therapists, the average amount reported was $ 75.92 per month (SD = 350.53). The large standard deviations in each category was indicative of the wide variation in amount spent on prescription drugs, non-prescription drugs, diets and visits to alternative/complementary therapists. For example, the majority of participants visiting a practitioner offering ACTs spent, on average, under $200 per month. However two women, who had travelled outside of Canada seeking ACTs, had spent over $2,000 dollars per month.

Length of Time Using Alternative/Complementary Therapies

Participant were asked "How long have you been using alternative/ complementary therapies for the treatment of your cancer?". Of participants who reported using ACTs, the majority (52.4%) had been using an ACT or visiting a practitioner for more than one year (Table 50). Almost 23 percent of women using ACTs had begun using an intervention considered beyond the scope of conventional medicine in the past four to six months.

Table 50 **Frequency and Percent Distribution of Length of Time using ACTs and/or ACT Practitioner(s)**

Category	Frequency (%)
Less than 1 month	2 (5.7)
1 to 3 months	3 (8.6)
4 to 6 months	8 (22.9)
7 to 12 months	4 (11.4)
Longer than 12 months	18 (51.4)

Total N = 35

Relationship Between Sociodemographic and Disease Variables and Use of ACTs

Table 51 presents the results of analyses of tests of association between sociodemographic and disease variables and the use of ACTs by participants. The null hypothesis for these analyses was that there would be no relationship between the use of ACTS and any demographic or disease characteristics. However, a significant relationship was found between education status and ACT use (Chi-square = 7.1, $p < .008$). The majority of participants (68.6%) who reported using ACTs had obtained an education beyond high school. In comparison, the majority of participants (70.6%) who used only conventional medical treatments had not achieved post-secondary education. No other significant relationships between sociodemographic and disease variables were observed.

Table 51 Relationship of Sociodemographic and Disease Variables and Use of ACTs

Sociodemographic and Disease Variables	Frequency (%)	Chi -Square	DF	p-value
Age				
40 yrs or less	26 (50.0)	.09	1	.77
greater than 40 years	26 (50.0)			
Family Income				
$40,000 or less	18 (36.7)	1.8	1	.19
more than $40,000	31 (63.8)			
Education				
high school or less	23 (44.2)	7.1	1	.008
more than high school	29 (55.8)			
Stage of Disease				
Stage 1 or 2	26 (50.0)	.09	1	.77
Stage 3 or 4	26 (50.0)			
Recurrence				
Yes	18 (34.6)	.12	1	.74
No	34 (65.4)			
Time Since Diagnosis				
2 years or less	32 (61.5)	.08	1	.78
greater than 2 years	20 (38.5)			

Total = 52

Relationship Between Beliefs and Use of Alternative/Complementary Therapies

Table 52 presents the results of parametric and non-parametric statistics which examined the associations between the use of ACTs and beliefs about cause of cancer, medical treatment, ACTs, satisfaction with health care providers, and will to live. No significant associations were found ($p<.05$). However, the association between ACT use and beliefs about the outcome of ACT resulted in a p-value of .0621, approaching the level of significance of .05. Given the limited sample size of 52 participants, a Type II error, where a significant result is not found because of insufficient sample size, may have occurred. Therefore, the relationship between beliefs about the outcome of ACTs and the use of ACTs warrants closer examination in future research.

Table 52 **Relationships Between Beliefs and ACT Use**

BTPS-BC Scales	Frequency	Mean Score	SD	DF	p-value
"Internal/Controllable Causes of Cancer" Subscale					
ACT Use	34	2.8	.68	33	0.90
No ACT Use	17	2.4	.65	16	
"External/Controllable Causes of Cancer" Subscale					
ACT Use	35	3.0	.79	34	0.25
No ACT Use	17	2.9	.60	16	
"Mechanism of Medical Treatments Subscale"					
ACT Use	34	3.1	.73	33	0.79
No ACT Use	17	3.1	.68	16	
"Outcome of Medical Treatments Subscale"					
ACT Use	35	24.7	50.9	1	0.22
No ACT Use	17	30.1			
"Mechanism of ACTs" Subscale					
ACT Use	35	3.9	.61	34	0.89
No ACT Use	16	2.8	.58	15	
"Outcome of ACTs" Subscale					
ACT Use	34	28.7	49.9	1	0.06
No ACT Use	17	20.5			
"Caring Behaviours of Health Care Professionals" Subscale					
ACT Use	35	24.4	48.7	1	0.47
No ACT Use	17	27.6			
"Understanding Health Care Professionals" Subscale					
ACT Use	35	27.6	48.7	1	0.44
No ACT Use	17	24.3			
"Will to Live" Scale					
ACT Use	34	26.7	49.7	1	0.62
No ACT Use	17	24.5			

Relationship Between Preferred Treatment Decisional Role and ACT Use

Table 53 presents the results of the analysis which examined the relationship between preferred treatment decisional role and ACT use. The null hypothesis was that there would be no relationship between the use of ACTs and the treatment decisional role preferred by participants. However, a significant relationship was found (Chi-square = 11.72, $p < .003$) between the two subsamples, use of ACTS and no use of ACTs, and the three types of decisional role, active, collaborative and passive. Only 6.25 percent of participants using only conventional medical treatments preferred an active role in treatment decision making. The majority of participants (50.0%), preferred to play a collaborative role with their physician when making decisions about treatment. Forty-three percent of women using only medical treatments were found to prefer a passive role in treatment decision making. In comparison, only two women (5.7%) who were using ACTs in conjunction with medical treatments wanted a passive role in making treatment decisions with their physician. The majority of participants (68.5%) who were using ACTs wanted to make treatment decisions in collaboration with their doctor. As well, a large percentage of ACT users (25.7) were found to prefer an active role in making decisions regarding treatment. From these findings, it is possible to conclude that participants using ACTs were more likely to prefer an active or collaborative role in treatment decisions than participants using only conventional medical treatments.

Table 53 Comparison of Preferred Treatment Decisional Role of Users and Non-Users of Alternative/Complementary Therapies

Treatment Practices	**Active Role** (# and row %)	**Collaborative Role** (# and row %)	**Passive Role** (# and row %)
ACT Use	9 (25.7)	24 (68.6)	2 (5.7)
No ACT Use	1 (6.25)	8 (50.0)	7 (43.74)

Chi-square = 11.73, p < .003

Relationship Between Congruence of Actual and Preferred Treatment Decisional Role and ACT Use

Table 54 presents the results of an analysis which explored the relationship between congruence of actual and preferred treatment decisional role and ACT use. The null hypothesis was that there would be no relationship between congruence of actual and preferred decisional role and the use of ACTs by participants. This hypothesis was confirmed, with a p-value equal to 0.56.

Table 54 Comparison of Preferred Treatment Decisional Role of Users and Non-Users of Alternative/Complementary Therapies

Treatment Practices	**Received Preferred Role** (# and row %)	**Received Less Active Role** (# and row %)	**Received More Active Role** (# and row %)
ACT Use	13 (61.9)	14 (77.8)	8 (66.7)
No ACT Use	8 (38.1)	4 (22.2)	4 (33.3)

Chi-square = 1.16, p = .56

Relationship Between Quality of Life and ACT Use

Table 55 and 56 presents the results of non-parametric statistical tests which examined the associations between the use of ACTs and various aspects of quality of life included on the EORTC QLQ-C30 (version 2) quality of life survey. No significant relationships were found between ACT use and physical, cognitive, emotional, social, and role functioning, symptom distress, financial impact, or global quality of life (p<.05).

Table 55 Relationship Between Functional Ability and ACT Use

Functioning Scales	Frequency	Mean Score	SD	DF	p-value
Physical Functioning					
ACT Use	35	25.6	47.1	1	0.52
No ACT Use	17	28.3			
Cognitive Functioning					
ACT Use	35	25.2	47.2	1	0.54
No ACT Use	17	27.7			
Social Functioning					
ACT Use	35	24.7	47.3	1	0.18
No ACT Use	17	30.3			
Emotional Functioning					
ACT Use	35	25.9	50.7	1	0.70
No ACT Use	17	27.6			
Role Functioning					
ACT Use	35	25.6	48.5	1	0.52
No ACT Use	17	28.3			
Global Quality of Life					
ACT Use	35	27.1	50.8	1	0.67
No ACT Use	17	25.2			

Total N = 52

Table 56 **Relationship Between Symptom Distress, Financial Impact and ACT Use**

Symptom Distress Scales and Items	Frequency	Mean Score	SD	DF	p-value
Fatigue					
ACT Use	35	28.0	50.6	1	0.31
No ACT Use	17	23.5			
Nausea and Vomiting					
ACT Use	35	25.8	37.7	1	0.50
No ACT Use	17	28.0			
Pain					
ACT Use	35	26.4	47.9	1	0.95
No ACT Use	17	26.7			
Dyspnea					
ACT Use	35	27.0	44.8	1	0.68
No ACT Use	17	25.4			
Sleep Disturbance					
ACT Use	35	27.8	47.9	1	0.33
No ACT Use	17	23.8			
Appetite Loss					
ACT Use	35	27.8	36.5	1	0.21
No ACT Use	17	23.8			
Constipation					
ACT Use	35	26.2	39.9	1	0.78
No ACT Use	17	27.2			
Diarrhea					
ACT Use	35	26.6	37.8	1	0.92
No ACT Use	17	26.3			
Financial Impact					
ACT Use	35	27.8	39.9	1	0.25
No ACT Use	17	23.8			

Total N = 52

Relationship between Quality of Life and Stage of Disease

Analysis was conducted to examine the relationship between various aspects of quality of life and stage of breast cancer (Table 57 and 58). A significant relationship was apparent between stage of breast cancer and role functioning. Participants who were diagnosed with stage 1 or 2 breast cancer reported a significantly higher role functioning than women with stage 3 or 4.

Table 57 Relationship Between Functional Ability and Stage of Breast Cancer

Functioning Scales	Frequency	Mean Score	SD	DF	p-value
Physical Functioning					
Stage 1 or 2	26	26.7	47.3	1	0.69
Stage 3 or 4	26	24.7			
Cognitive Functioning					
Stage 1 or 2	26	23.8	48.6	1	0.39
Stage 3 or 4	26	27.2			
Social Functioning					
Stage 1 or 2	26	28.7	50.4	1	0.25
Stage 3 or 4	26	24.3			
Emotional Functioning					
Stage 1 or 2	26	23.5	50.9	1	0.32
Stage 3 or 4	26	27.5			
Role Functioning					
Stage 1 or 2	26	29.3	48.7	1	0.05
Stage 3 or 4	26	21.7			
Global Quality of Life					
Stage 1 or 2	26	39.5	54.2	1	0.14
Stage 3 or 4	26	23.5			

Total N = 52

Table 58 **Relationship Between Symptom Distress, Financial Impact and Stage of Disease**

Symptom Distress Scales and Items	Frequency	Mean Score	SD	DF	p-value
Fatigue					
Stage 1 or 2	26	26.9	50.9	1	0.49
Stage 3 or 4	26	24.1			
Nausea and Vomiting					
Stage 1 or 2	26	25.6	38.5	1	0.96
Stage 3 or 4	26	28.4			
Pain					
Stage 1 or 2	26	26.8	48.2	1	0.51
Stage 3 or 4	26	24.2			
Dyspnea					
Stage 1 or 2	26	22.7	44.8	1	0.13
Stage 3 or 4	26	28.2			
Sleep Disturbance					
Stage 1 or 2	26	25.4	48.2	1	0.94
Stage 3 or 4	26	25.6			
Appetite Loss					
Stage 1 or 2	26	25.7	37.3	1	0.87
Stage 3 or 4	26	25.2			
Constipation					
Stage 1 or 2	26	24.6	40.7	1	0.58
Stage 3 or 4	26	26.4			
Diarrhea					
Stage 1 or 2	26	24.7	38.5	1	0.62
Stage 3 or 4	26	26.3			
Financial Impact					
Stage 1 or 2	26	24.9	39.6	1	0.71
Stage 3 or 4	26	26.1			

Total N = 52

Summary

The results can be summarized as follows:

1. Pilot study results, using methodology recommended by Imle and Atwood (1988), suggest the BTPS-BC is clear, internally consistent and content valid with a sample of women with breast cancer. Minor modification to 13 items of the BTPS-BC was recommended by panel members. Two items were deleted from the questionnaire and six items were added to improve the consistency and validity of the BTPS-BC. The resulting questionnaire consisted of 128 items.
2. Factor analyses results suggest that there were interpretable subdimensions present on the seven scales of the BTPS-BC. In total, nine new subscales were developed from the original seven scales. Twelve items failed to factor meaningfully and may be eliminated following future research if similar results occur upon replication of the study.
3. Fifty-five percent of participants reported consulting an alternative/ complementary therapist. The three most frequently reported alternative/complementary practitioners were spiritual/faith healers, massage therapists and nutritionists. The three least reported alternative/ complementary therapists were medical doctors offering ACTs, acupuncturists and homeopaths.
4. Sixty-seven percent of participants reported using at least one ACTs. The three most frequently reported ACTs were meditation/relaxation, vitamins/tonics and faith healing. The three ACTs reported to be used the least were detoxification therapies, immune therapies and special diets.

5. The highest ranked beliefs about causes of cancer by women with breast cancer were those related to external/uncontrollable causes of cancer. The lowest ranked beliefs about causes of cancer were those related to internal/controllable causes of cancer.
6. There was a significant relationship between ACT use by women with breast cancer and preferred treatment decisional role (Chi-square = 11.72, $p < .003$). The majority of women (94.3%) using ACTs were found to prefer either an active or collaborative role in treatment decisions. In comparison, only 56.3 percent of women using only conventional treatment preferred an active or collaborative role in decision-making. No relationship was found between congruence of actual and preferred decisional role and the use of ACTs.
7. One demographic variable, education, was found to have a significant relationship with ACT use by women with breast cancer (Chi-square = 7.1, $p < .008$). Sixty-eight percent of women using ACTs had obtained more than a high school education. In comparison, only 29.4 percent of women using only conventional medical treatment had achieved greater than high school education.
8. No significant relationships were found between ACT use and beliefs about cause of cancer, treatments, satisfaction with health care professionals, support to use ACTs and will to live. No relationship was found between ACT use and quality of life.

CHAPTER FIVE

DISCUSSION

Introduction

The final chapter of this thesis provides an interpretation of the major findings of the study and discusses the clinical, methodological, and theoretical implications of the study outcomes. As well, recommendations are made regarding education and future research. This chapter also examines the limitations of the study.

Interpretation of the Findings

Women with breast cancer in Canada have called for research which examines the role ACTs may play in the holistic treatment of cancer (National Breast Cancer Forum, 1994). Few research studies have been conducted in Canada to explore the use of therapies considered alternative or complementary to conventional medical treatments by individuals with cancer. However, without this information, health care professionals in Canada are providing care in the context of an unknown treatment entity that may have positive or negative outcomes on conventional medical care. Without open and knowledgeable communication about the use of ACTs, the information and support needs of individuals using ACTs will not be addressed. As well, the validity of future studies exploring the efficacy of ACTs may be threatened by the biomedical perspective of health care researchers.

The first aim of this study was to refine and test the reliability and validity of a questionnaire (i.e., BTPS-BC) that would explore the beliefs and treatment practices of Canadian women with breast cancer who were using ACTs. The second aim of this study was to use the BTPS-BC to examine ACT use in a convenience sample of women with breast cancer and related beliefs that may influence women's decision to use ACTs. With this knowledge, communication between health care providers and women with breast cancer using ACTs could be strengthened and future directions of ACT research be identified.

Alternative/complementary therapy use by women with breast cancer.

The majority of women in the study (67.3%) had at some point in their disease trajectories used treatments they considered to be ACTs. The prevalence of ACT use by women in this study was higher than the prevalence reported for general cancer populations from Australia and the United States (Cassileth et al., 1984; Lerner & Kennedy, 1992; Yates, 1993). In comparison to Canadian ACT research by Montbriand (1993), who reported that approximately 81 percent of cancer patients in her study used ACTs, the frequency of ACT use in this sample appeared slightly less. However, caution must be used in comparing results from this study of women with breast cancer with the findings from previous research because of differences in sampling methodology, setting, definition of ACT use, and study instruments. Nonetheless, it is reasonable to suggest that ACT use by women with breast cancer in Canada is not a trivial event, but may be a frequent clinical occurrence that warrants continued research.

Types of alternative/complementary therapies used.

Previous researchers who have studied ACT use have reported physical therapies to be the most frequently used type of alternative or complementary treatments by individuals with cancer (Cassileth et al., 1984; Montbriand, 1993). As well, intervention studies exploring the efficacy of ACTs have focused extenstively on therapies such as diet interventions, herbal supplements and drug therapies (ACS, 1991; 1993a; 1993b). However, the results of this study suggest physical therapies, such as detoxification and diets, may be used the least by women with breast cancer. Many women reported a lack of knowledge regarding biological interventions and disbelief in radical diet modifications. However, one exception was use of vitamins, which were reported by women in the study to be the ACT used with the most commitment, with forty-four percent of the sample stating they "frequently" used vitamin supplements. The most prevalent vitamin therapies described by participants included supplementary doses of vitamin C, E and beta-carotene. Few individuals reported using "mega-dosages" of vitamins. Often women stated the purpose of vitamin therapy was to improve their healing following breast surgery or to increase their immune system functioning during adjuvant medical treatment (Field Notes, Participants 3, 23, 39, 45, 53, and 54).

Possibly, the high use of vitamins by women with breast cancer in this study was reflective of the current societal trend towards self-care and fitness. Vitamins may be perceived as a relatively benign nutritional supplement that will promote health without excessive side effects, protocols or expense. As well, participants' use of vitamins may have been encouraged by the favourable presentation of vitamin therapy in the lay literature. Brown (1987) and Lerner and Kennedy (1992) also suggested that the use of ACTs by individuals with cancer may be influenced by the exposure of ACTs in the media. For example, during recruitment and data collection, 714X (an immune system booster) and shark cartilage both received attention in the local media as alternative cancer therapies. Not surprisingly, numerous participants expressed interest in these two ACTs, asking the researcher for additional information on the efficacy, known side effects and principles underlying these treatments. This would suggest that health care professionals should be aware of current ACT trends within the lay literature and media and be prepared to answer for resulting questions by patients.

Psychological/spiritual therapies, such as meditation, relaxation and faith healing, were the types of ACTs used by the largest percentage of women with breast cancer in this study. In comparison to studies conducted by Cassileth et al. (1984), Lerner and Kennedy (1992) and Montbriand (1993), the use of psychological and spiritual therapies was found to be more frequently reported. Approximately 60 percent of participants reported some use of meditation/relaxation therapies. In contrast, 24 to 49 percent of cancer patients in previous research studies reported the use of complementary, psychological therapies (Cassileth et al., 1984; Lerner & Kennedy, 1992). Montbriand (1993) found only eight percent of cancer patients surveyed in her Canadian study had used spiritual/faith therapies. This finding is substantially less than the approximately 53 percent of women with breast cancer in the study who reported use of spiritual or faith therapies. These discrepancies in use of psychological/spiritual therapies by individuals with cancer may reflect differences between the studies in terms of population, sampling methodology, definition of ACTs, and instrumentation. As well, the in-person administration of the BTPS-BC may have influenced the findings by providing an opportunity to more extensively explore participants' use of ACTs.

With regard to anecdotal information about psychological therapies, numerous participants reported using psychological therapies to reframe their diagnosis of breast cancer and to improve their ability to cope with conventional medical treatments. For example, one woman with anticipatory nausea and vomiting used visualization to alleviate her distress, describing how she would imagine the chemotherapy to be "liquid sunshine" flowing through her body (Field Notes, Participant 3). As well, several women reported using relaxation techniques to help them cope with the stresses associated with the diagnosis of breast cancer, treatment decisions, and uncertainty related to prognosis. These comments by the women participating in the study suggest that psychological ACTs were considered to be supportive treatments that helped participants manage the crisis of being diagnosed with breast cancer. This conclusion is shared by Cassileth et al. (1991) and McGinnis (1991), who found the goal of the majority of individuals with cancer using ACTs was to improve physical and emotional well-being.

Study participants reported spiritual/faith healers to be the most frequently consulted complementary therapist regarding their diagnosis of breast cancer. However, not all women perceived their consultations with a spiritual counsellor to be a form of alternative/complementary treatment. Instead, spiritual and faith issues were considered to be more reflective of the women's lifestyle and religiosity. Nevertheless, stories of improved psychological well-being, inner healing and "peace of mind" were shared by many participants. Researchers endeavouring to explore spiritual ACTs should be alert to the language used by different respondents when discussing the role that their religion/faith practices might play in their care and well-being. Additional probing may be required to uncover the use of spiritual therapies by individuals with cancer.

Numerous women in the study (32.9 to 69.2%) reported an intention to explore ACTs in the future. The three most frequently reported ACTs that women intended to use were vitamins, meditation/relaxation therapies and herbal remedies. As well, women were most likely to report a future intention to visit a nutritionist, medical doctor offering ACTs or spiritual healer. However, women's intention to consult alternative/complementary therapists did not appear to reflect a dissatisfaction with conventional health care professionals. Instead, the majority of participants (88.5 to 100.0%) perceived medical oncologists, radiologists and surgeons as continuing to play a central role in their cancer care. Therefore, as previously reported by Montbriand (1995), the use of ACTs or alternative/complementary therapists does not appear to exclude the use of conventional medical practitioners. This finding may address the concern held by other researchers that the use of ACTs may disrupt conventional medical treatment and care (Brown, 1987; Danielson et al., 1988). Future research on when ACTs are used in the cancer trajectory and the relationship to conventional treatment regimen(s) in women with breast cancer is indicated to fully explore this concern.

Overall, the reported use of psychological and spiritual ACTs by participants, the anecdotal comments from participants regarding the supportive nature of these ACTs, and the reported intention to continue using conventional health care providers, suggested that ACTs were perceived by the women in this study to be supportive rather than alternatives to medical treatment(s). Women using ACTs in this study did not appear to be exploring treatment options outside of conventional medicine in an attempt to replace the medical treatments they were using. The use of ACTs as adjuvants to medical care would dispel the prevalent belief that users of ACTS are seeking a "cure" for cancer (Brown, 1987; Cassileth et al., 1984; Lerner & Kennedy, 1992; Montbriand

& Laing, 1991). Although rationale for use of ACTs in this study was not explored, these results indicate that women were supportive of conventional medical treatment. This finding suggests that other factors may be motivating women to use ACTs. Anecdotal comments by participants suggest that women may use ACTs to increase the effectiveness of medical therapies, strengthen coping ability and improve physical, emotional and spiritual well-being. Future research on the rationale behind the use of specific ACTs is necessary to explore these hypotheses.

Factors associated with use of alternative/complementary therapies.

Previous research has identified several factors which may motivate individuals with cancer to use ACTs. These factors include beliefs about cause of cancer, beliefs about medical treatment and ACTs, satisfaction with health care providers, a desire for an active role in health care decisions and social support (Cassileth et al., 1984; Lerner & Kennedy, 1992; Montbriand, 1993; and Yates et al., 1993). In this study, the only significant relationship found was between the use of ACTs and preferred treatment decision role by women with breast cancer. The majority of women (94.3%) using ACTs were found to prefer either an active or collaborative role with their physician when making treatment decisions. In comparison, 56.2 percent of women using only conventional medical treatments wanted an active or collaborative role in treatment decisions.

This finding suggests that the use of ACTs by women with breast cancer is associated with the desire to play a more active role in decisions regarding treatment. Possibly, the use of ACTs provided women with breast cancer with the opportunity to make independent decisions regarding treatment that had not been provided by their physician(s). However, the lack of a relationship between the congruence of actual and preferred decisional role and ACT use does not support this hypothesis. The use of ACTs by participants preferring a more active role in treatment decision-making may be a consequence of these women being better informed and knowledgeable about their disease and treatment options. This hypothesis is supported by Hack, Degner and Dyck (1994), who reported women with breast cancer who preferred a more active decisional role also wanted more disease and treatment information from their physician. Montbriand and Laing (1991) also conceptualized the use of ACTs by individuals with cancer as an attempt to regain a sense of control after receiving a potentially threatening diagnosis. To address these hypotheses, future exploration of the exact nature of the relationship between ACT use, preferred decisional role, information needs and locus of control is required with a larger breast cancer population in Canada.

The overall results of the preferred decisional role card-sort varied slightly from the findings of Degner, Kristjanson, Bowman, et al.'s research (under review), that explored preferred decisional preference with a quarter of the women living with breast cancer in Manitoba. These researchers reported that 44 percent of the women they studied (N=1012) preferred a collaborative role in treatment decisions and approximately 34 percent selected a passive decision making role. In contrast, 62.7 percent of the women with breast cancer in this study were found to prefer a collaborative role in making treatment decisions with their doctor. Only 17.6 percent of participants expressed the desire for a passive decisional role. These discrepancies may be a result of the younger age and higher education status of the study's participants, resulting in a more autonomous and informed sample of women. This conclusion was supported by Degner and Sloan (1992), who reported age to be significant associated with preferred decisional role, with younger women preferring a more active role in treatment decisions. As a result of this comparison, it is possible to conclude that the sample of women with breast cancer in the study were different with regard to preferred treatment decision role than the larger Manitoba population of women with breast cancer.

No significant relationship was evident between beliefs about cause of cancer and ACT use. However, exploration of participants' beliefs about cause of cancer demonstrated that women in the study perceived cancer as uncontrollable, arising from an unknown source or from multiple factors. This uncertainty about the diagnosis of cancer and resulting treatment was confirmed by Yates (1991), who found a high degree of ambiguity in the beliefs held by advanced cancer patients. Sociological work by Susan Sontag (1978) has further contributed to cancer being conceptualized as a disease of uncertainty, where an individual's mortality and self-concept are threatened. This threat and the resulting uncertainty about prognosis may contribute to women's use of ACTs, who may believe ACT use will increase their chance of survival. It will be important in future research to explore the concept of uncertainty and its relationship to treatment decisions, including therapies considered alternative or complementary.

However, a review of the literature revealed that not all studies have found cancer patients using ACTs to perceive cancer and medical treatment to be surrounded with uncertainty and ambiguity. Cassileth et al. (1984) found that individuals with cancer using ACTs believed cancer to be a preventable disease, amenable to therapies such as diet manipulation. However, Cassileth et al.'s (1984) results must be viewed cautiously because the sample included individuals with cancer receiving treatment at an alternative cancer treatment centre. These individuals may have had a unique perspective of cancer and treatment in comparison to cancer patients using ACTs outside of a clinical setting. Possibly, a biased perspective of cause of cancer was presented by Cassileth et al., 1984). Replication of the "Causes of Cancer" scale is required with a larger breast cancer population to determine the generalizability of this study's findings regarding the lack of certainty in beliefs about cause of cancer.

Some women in the study identified stress and a weakness in the immune system as possible causes of their disease. Numerous women related the development of their breast cancer to a stressful work or home environment, which decreased their level of health or created an imbalance within their body (Field Notes, Participant 3, 24, and 47). Breast cancer was conceptualized by these individuals as a symptom of dysfunction rather than an independent disease entity. This perception of cancer as a product of one's coping ability may have influenced participants' decisions to use meditation/relaxation and spiritual/faith therapies. Previous literature has suggested a link between the type of ACT used and beliefs about cause of cancer (Yates et al., 1993). Replication studies with a larger sample of women with breast cancer will allow more detailed analyses of the relationships between the types of ACTs selected and related cause(s) of cancer.

Overall, women in this study were found to be extremely satisfied with their conventional medical care providers and optimistic about the mechanisms of and outcomes offered by medical treatment. Whether this optimism is due to the positive outlook ascribed to by many cancer patients ("Cancer can be beaten") or the confidence the women have in western medicine is uncertain. For the women in this study, satisfaction with medical treatment and providers had no influence on their decision to use ACTs; however, this finding is limited by the fact that women with breast cancer who had withdrawn from conventional medical treatments were not included in the sample. Cassileth et al.'s (1984) research with cancer patients from both conventional and alternative care settings showed individuals who used ACTs reported decreased satisfaction with their medical care and held negative perceptions of medical treatments. It would be important to measure the attitudes of women with breast cancer in Canada who have refused the traditional treatments of chemotherapy, radiotherapy and surgery in favour of alternative therapies to more fully examine this hypothesis.

Previous research has linked the decision to use ACT with social support and encouragement from significant others (Montbriand, 1995; and Yates et al., 1993). However, in this study, no relationship was found between the use of ACTs and encouragement by family members, friends, physicians or other health care professionals. The majority (52.6%) of participants using ACTs believed they had received support from significant others to use ACTs, with the exception of physicians and other health care professionals. A clinically significant number of participants in the study (N=8) failed to inform their health care provider(s) about their use of ACTs. The implication of this finding will be further discussed in the Clinical Implications section.

The absence of additional significant relationships between beliefs and ACT use may have been due to the study's small sample size, resulting in a Type II error. As well, the lack of relationships between ACT use by women with breast cancer and beliefs may have been a result of a specification error. Possibly, the measurement of other variables and beliefs not included on the study's instruments might have explained the use of ACTs by women with breast cancer in this study. Future replication of the BTPS-BC with a larger sample size is required to explore these issues and test the stability of the results of this study.

Demographic variables associated with alternative/complementary use.

Numerous sociodemographic variables have been associated with ACT use in cancer populations. Yates (1991) found a significant relationship between age, education and socioeconomic status and the use of ACTs by advanced cancer patients. Cassileth et al. (1984) also correlated level of education with the use of ACTs. In this study, a significant relationship was found between ACT use and level of education. Sixty-eight percent of women with breast cancer in the study who used ACTs had achieved a high school diploma or higher. In comparison, only 29 percent of participants using only conventional medical treatments were found to have achieved greater than a high school education.

Perhaps, women with breast cancer who obtain post-secondary education may have more opportunities and resources than women less educated to explore information regarding ACTs. A higher education may also expose women with breast cancer to different cultural beliefs or conceptualizations of health beyond the conventional western medical model. These women may be more likely to question their reliance on only one form of health care and, as a consequence, seek out alternative treatment options. Replication studies exploring the relationship between demographic characteristics and ACT use with a larger breast cancer population will confirm the stability of this finding and provide an opportunity to explore the relationship between education and ACT use.

The lack of additional significant relationships between demographic characteristics and ACT use may have been a result of the small sample size, causing a Type II error. As well, the skewed distribution of participants with regards to family income and age, limited the power of the study in comparing ACT use across income levels. Future replication studies with a larger sample of women with breast cancer will allow more informative analyses of the relationships between age, income and ACT use.

Summary.

In summary, a significant portion of the women with breast cancer in the study reported use of ACTs. In contrast to previous research findings which reported physical ACTs to be the most prevalent cancer ACTs, the most frequently reported ACTs by women in the study were psychological or spiritual therapies. The use of these types of ACTs may reflect the belief by women with breast cancer that ACTs are complementary to medical treatments rather than curative, alternative therapies. The limited use of invasive and intensive physical ACTs, such as detoxification, also suggests that participants were seeking treatments dissimilar to medical interventions. However, the use of ACTs did not appear to affect participants' commitment to conventional medical treatment. Larger scaled replication studies will allow exploration of the cross-sectional use of ACTs across the cancer trajectory and the impact on compliance and use of conventional medical treatment.

The only significant relationship between beliefs and ACTs evident in the study was between preferred treatment decision role and the use of ACTs. Women who used ACTs were found to be more likely to prefer an active or collaborative role in making decisions with their physicians than women who used only conventional treatments. Further study is required to explore the underlying rationale for this relationship. A significant relationship was also found between education level and use of ACTs. Women who used ACTs were more likely to have achieved greater than a high school education than women using only medical therapies. This association may reflect the increased opportunities with regard to access to information about ACTs for women with an education level greater than high school.

The lack of associations between beliefs, demographic characteristics and ACT use by women in the study may be attributed to the small sample size, resulting in a possible Type II error. However, replications studies with a larger sample of women with breast cancer are required to test the stability of the study's findings and allow generalizations to the Canadian breast cancer population.

Methodological Implications

This section will discuss the methodological implications with respect to tool properties, validity and reliability of the BTPS-BC, the decisional preference card-sort, and the EORTC QLQ-C30 (version 2). As well, sampling issues specific to this population and ACT research will be addressed.

Tool properties of the BTPS-BC.

Results of the pilot study suggested that the BTPS-BC was clear, internally consistent and valid for a breast cancer population. Minor modifications recommended by panel members were made to the BTPS-BC to improve the applicability of the survey to Canadian women with breast cancer. All scales obtained sound psychometric estimates with the exception of the "Efficacy of Medical Treatments" and the "Causes of Cancer" subscales. The BTPS-BC was relatively easy to administer and was answered with interest by participants. Although suitable for this study sample, the length of the questionnaire (128 items) may create subject burden for an advanced cancer population. Replication of the BTPS-BC with a larger breast cancer population will assist in the elimination of additional scale items and the development of a more succinct instrument. Deletion of items following factor analysis would have been premature at this preliminary stage of research. However, items that may be deleted if they continue to not perform well with subsequent samples would be: "Causes of Cancer" scale items D, H, J, L, and N; "Efficacy of Medical Treatments" scale items E and H; "Efficacy of Alternative/Complementary Therapies" items I and N; and "Encouragement to use Alternative/Complementary Therapies" scale items A, B, C, D.

Validity issues of the BTPS-BC

When a multi-item scale is hypothesized to measure more than one concept, factor analysis can be used to expose the underlying dimensions (Carmines & Zeller, 1979). Factor analyses were conducted on all BTPS-BC scales to assess the internal structure of each scale, delineate subscales relevant to the study of ACT use by women with breast cancer, and identify possibly irrelevant items.

Three of the scales retained a factor structure similar to Yates' (1991) original findings. Scale items retained on the "Support for Using ACTs" and the "Will to Live" scales on the BTPS-BC were identical to those used by Yates (1991) to examine social support and determination to survive in advanced cancer patients. This supports the internal structure of these scales. The "Satisfaction with Health Care Professionals" was found to have a dissimilar internal factor structure than previously found by Yates (1991). However, all scale items were retained, with the exception of two items, which loaded on a factor considered distinct from the broader concept of "satisfaction". Further testing of the BTPS-BC will assess the stability and validity of this scale.

Items on the "Efficacy of ACTs" and the "Reasons to use ACTs" scales were combined because of the observation by participants of the conceptual similarity between the two scales. Exploratory factor analysis and reliability and validity estimates were then used to confirm the soundness of this decision. The resulting psychometric properties for the new scale suggested that the two scales were comprised of correlated items exploring the mechanisms of and possible outcomes of ACTs.

The "Causes of Cancer", "Efficacy of Medical Treatments" and the "Efficacy and Reasons to Use ACTs" scales were found to have different internal factor structures when compared to Yates' (1991) findings. This suggests that Canadian women with breast cancer may have unique conceptualizations about cancer and treatment compared to Australian advanced cancer patients. Women with breast cancer were able to define causes of cancer as either internal or external, controllable or uncontrollable. In contrast, participants in Yates' (1991) study held beliefs about causes of cancer that were either alternative or behavioural/environmental. The internal factor structure defined by women with breast cancer in this study permitted exploration of the association between perceptions of internal and external causes of cancer and the use of ACTs. This factor structure will be meaningful in future studies because it will allow comparisons with Montbriand and Laing's (1992) past research on control and ACT use by Canadian cancer patients.

The "Efficacy of Medical Treatments" and "Efficacy of Alternative/ Complementary Therapies" scale were originally factored by Yates (1991) into a two factor solution - efficacy of treatment and adverse effect of treatment. However, this internal factor structure may have been an artifact of scale wording, with negatively-worded items being labelled as adverse. In comparison, the factor analyses in this study of women with breast cancer resulted in a two factor solution - "mechanism of treatment" and "outcome of treatment". This internal factor structure indicates that women with breast cancer may perceive treatment at two levels. At the first level, medical treatments are conceptualized by the process through which treatments function and immediately effect the body. The second level is the actual consequence of treatment, a long-term perspective of the disease course and the effect of both medical therapies and ACTs. This factor structure suggests women with breast cancer may distinguish between the physical experience of undergoing treatment and the more existential hope for a positive outcome.

Of interest is the differences between the items composing the two factors on the medical and ACT scales. On the "Mechanisms of Medical Treatments" subscale, negative side effects are perceived to be a part of the process of chemotherapy, radiotherapy and surgery. In contrast, side effects are not considered part of the internal factor structure underlying the "Efficacy of ACTs" scale. This is consistent with lay beliefs that ACTs are natural products or therapies that are non-toxic and less intrusive than medical therapies (Lerner, 1994). The "Outcome of ACTs" scale also included the item "It is the patient's fault if ACTs don't work", which failed to load on either factor on the "Efficacy of Medical Treatment" scale. Perhaps, women with breast cancer believe ACTs and their outcomes are the responsibility of the patient, in contrast to medical treatments which are controlled by an external source, the physician. This finding supports the belief that some ACTs may contribute to a feeling of guilt, if the patient perceives it is his/her responsibility that determines the success or failure of the ACT (McGinnis, 1991; Siegel, 1990).

Following factor analysis, the "Will to Live" scale on the BTPS-BC retained the original number of items used by Yates (1991). The internal consistency of the "Will to Live" scale in this study was similar to Yates et al.'s, (1993) results, who reported a Cronbach's alpha of 0.87. This finding supports the reliability and stability of this measure in measuring women with breast cancer's will to live.

The longest scale on the BTPS-BC contained 13 items, with scale length ranging from 2 to 13. Hazard Munro, Visintainer and Batten Page (1986) recommended a ratio of at least five subjects per variable if generalizations are to be made from a sample to a larger population. Thus, a sample size of at least 65 subjects in this study would have met this criteria for testing the BTPS-BC. However, the actual sample size of 52 women with breast cancer in this study approximated the recommended sample size (Hazard Munro, Visintainer, & Batten Page, 1986). Therefore, the results of the study are likely relatively stable for this sample. Ideally, a larger sample (N=100) of women with breast cancer from across Canada would result in a more stable factor structure (Aleamoni, 1975).

Reliability issues of the BTPS-BC.

Following factor analyses and the development of nine new subscales representing subdimensions of the seven original scales, reliability estimates using Cronbach's standardized alpha coefficient, inter-item correlations and item-to-total correlations were calculated. Overall, considering the limited sample size of the study, the reliability estimates of the scales and revised subscales of the BTPS-BC were respectable. All scales and subscales, with the exception of the "Cause of Cancer" scale, the "Efficacy of Medical Treatments" scale, and the "Understanding Health Care Professionals" subscale, achieved Cronbach's alpha coefficient between .62 and .91. These findings approximate the pre-set criteria of .70 established by Nunnally (1978) for immature scales. Future replication of the BTPS-BC with a larger sample of women with breast cancer will confirm the internal structures of the scales and the stability of the instrument in terms of reliability. However, the reliability estimates of the BTPS-BC generated in this study allow the findings to be considered with confidence.

The low internal consistency estimates (i.e., Cronbach's alpha = .66, inter-item correlations not achieving the criteria of 50% of items between .30 and .70, and only 43.0% of item-to-total correlations between .40 and .70) obtained for the "Cause of Cancer" subscale suggests that causes of cancer are independent concepts that may not be parallel to one another. For example, the belief in pollution as a cause of cancer is not necessarily associated with the belief in stress as a cause of cancer. Instead, a test-retest reliability estimate is recommended for future research using the BTPS-BC to investigate the stability of this subscale.

The low reliability of the "Efficacy of Medical Treatment" scale (i.e.

Cronbach's alpha = 0.49) was indicative of a lack of parallelism between scale items. This was further supported by the improved performance of scale items, with regard to reliability, following factor analysis and the development of the "Mechanisms of Medical Treatment" and "Outcomes of Medical Treatment" subscales (i.e., Cronbach's alpha = 0.66 and 0.65). However, future replication is required to ensure the internal structure of the two subscales are stable and valid.

The "Understanding Health Care Professionals" subscale achieved a Kendall's Tau B correlation of .52. This moderate reliability estimate is acceptable considering the small sample size of the study and the limited number of items (i.e. two) composing the subscale. Replication studies using the BTPS-BC and the "Understanding Health Care Professionals" subscale will determine the stability and validity of this subscale. Qualitative research may be required with women with breast cancer to determine additional items that are relevant to understanding the knowledge provided by health care professionals and patient comprehension of clinical information. Increasing the number of items on the subscale may improve the reliability estimates for this measure.

Reliability and validity of the decisional preference card-sort.

The decisional preference card-sort was constructed by Degner and Sloan (1992) to assess the underlying psychological dimension of treatment decision making by women with breast cancer. According to unfolding theory, "50 percent plus one" of the responses to the card-sort should fall along the dimension, represented by 11 valid permutations of the cards (i.e. ABCDE) (Coombs, 1978). Responses to the card-sort using this study's data failed to meet this criteria, with 47.1 percent of observations following along the theoretical "J" scale. However, Sloan and Yueng (1994) question the validity of Coombs' criteria, stating that there is no strict rule for goodness of fit provided by Coombs. Lord and Wilkin (1974, cited in Sloan & Yueng, 1994) also recommend that 50 percent is an acceptable criterion for five stimuli.

Women in this study were able to distinguish between the three cards representing the active, shared and passive roles. However, some participants had difficulty ranking the active-collaborative and the passive-collaborative roles represented by cards B and D. The failure of the study's data to conform to the criteria set by Coombs (1978) may be a consequence of this discrepancy in selecting preferred decisional role. Also, the small sample size (N=52) of the study may have contributed to the findings. However, given the near approximation of Lord and Wilkin's criteria and the possibility that the scale indexed only three decisional points with this sample, the results of the decisional preference card-sort are reasonable.

Reliability and validity of the EORTC QLQ-C30 (version 2).

The EORTC QLQ-C30 (version 2) was tested for reliability and internal consistency using Cronbach's alpha coefficient, Kendall Tau B correlation coefficient and item-to-total correlations. These estimates lend support to the instrument's reliability, with the exception of the Cognitive Functioning, Nausea and Vomiting, and Pain scales, which failed to meet pre-set criteria of .70 for an immature scale (Nunnally, 1978).

The reliability estimates of the EORTC QLQ-C30 (version 2) scales were similar to Aaronson et al.'s (1993) findings following initial testing of the EORTC QLQ-C30. Using a sample of 305 non-resectable lung cancer patients, Aaronson et al. (1993) reported Cronbach's alpha coefficients from .52 to .89 for the scales. Two of the six major scales (i.e. Physical and Role Functioning) had higher alpha values than previously reported by Aaronson et al. (1993). The Cognitive Functioning, Emotional Functioning, Social Functioning, Global Quality of Life, Nausea and Vomiting and Pain scales all achieved reliability estimates below the levels reported by Aaronson et al. (1993). Differences in reliability estimates may have been a consequence of the smaller sample.

To provide a more accurate assessment of the overall reliability of EORTC QLQ-C30 (version 2), a *theta* coefficient could be computed based on results using a larger sample. According to Carmines and Zeller (1979), a *theta* coefficient provides an assessment of the overall reliability of a multi-dimensional scale. Based on the premises of principal component factor analysis, scale items and their respective weights are added, leading to reliability coefficient less stringent than an *alpha*, which presumes items are parallel (Carmine & Zeller, 1979). A factor analysis of the EORTC QLQ-C30 (version 2) would also contribute knowledge regarding the validity of the instrument's underlying theoretical dimensions and scales. However, at least 150 women with breast cancer would be needed to conduct a stable principle component analysis based on the 30-item EORTC QLQ-C30 (version 2) (Hazard Munro, Visintainer, & Batten Page, 1986).

Representativeness of the sample to the Manitoba population.

Comparisons were made between the sociodemographic and disease characteristics of this study's participants and a sample of Manitoban breast cancer patients obtained by Degner et al. (under review). The researchers recruited a consecutive sample of 1012 women with breast cancer in Manitoba to explore the information needs and decisional preferences of this population. This sample represents approximately 25 percent of all women in the province living with breast cancer (Manitoba Cancer Treatment and Research Foundation, 1992).

The two sample were found to be similar with regard to marital status, ethnicity, and time since diagnosis. However, differences were found between the samples with regard to age, education, stage of disease, and treatment protocol. Women in this study were slightly younger than those participating in the information needs and decisional preference study, with approximately 44 percent of participants being 50 years of age or younger. In comparison, only 29 percent of women in Degner et al.'s (under review) study were under 50 years of age. A selection bias on the part of clinic nurses may have been responsible for the age distribution in the sample, with younger women being perceived as being more "open" towards ACTs research. This hypothesis is supported by the fact that on several occasions, clinic nurses were observed by researcher to avoid approaching older women in the clinic regarding study recruitment.

Participants in this study were also more highly educated than the women in Degner et al.'s (under review) research project. Over 85 percent of study participants had achieved high school or post-secondary education in comparison to only 57 percent of women in the information needs and decisional preference study (Degner et al., under review). This finding could have been a consequence of the nature of the study and the study's recruitment protocol. First, some nurses and physicians at the three clinical sites were concerned that participants would be "unduly" influenced to use ACTs following participation in the study. As a consequence, clinic nurses may have approached potential subjects that they believed were "well-educated" and able to maintain a balanced perspective of medical treatments and ACTs. Secondly, clinic nurses may have been inclined to approach potential subjects who were well-read and had been exposed to ACT literature. On several occasions, clinic nurses provided potential subject names to the researcher with the adage, "...she has a lot of questions about ACTs that you could answer....". Thus, study participation was seen by some clinic nurses as a method of providing information to breast cancer patients about ACTs. This finding further confirms the need for education on the use of ACTs for both health care providers and patients.

No information regarding socioeconomic status was collected by Degner et al. (under review). However, in this study, approximately 60 percent of this study's sample reporting a family income of $40,000 or greater. Therefore, it is reasonable to suggest that the sample under-represented lower socioeconomic levels. Data regarding ACT use and money spent on ACTs may have been influenced by the skewed socioeconomic status of the sample. It is also possible that women with breast cancer in this study had more financial access to alternative or complementary therapists and treatments and could afford to try the more expensive forms of therapies (e.g. shark cartilage). A larger sample of women with breast cancer may have provided a more evenly distributed sample with regard to socioeconomic status.

Women with more advanced disease (Stage 3 and 4) were also more frequently represented in this study than in Degner et al.'s (under review) research. This finding may have been a consequence of a selection bias on the part of clinic nurses. Women with advanced breast cancer may be perceived as having a greater interest in ACTs because of unsatisfactory outcomes of conventional medical treatment.

In summary, the sample of 52 women with breast cancer participating in the study were younger, more educated and from a higher socioeconomic status than the larger population of women with breast cancer in Manitoba. As well, women participating in the study had more advanced disease than the larger Manitoba population of women with breast cancer. These findings may have been a consequence of selection bias on the part of clinic nurses, who were influenced by the nature of the study. Possibly, nurses involved in subject recruitment may have approached women who had expressed an interest in ACTs or were believed to be potential users of ACTs. As well, the controversial nature of ACTs in the medical health care system may have influenced which patients were approached in the clinical setting regarding study participation. In future studies, recruitment through a general cancer registry may increase the representativeness of the sample.

Sampling methodology.

One consequence of the sampling methodology was the absence of women in the study who were using ACTs alone, having withdrawn or refused conventional medical treatments. This population of women was predicted to be a difficult group to identify. This challenge was confirmed. Only one participant had refused medical adjuvant treatment following surgery in favour of homeopathic and traditional chinese medicine remedies.

Identification of women with breast cancer using ACTs only was difficult. Firstly, women who have refused medical treatment have often chosen to also remove themselves from their oncologist's care, making access through the health care system difficult. Secondly, many of the ACTs used by individuals with cancer who have withdrawn from medical treatment are highly invasive and may be considered illegal (i.e. ozone therapy). As a consequence, these individuals are reluctant to share their treatment practices for fear that they may lose the right to pursue their treatment of choice. Thirdly, some women with breast cancer who were using ACTs in conjunction with medical treatments reported feeling humiliated, embarrassed and unsupported when they had shared their treatment practices with health care professionals. It would not be surprising if women who are using only ACTs have similar experiences.

Recruiting women with breast cancer who are using ACTs as an alternative to medical treatment will require time, sensitivity, trust, and use of networking within the alternative/complementary community. Sampling methodologies such as network sampling may help identify this group of women with breast cancer. The provincial cancer registries may also assist in identifying women diagnosed with breast cancer who have not received medical treatment. An additional challenge in recruiting this type of sample is the ethical issues surrounding patient confidentiality, patient autonomy and the duty of nonmaleficence on the part of health care professionals (e.g., risks of ACTs, side effects of ACTs).

Clinical Implications

The findings of this study suggest some women with breast cancer use ACTs, with the majority of women (67.3%) having tried at least one therapy they considered alternative or complementary to medical care. This finding has several implications for health care professionals in the clinical setting.

Several women commented on the lack of knowledge by health care professionals on the pros and cons of ACTs and the possible interactions with conventional medical treatment. Women with advanced disease were particularly interested in receiving information from their doctors and nurses about what ACTs were available as their medical treatment options became fewer. The Guide to Unconventional Cancer Therapies, by the Ontario Breast Cancer Information Exchange Project, is one resource health care professionals may find useful in answering clients' questions and gaining a beginning knowledge on the various types of ACTs. This guide to ACTs provides a brief overview of specific physical and psychological therapies, including known side effects, mechanism of action, and additional resources. In Manitoba, The Guide to Unconventional Cancer Therapies, has been distributed to many urban and rural oncology centres through the support of the Manitoba Cancer Treatment and Research Foundation.

Fifteen percent of participants indicated that they had chosen not to inform their physician or other health care professionals about their use of ACTs. This decision was based on a fear of being ridiculed for using an "unproven" therapy that did not conform to the ideals of western medicine. Some women also reported that they did not believe their doctor or nurses would be interested, or have the time, to hear about ACTs. One clinical implication of this finding is the need for health care professionals to present an unbiased, supportive and open attitude towards ACTs and to encourage discussion with clients regarding treatment choices outside of the conventional medical system. Through this type of open discussion, ACTs will no longer be unknown treatment entities, whose impact on physical, emotional, spiritual dimensions is hidden.

Cassileth et al. (1984) suggested that the decision to use ACTs may reflect cancer patients' dissatisfaction with some aspect of conventional medical treatment.

This dissatisfaction may stem from a lack of communication between the client and health care professionals, dissatisfied client needs, noxious side effects, or poor response to medical treatments (Cassileth et al., 1984). ACTs may function to increase women with breast cancer's satisfaction with care and address concerns that have gone unnoticed by health care professionals (e.g., stress associated with conventional treatments, altered body image). The use of ACTs may be an indication that a woman with breast cancer's needs are not being adequately addressed within the conventional health care system. Open discussion with women regarding why they have chosen to use an ACT(s) may assist health care professionals to identify unrecognized needs and concerns of women with breast cancer.

For some women with breast cancer, a primary concern following diagnosis and during adjuvant medical treatment is the role nutrition may play in managing the physiological side effects of chemotherapy, radiotherapy and surgery and in the prevention of future recurrences. For some of these women, nutritional supplements, such as vitamins and herbal remedies, are viewed as appropriate and reasonable ACTs. These women may consult a nutritionist regarding diet therapies, food supplements, and eating habits. Possibly, this trend in ACT use could be addressed within the medical health care system through consults with dieticians, pharmacists and nutritionists. By providing women with breast cancer with the opportunity to explore nutrition and diet concerns as part of their medical care, women's information needs and interests regarding nutrition may be addressed.

Two of the most frequently reported ACTs used by women with breast cancer were meditation/relaxation therapies and spiritual/faith healing. Health care professionals could facilitate use of these therapies in the clinical setting in several ways. First, the provision of a quiet, dimly-lit, private area for individuals using meditation, visualization or relaxation techniques during adjuvant therapy would prevent distractions and reduce unnecessary interruptions. A "Do Not Disturb" sign for in-patient oncology clients would also be helpful. Another way of facilitating use of ACTs is by having personal tape-recorders and selected relaxation tapes available for oncology patients who are practicing relaxation or for individuals experiencing stress related to adjuvant treatment.

If ACTs were incorporated into conventional medical care, the question would arise whether these therapies would continue to be considered an "alternative" to medical treatment. Perhaps the inclusion of these therapies, such as meditation/relaxation, within conventional medical care will result in the acceptance of ACTs as adjuvant medical treatments by health care professionals. However, the consequences of the inclusion of ACTs in conventional medical care is unknown because of the present exclusion of ACTs in western medicine in North America. The use of ACTs within conventional medicine may increase the acceptance of more diverse and eclectic ACTs used by women with breast cancer outside of the health care system. However, for health care professionals, there would be no guarantee that the inclusion of selected ACTs in medical care would preclude women with breast cancer's exploration of other ACTs. Perhaps the use of ACTs by women with breast cancer is symbolic of the need to try treatments that are external from conventional medicine. The clinical implications of ACT use within the health care system will require extensive research to understand the benefits and risks for patients and health care providers and the impact on the health care system.

Theoretical Implications

The Health-Error-Change (H-E-C) model developed by Kristjanson, Tamblyn and Kuypers (1987) proved to be a flexible and appropriate conceptual framework to explore women with breast cancer's treatment practices and beliefs. The significant number of women using both conventional medical treatment and ACTs confirmed the need for a conceptual model which would allow multiple beliefs systems to exist concurrently. As well, the uncertainty and ambiguity surrounding beliefs about breast cancer also emphasized the need for a theoretical framework, such as the H-E-C model, which would prevent premature conceptual closure.

The H-E-C model allowed an exploration and understanding of the ways women with breast cancer view their disease, treatment options and related decisions (Kristjanson, Tamblyn, Kuypers, 1987). The first domain in the H-E-C model, "health", was represented by the women's subjective assessment of their quality of life, symptom distress and financial situation. Overall, participants' responses to the EORTC QLQ-C30 (version 2) were highly positively skewed, demonstrating women with breast cancer's optimistic perspective of their quality of life irrespective of treatment and prognosis. With the exception of role functioning, there was no significant differences in quality of life scores between women with advanced cancer and women with stage 1 or stage 2 breast cancer. This finding and the lack of association between ACT use and quality of life suggests women with breast cancer's perceptions of quality of life were independent of their diagnosis, prognosis and treatment of breast cancer.

However, the lack of association between ACTs and quality of life does not necessarily imply that the use of ACTs has no effect on quality of life. Women with breast cancer who use ACTs may be motivated to chose treatments that are alternative or complementary to their conventional medical care in order to achieve their preferred level of quality of life. These women may have unique perspectives and needs regarding their health which require use of therapies that are not typical of conventional medicine. As well, women with breast cancer using ACTs may have had poorer quality of life which influenced the decision to use different treatments in an attempt to improve their quality of life (Cassileth et al., 1991). Research exploring the relationship between ACT use and quality of life has been limited to Cassileth et al. (1991), who found ACT use was associated with a lower reported quality of life by cancer patients. However, Cassileth et al.'s (1991) results and the findings of this study must be viewed with caution because subjects' quality of life was measured only after ACTs and conventional treatments had been undertaken, resulting in a possible design error. Longitudinal research is required which explores quality of life of women with breast cancer both before and after the administration of conventional and ACTs. This type of research would provide a clearer assessment of the impact ACTs have on women with breast cancer's perceived level of quality of life.

The second domain of the H-E-C model was "error", which represented the circumstances preventing the ideal level of health from being achieved by women with breast cancer. "Error" was operationalized in the study as women with breast cancer's beliefs about causes of cancer. No significant relationship was apparent in the study between women with breast cancer's use of ACTs and beliefs about the internal/ uncontrollable and external/controllable causes of cancer. However, uncertainty and ambiguity were prevalent in women's beliefs about what led to the development of their breast cancer. This uncertainty may have influenced women's decisions to use ACTs in conjunction with conventional medical treatment. The inability to identify a causal agent of breast cancer may have motivated some women to use a variety of treatments, both conventional and alternative/complementary, in the hopes of addressing the unknown cause of their cancer. Participants who were able to identify a possible cause of their breast cancer were most likely to believe stress or a weakness in their immune system was responsible. Similar beliefs were also reported by the National Breast Cancer Forum (1994) who found 38 percent of women with breast cancer surveyed believed stress was related to the development and progression of their disease.

The relationship between beliefs about causes of cancer and types of ACTs has not been explored in the literature. Women with breast cancer may use a particular ACT that addresses their perceived physiological, psychological and/or spiritual cause of cancer. For example, the use of meditation/relaxation techniques may be directly related to the belief in stress as being a causal agent of breast cancer. The congruence between ACTs, conventional medical treatments and perceived cause of cancer may allow women to develop meaning and a sense of control over an often bewildering and uncontrollable disease. Exploration of the relationship between type of ACTs and beliefs about cause of cancer may result in more appropriate recommendations by health care professionals and alternative/complementary therapists regarding which ACTs would best meet women with breast cancer's individual needs and beliefs.

The final central domain of the H-E-C model, "change", was operationalized in the study as beliefs about treatment (both conventional and ACTs) and prefered treatment decisional role. The "change" domain encompasses treatment choices made by women with breast cancer to correct the "error" and return to the prefered healthy state. Using the H-E-C model, it was hypothesized that women's beliefs about the mechanisms and outcomes of medical cancer treatments and ACTs would influence which therapies were chosen. As well, past research by Montbriand (1993) and Yates et al. (1993) suggested that the level of involvement in treatment decisions by individuals with cancer may influence which types of treatments are selected.

In the study, no significant relationships were found between beliefs about medical treatments and ACTs and the use of ACTs. However, in general, participants were found to have positive beliefs surrounding conventional medical treatment, particularly the physiological outcomes of medical care. Not surprisingly, a commitment to maintaining follow-up and treatment within the conventional medical system was expressed by all participants. However, the lack of relationship between beliefs about conventional medical treatment and ACT use suggests the decision to use ACTs is independent from how medical cancer care is perceived. This finding is in contrast to Cassileth et al.'s (1984) research, which found individuals using ACTs perceived conventional cancer therapies to be ineffective and harmful.

Positive beliefs were also expressed by women regarding the mechanisms through which ACTs function within the body. However, the majority of women (76.5%) were more sceptical of the positive outcomes of ACTs. Despite this scepticism, a near significant relationship ($p < .062$) was apparent between beliefs about outcomes of ACTs and the use of ACTs. Further exploration of this relationship with a larger sample of women with breast cancer may reveal that ACT use is influenced by positive beliefs in the outcomes of ACTs. This would support previous research by Lerner and Kennedy (1992), who found patients using ACTs believed the therapies would be curative.

The hypothesized relationship between desired treatment decisional role in the "change" dimension and the resulting use of ACTs was supported in the study. This relationship was similar to Yates et al.'s (1993) research which found a strong desire for decisional control by individuals with advanced cancer resulted in increased ACT use. Women with breast cancer who used ACTs were also found to be more likely to prefer an active/collaborative role in treatment decisions than women using only conventional treatments. However, whether the decision to use ACTs is the result of increased perception of control over treatment decisions or a method of regaining control following the diagnosis of breast cancer is uncertain. It will be important in future ACT research with the breast cancer population to determine the nature of this relationship.

Further examination of the theoretical issues surrounding the use of H-E-C model (Kristjanson, Tamblyn, & Kuypers, 1987) revealed possible specification errors in the operationalization of the model's concepts. In retrospect, the strict operational definitions applied to the concepts of "goal" and "problem" may have been too rigid and pre-specified how women might view these variables. "Goal" was operationalized using the "Will to Live" scale on the BTPS-BC. However, through anecdotal evidence provided by women interviewed, not all participants believed "will to live" was the ultimate goal of their treatment practices. Women with a terminal prognosis of breast cancer instead spoke of "living with dying", directing their energy towards improving the quality of their remaining life without trying to avoid death. Many of these women found the "Will to Live" scale on the BTPS-BC disheartening as it denied them the reality of their situation. Qualitative studies exploring the outlook of women with all stages of breast cancer would contribute a more appropriate definition of the goal(s) held by those individuals using ACTs.

The concept "problem" was operationalized using the TNM staging system for cancer (UICC, 1987). However, for some women who were more than five years post-diagnosis, their disease was no longer conceptualized as a threat to health. Rather, issues regarding prevention of cancer and improved general well-being were paramount. Possibly, as time since diagnosis and treatment increases, women with breast cancer's perceptions of their health "problem" become less disease-oriented. Further conceptual exploration of women with breast cancer's perceptions of what type of problem(s) is being addressed by their treatment practices would provide a more representative definition of this variable.

Examination of recent work by Montbriand (1995) revealed additional variables that may augment the explanatory power of the H-E-C model (Kristjanson, Tamblyn & Kuypers, 1987). Montbriand (1995) developed a treatment decisional tree model in which an individual moves through a series of questions regarding personal methodology in health care, social group influence, cost consideration, judgements about cure, change and searching, decisional control and faith in practice. The predictive power of this model in determining treatment practices was established at 90.4 percent (Montbriand, 1995). Possibly, the addition of variables representing faith and personal methodology about health care, cure, change and searching to the H-E-C model (Kristjanson, Tamblyn & Kuypers, 1987) would reveal beliefs relevant to the decision to use ACTs not explored in this study.

A final theoretical issue related to the conceptual framework used in the study was the delineation of treatment decision-making process as the intellectual movement by women with breast cancer among the domains of the H-E-C model (Kristjanson, Tamblyn & Kuypers, 1987). However, the lack of relationship between beliefs about cause of cancer, medical treatments, ACTs, and quality of life suggests that the decision to use ACTs was not influenced by how "health", "error" and "change" dimensions were conceptualized. This finding, along with the significant relationships between preferred treatment decisional role, education status and ACT use raises the question about the extent to which the decision to use ACTs is an intellectual process, a value-driven decision or a contextual outcome. Prior to the development of future research examining ACTs use by women with breast cancer and the efficacy of ACTs, further studies exploring the theoretical nature of the decisions to use ACTs are required.

Limitations of the Study

Several study limitations were identified. The major study limitation was related to sampling issues. First, the study was limited by the small sample size of 52 women with breast cancer. Although this sample size was feasible for the scope of the thesis research, the limited number of subjects makes generalizations to the larger breast cancer population in Canada impossible. As evidenced by the comparison of the demographic characteristics of study participants to the larger sample interviewed by Degner et al. (under review), women in this study were younger and more educated than the typical woman with breast cancer in Manitoba. As well, the convenience sampling methodology used in the study is the weakest form of sampling, which could have accounted for the sample being atypical of the Manitoba breast cancer population (Polit & Hungler, 1991). It could be assumed that the breast cancer population at MCTRF, St. Boniface Hospital and Victoria Hospital outpatient oncology clinics is homogeneous because the clinics treat a large percentage of breast cancer patients in Manitoba. However, the sampled outpatient clinics are situated in an urban centre. Thus, the patients at these facilities may not be representative of rural cancer populations. Also, the sample from the outpatient clinics did not include women diagnosed with terminal breast cancer unamendable to conventional treatment.

Another limitation may have been the immaturity of the BTPS-BC and the need for replication with a larger sample of women with breast cancer. Possibly, women with breast cancer's beliefs about cancer, medical treatments and ACTs are not formally developed, leading to a high degree of uncertainty or instability. The assumption that women with breast cancer are able to articulate their beliefs about their disease and treatment decisions may therefore be false. As well, the lack of knowledge about ACTs may lead to misleading conclusions about women with breast cancer's beliefs about treatment.

Participants had some difficulty completing the BTPS-BC, despite help from the interviewer. Many women were unfamiliar with the various types of ACTs and alternative/complementary practitioners and required clarification. This limitation has implications for future replication studies, especially if a mail-out format for questionnaire administration was implemented.

The results of the "Support to use ACTs" scale were difficult to incorporate into the findings of the study because of the unintended bias towards women who were using ACTs. Women with breast cancer who were not using ACTs did not find this scale to be as relevant. Qualitative research may assist in the development of a new scale, measuring social support to use ACTs, that would be applicable to users and non-users.

Results of the factor analyses are limited by the small sample size. To confirm the internal validity of the scales, it is recommended to have a ratio of at least five subjects per variable (Hazard Munro, Visintainer, and Batten Page, 1986). Thus, the revised scales and subscale of the BTPS-BC must be considered with caution until replication studies confirm the stability of the internal structure of the scales.

Recommendations

Based on the findings presented from this study, the following recommendations are offered for research and education.

Recommendations for Education

Health care professionals are left with three choices when confronted with ACTs, ignore them, study them, or learn from them (Tataryn, 1995). The prudent and professional response for nurses and other health care providers is to accept ACT use as a reality in today's health care system and to become knowledgeable about these practices. Through education, health care professionals will be able to communicate intelligently with women with breast cancer about ACTs and provide informed support.

In Canada, there is a lack of educational opportunities for nurses who wish to learn more about ACTs. Courses are offered through the Canadian Holistic Nurses Association, a recognized interest group of the Canadian Nurses Association, on treatment modalities such as therapeutic touch, educational kinesiology and relaxation (Petersen, 1996). However, these courses are available only in selected areas of Canada, limiting access to ACT educational opportunities. Individualized training courses on ACTs are available from private ACT practitioners across Canada, however the lack of educational and clinical standards threatens the credibility of these practices and programs.

Collaborative efforts are required by the Canadian Nurses Foundation, provincial nursing associations, and ACT therapists to develop ACT educational programs at the baccalaureate and continuing education level. These programs could provide both basic and advanced understanding of the philosophies underlying prevalent

ACTs, known costs and benefits of ACTs, and the practice of selected ACTs. Program content could include: exploration of the beliefs of alternative health belief systems; helping nurses identify their attitudes and biases towards ACT use by clients; discussion of the concept of holism; examination of intervention studies on ACTs; and the possible implementation of selected ACTs in the clinical setting.

Educational programs on ACTs are also required for individuals with cancer and their family members. These programs need to provide an objective, open perspective on the variety of ACTs that are available. Program content could include: rationale underlying use of popular ACTs; the known side effects of selected ACTs; how to approach health care providers about the use of ACTs; and how to access ACT resources. These programs could be offered through the clinical setting, the Canadian Cancer Society or independently within the community. The key is to provide knowledgeable, unbiased and inexpensive information to those individuals who may potentially use ACTs in the future.

Recommendations for Future Research

Four recommendations are made for future nursing research with regard to ACT use by women with breast cancer. Firstly, a replication study, using a larger Canada-wide sample of women with breast cancer, is required to test the reliability and validity of the BTPS-BC in measuring the beliefs and treatment practices of this population. A multi-site research study would also lead to the development of a profile of women with breast cancer who use ACTs across Canada. Generalizability of the findings of the BTPS-BC to the larger breast cancer population in Canada would also be possible through a multi-site study, especially with improved sampling methodology using a random sample of women with breast cancer obtained from provincial cancer registries. Results of this type of study would result in a re-examination of the relationships between ACT use and beliefs about cancer and treatment and more reliable conclusions.

Secondly, qualitative research on the experience of women with breast cancer using ACTs is required to clarify specifications error identified in this study and address theoretical gaps in knowledge related to the use of ACTs. For instance, the role of uncertainty in the decision to use ACTs was unclear following analysis of the BTPS-BC. In-depth, qualitative interviews with women using ACTs may elucidate additional information regarding the relationship between the ambiguity of the diagnosis and prognosis of breast cancer and the search for alternate or complementary treatments. To date, there has been a lack of qualitative studies exploring the experiences of individuals with cancer who use ACTs.

Thirdly, research exploring the experiences of women with breast cancer who are using only ACTs is essential to the understanding of the use of ACTs by this cancer population. This group of individuals may hold unique perspectives on conventional treatments and ACTs, which will assist researchers in developing a framework on which to examine the continuum of ACT use by women with breast cancer. Sensitive and intensive communication between the health care research community and alternative/complementary practitioners will be necessary in order to access women who have refused or withdrawn from conventional medical treatment. Provincial cancer registries may also assist in the identification of women who have been diagnosed with breast cancer, but have not received conventional therapies. As well, extensive networking with women who are using only ACTs will facilitate recruitment of this hidden population.

Finally, once the stability of the tool over time has been established, longitudinal research with women with breast cancer would assess how perceptions, beliefs and treatment practices change over time. Longitudinal research would also be helpful to determine at what point in the disease trajectory do women decide to use ACTs and what factors are associated with that decision. Replication of this study using a longitudinal design (i.e. data collection following diagnosis and 2 years later) might also demonstrate the effect of medical treatment, recurrence or remission on the decision to use ACTs.

Summary

Women diagnosed with breast cancer are faced with many new concepts, experiences and decisions. For some women with breast cancer, this includes the decision to use therapies they consider to be alternative or complementary to medical treatments. Results of this study suggest that this decision may be made by a large percentage of women with breast cancer.

Overall, the most popular ACTs for this population included meditation/ relaxation therapies, vitamin supplements, and spiritual/faith healing. Alternative/ complementary therapists who were seen most by women with breast cancer included spiritual/faith healers, massage therapists, and nutritionists. It can be concluded from these findings that women with breast cancer in the study were involved with the complete spectrum of ACTs - physical, psychological and spiritual.

A significant relationship was found between ACT use by women with breast cancer in the study and preferred treatment decisional role. Women who used ACTs were found to prefer an active/collaborative role rather than a passive role in treatment decisions. Women using conventional medical treatments were less likely to prefer an active or collaborative role with their physician during treatment decisions. No other significant associations between the use of ACTs and beliefs about cancer, treatment, health care professionals and will to live were found in the study. Women were reported to be uncertain about the cause of their disease, with some individuals linking stress and a weakness in the immune system to the development of breast cancer. The majority of women held positive beliefs about medical treatments and the care provided by health care professionals, indicative of satisfaction with the conventional medical system. Women were less certain of their beliefs about ACTs, possibly reflecting a lack of knowledge.

Women who had obtained a high school education or greater were found to be more likely to use ACTs than those with less education. This finding suggests that knowledge may play an important role in the decision to use therapies outside of the conventional medical system. No other distinctions were found between users of ACTs and non-users.

This study provided a preliminary foundation for future replication of the BTPS-BC, a questionnaire assessing the beliefs and treatment practices of women with breast cancer. Replication of factor analyses and psychometric estimates, with the addition of qualitative data from women with breast cancer using ACTS, will assist in the development of a mature, reliable and valid instrument. This tool may lead to better assessment of the needs, concerns, and practices of individuals with cancer who may use ACTs.

Conclusion

The aim of this study was to first test the appropriateness, reliability and validity of an instrument, the BTPS-BC, which was designed to explore the beliefs and treatment practices of Canadian women with breast cancer. Secondly, the study described a non-random sample of Manitoba women with breast cancer's treatment practices and their beliefs about cause of cancer, medical treatment, ACTs, satisfaction with health care providers, support to use ACTs, and will to live. Quality of life estimates and preferred decisional role were also assessed. The findings of the study were interpreted in terms of discussion of the findings, methodological, theoretical, and clinical issues. Limitations of the study were also presented. Recommendations were made regarding nursing education and research.

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APPENDIX A

Study Instruments

Beliefs and Treatment Practice Survey - Breast Cancer

1. **Have you seen any of the following practitioners about your illness? (CIRCLE ALL THAT APPLY)**

		Yes	No
a.	Acupuncturist	___	___
b.	Chiropractor	___	___
c.	Doctor who offers alternative therapies	___	___
d.	Homeopath	___	___
e.	Medical Oncologist	___	___
f.	Naturopath	___	___
g.	Nutritionist	___	___
h.	Radiation Oncologist	___	___
i.	Spiritual/Faith Healer	___	___
j.	Surgeon	___	___
k.	Other (please state)	___	___

____

2. **How often have you used any of the following alternative/complementary therapies for the treatment of your illness? (CIRCLE ONE NUMBER FOR EACH ITEM)**

		Never	**Rarely**	**Occasionally**	**Frequently**
a.	Detoxification	1	2	3	4
b.	Faith healing	1	2	3	4
c.	Herbal remedies	1	2	3	4
d.	Immune therapy	1	2	3	4

2. **How often have you used any of the following alternative/complementary therapies for the treatment of your illness? (CIRCLE ONE NUMBER FOR EACH ITEM)**

		Never	**Rarely**	**Occasionally**	**Frequently**
e.	Meditation/relaxation therapy	1	2	3	4
f.	Special foods or diets	1	2	3	4
g.	Vitamins or tonics	1	2	3	4
h.	Other (please state)	1	2	3	4

____

It would also be helpful to understand what you might do in the future for your illness.

3. **Do you intend to see any of the following practitioners about your illness in the future? (CIRCLE ONE NUMBER FOR EACH ITEM)**

		Definitely	**Probably**	**Uncertain**	**Probably not**	**Never**
a.	Acupuncturist	1	2	3	4	5
b.	Chiropractor	1	2	3	4	5
c.	Doctor who offers alternative therapies	1	2	3	4	5
d.	Homeopath	1	2	3	4	5
e.	Medical oncologist	1	2	3	4	5
f.	Naturopath	1	2	3	4	5
g.	Nutritionist	1	2	3	4	5

3. **Do you intend to see any of the following practitioners about your illness in the future? (CIRCLE ONE NUMBER FOR EACH ITEM)**

		Definitely	Probably	Uncertain	Probably not	Never
h.	Radiation Oncologist	1	2	3	4	5
i.	Spiritual/Faith healer	1	2	3	4	5
j.	Surgeon	1	2	3	4	5
k.	Other (please state) ________________________	1	2	3	4	5

4. **Do you intend to use any of the following therapies in the treatment of your illness in the future? (CIRCLE ONE NUMBER FOR EACH ITEM)**

		Definitely	Probably	Uncertain	Probably not	Never
a.	Detoxification	1	2	3	4	5
b.	Faith healing	1	2	3	4	5
c.	Herbal remedies	1	2	3	4	5
d.	Immune therapies	1	2	3	4	5
e.	Meditation/relaxation therapy	1	2	3	4	5
f.	Special foods or diets	1	2	3	4	5
g.	Vitamins or tonics	1	2	3	4	5
h.	Other alternative/ complementary therapies (please state) ________________________	1	2	3	4	5

5. **How much do you agree with the following reasons of why you would use alternative/complementary therapies (ACTs)? (CIRCLE ONE NUMBER FOR EACH ITEM)**

		Strongly Agree	**Agree**	**Uncertain**	**Disagree**	**Strongly Disagree**
a.	I believe ACTs can cure my cancer	1	2	3	4	5
b.	I don't know if ACTs can cure my cancer but I will try any treatment	1	2	3	4	5
c.	I believe ACTs will improve my quality of life	1	2	3	4	5
d.	ACTs help me manage the side effects of medical treatment(s)	1	2	3	4	5
e.	I feel ACTs increase my control over my treatment choices	1	2	3	4	5
f.	Alternative/complementary practices are part of my daily life already	1	2	3	4	5
g.	Other (please state) ________________	1	2	3	4	5

6. **How much do you agree with the following statements about your cancer? (CIRCLE ONE NUMBER FOR EACH ITEM)**

	My cancer:	**Strongly Agree**	**Agree**	**Uncertain**	**Disagree**	**Strongly Disagree**
a.	Was caused by a weakness in the immune system	1	2	3	4	5
b.	I could have prevented my cancer	1	2	3	4	5
c.	Was caused by pollution	1	2	3	4	5

6. **How much do you agree with the following statements about your cancer? (CIRCLE ONE NUMBER FOR EACH ITEM)**

My cancer:	**Strongly Agree**	**Agree**	**Uncertain**	**Disagree**	**Strongly Disagree**
d. Was caused by smoking	1	2	3	4	5
e. Was caused by a build-up of toxins in the body	1	2	3	4	5
f. Was caused by stress	1	2	3	4	5
g. Was caused by eating the wrong foods	1	2	3	4	5
h. Was the result of a disturbance in my body	1	2	3	4	5
i. Was caused by excessive sunlight	1	2	3	4	5
j. Was caused by a micro-organism	1	2	3	4	5
k. Was caused by my lifestyle	1	2	3	4	5
l. Was caused by drinking alcohol	1	2	3	4	5
m. Was the result of exposure to insecticides	1	2	3	4	5
n. Was a result of genetic factors	1	2	3	4	5
o. Was caused by multiple factors	1	2	3	4	5
p. The cause of my cancer is not known	1	2	3	4	5

7. **How much do you agree with the following statements about the medical treatments for cancer (e.g. surgery, radiation therapy, chemotherapy, hormone therapy)? (CIRCLE ONE NUMBER FOR EACH ITEM)**

The medical treatments:	**Strongly Agree**	**Agree**	**Uncertain**	**Disagree**	**Strongly Disagree**
a. Can cure my cancer	1	2	3	4	5
b. Prevent the spread of my cancer	1	2	3	4	5
c. Could cause a remission of my cancer	1	2	3	4	5
d. Assist other treatments to work	1	2	3	4	5
e. Relieve my symptoms	1	2	3	4	5
f. Have side effects	1	2	3	4	5
g. It is easy to understand how medical treatments work	1	2	3	4	5
h. It is the patient's fault if medical treatments don't work	1	2	3	4	5
i. Assist the body's natural forces to heal	1	2	3	4	5
j. Strengthen the body's natural reserves	1	2	3	4	5
k. Are more important than alternative/complementary therapies	1	2	3	4	5
l. Reduce the chance that alternative/complementary therapies will work	1	2	3	4	5

8. How much do you agree with the following statements about alternative/ complementary therapies (ACTs) (CIRCLE ONE NUMBER FOR EACH ITEM)

		Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
Alternative/Complementary therapies (ACTs):						
a.	Are helpful	1	2	3	4	5
b.	It is wise to use ACTs	1	2	3	4	5
c.	Will cure my cancer	1	2	3	4	5
d.	Will prevent the spread of my cancer	1	2	3	4	5
e.	Could cause a remission of my cancer	1	2	3	4	5
f.	Will assist other treatments to work	1	2	3	4	5
g.	Will relieve my symptoms	1	2	3	4	5
h.	Have side effects	1	2	3	4	5
i.	It is easy to understand how ACTs work	1	2	3	4	5
j.	It is the patient's fault if ACTs don't work	1	2	3	4	5
k.	Assist the body's natural forces to heal	1	2	3	4	5
l.	Strengthen the body's natural reserve	1	2	3	4	5
m.	Are more important than medical treatment	1	2	3	4	5
n.	Reduce the chances that medical treatment will work	1	2	3	4	5

9. **How much do you agree with the following statements about your conventional health care professional(s) (doctor, nurse, social worker?) (CIRCLE ONE NUMBER FOR EACH ITEM)**

Conventional health care professionals:	**Strongly Agree**	**Agree**	**Uncertain**	**Disagree**	**Strongly Disagree**
a. Are hard to talk to	1	2	3	4	5
b. Are very sympathetic people	1	2	3	4	5
c. Use simple explanations	1	2	3	4	5
d. Have a good manner	1	2	3	4	5
e. Provide emotional support	1	2	3	4	5
f. Don't spend enough time with their patients	1	2	3	4	5
g. Are well trained	1	2	3	4	5
h. Care more about the disease than the person	1	2	3	4	5
i. Give realistic hope	1	2	3	4	5
j. You can trust them to tell you the truth	1	2	3	4	5
k. Sometimes make you feel angry	1	2	3	4	5
l. Inspire confidence	1	2	3	4	5
m. Are up-to-date in their knowledge about my disease	1	2	3	4	5
n. Don't encourage their patients to ask questions	1	2	3	4	5
o. I can understand what they are telling me	1	2	3	4	5

10. How much do you agree with the following statements about the encouragement you received to use alternative/complementary therapies in the treatment of your illness (CIRCLE ONE NUMBER FOR EACH ITEM)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
a. My family has tried to convince me to use alternative/ complementary therapies	1	2	3	4	5
b. My friends have tried to convince me to use alternative/ complementary therapies	1	2	3	4	5
c. My doctor has tried to convince me to use alternative/complementary therapies	1	2	3	4	5
d. Other health care professionals have tried to convince me to use alternative/complementary therapies	1	2	3	4	5
e. My family have supported me in using alternative/complementary therapies	1	2	3	4	5
f. My friends have supported me in using alternative/complementary therapies	1	2	3	4	5
g. My doctor has supported me in using alternative/complementary therapies	1	2	3	4	5
h. Other health care professionals have supported me in using alternative/complementary therapies	1	2	3	4	5

11. How much do you agree with the following statements about your will to live? (CIRCLE ONE ANSWER FOR EACH ITEM)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
a. It's worth having any treatment even if the chances they will work may not be high	1	2	3	4	5
b. I don't care how uncomfortable a treatment is, I will have it if it improves my chance	1	2	3	4	5
c. I will hang on to life at any cost	1	2	3	4	5
d. I am prepared to have any treatment to get better	1	2	3	4	5
e. I desperately want to live	1	2	3	4	5
f. I have a lot to live for	1	2	3	4	5
g. I'm going to beat cancer regardless of what happens	1	2	3	4	5
h. I am determined to beat cancer	1	2	3	4	5
i. I am hoping my treatments will work a cure	1	2	3	4	5
j. If my current treatment does not work I will find something that will	1	2	3	4	5
k. I am optimistic and hopeful	1	2	3	4	5
l. I really don't care anymore whether I live or die	1	2	3	4	5

12. In the last week, how much money have you spent on the following?

a. Medication prescribed by your doctor for your cancer $ ____________

b. Visits to alternative practitioners $ ____________

c. Special diet for cancer $ ____________

d. Special pills, vitamins, tonics for your cancer (not prescribed by your doctor $ ____________

13. How long have you been using alternative therapies for the treatment of your cancer? (CIRCLE ONE ONLY)

1. Less than one month
2. 1-3 months
3. 4-6 months
4. 7-12 months
5. Longer than 12 months

14. How strictly do you adhere to any alternative/complementary treatment regime used for your cancer (CIRCLE ONE ONLY)

1. Completely
2. Almost completely
3. Only partially
4. Not applicable (have not used alternative/complementary therapies)

Thank you for your assistance with this questionnaire.

EORTC QLQ-C30 (version 2.0.)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your inititals:
Your birthdate (Day, Month, Year):
Today's date (Day, Month, Year): 31

		No	Yes
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2
2.	Do you have any trouble taking a <u>long</u> walk?	1	2
3.	Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2
4.	Do you have to stay in a bed or a chair for most of the day?	1	2
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2

During the past week:

		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4

<u>Please go on to the next page</u>

During the past week:	Not at All	A Little	Quite a Bit	Very Much
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

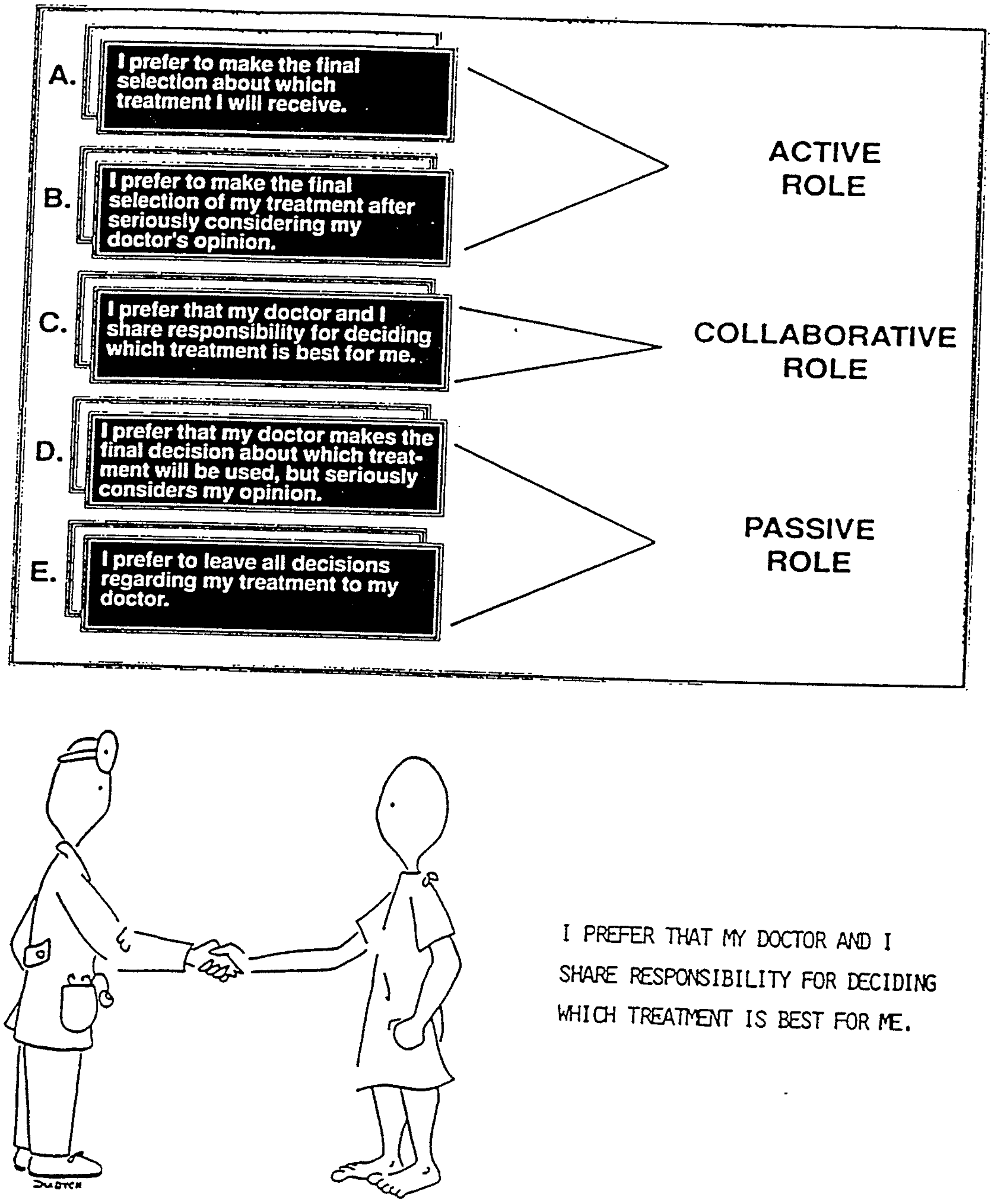
Very poor Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor Excellent

Version 2.0



A. I prefer to make the final selection about which treatment I will receive.

B. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

E. I prefer to leave all decisions regarding my treatment to my doctor.

I PREFER THAT MY DOCTOR AND I SHARE RESPONSIBILITY FOR DECIDING WHICH TREATMENT IS BEST FOR ME.

Fig. 1. Statements on the role preferences card sort.

(Degner & Sloan, 1992)

Personal Demographic Form

1. Marital Status:

Married ___
Divorced ___
Never Married ___
Widowed ___
Common-law ___

2. Age:

20- 30 years ___
31- 40 years ___
65 and over ___
41- 50 years ___
51- 65 years ___

3. Education:

grade 8 or less ___
some high school ___
high school diploma ___
some college ___
college degree ___
graduate degree ___

4. Occupation:

clerical ___
labourer ___
retail ___
retired ___
management ___
professional ___
homemaker ___
other ______________
(please specify)

5. Family Income:

below $10,000 ___
$11,000 - 20,000 ___
$21,000 - 30,000 ___
$31,000 - 40,000 ___
$41,000 - 50,000 ___
over $50,000 ___

6. Ethnic Background:

European ___
Asian ___
French ___
Aboriginal ___
British Isles ___
Other ______________
(please specify)

7. Religion:

Catholic ___
None ___
Protestant ___
Other ______________
(please specify)
Jewish ___

Personal Demographic Form (cont'd)

Chart Data

** 8. Stage of Illness: ______________________

** 9. Date of Diagnosis: ______________________

** 10. Medical Treatment Received:

Surgery __ Radiotherapy __ Other ______________

Chemotherapy __ Hormone Therapy __ (please specify)

** data to be obtained from medical record
c Kristjanson, 1992

APPENDIX B

H-E-C Conceptual Framework and Definitions

Appendix B: H-E-C Conceptual Framework

Constructs, Concepts and Definitions

Construct	Concepts/Variables	Operational Definition
Health	Quality of Life	- The subjective interpretation of a person's satisfaction and happiness with physical, psychological and spiritual wellbeing at a given moment. Definition of health by patient affects how problems and goals are conceptualized.
Action	1. Alternative/Complementary Therapies	- Any treatment a patient defines as being alternative or complementary. Represents a chosen action in the H-E-C Model.
	2. Conventional Therapies	- Any treatment prescribed by a physician (M.D.) and recognized by the Canadian Cancer Society as being a proven cancer therapy. Represents a chosen action in the H-E-C Model.
	3.Decision-Making	- The process by which a patient considers treatment alternatives, using beliefs, assumptions, and knowledge. This process represents the movement among the domains of the H-E-C Model, towards the goal of Health.
Error	Beliefs about cancer	- Statements which reflect a patients' understanding of the cause of their breast cancer and the effect of lifestyle on cancer (Yates et al., 1993). Considered as part of the error domain in the H-E-C Model.
Change	Beliefs about treatment	- Statements which reflect a patients' understanding of the efficacy of conventional medical and alternative/complementary treatment on cancer. Considered an aspect of the change domain in the H-E-C Model.

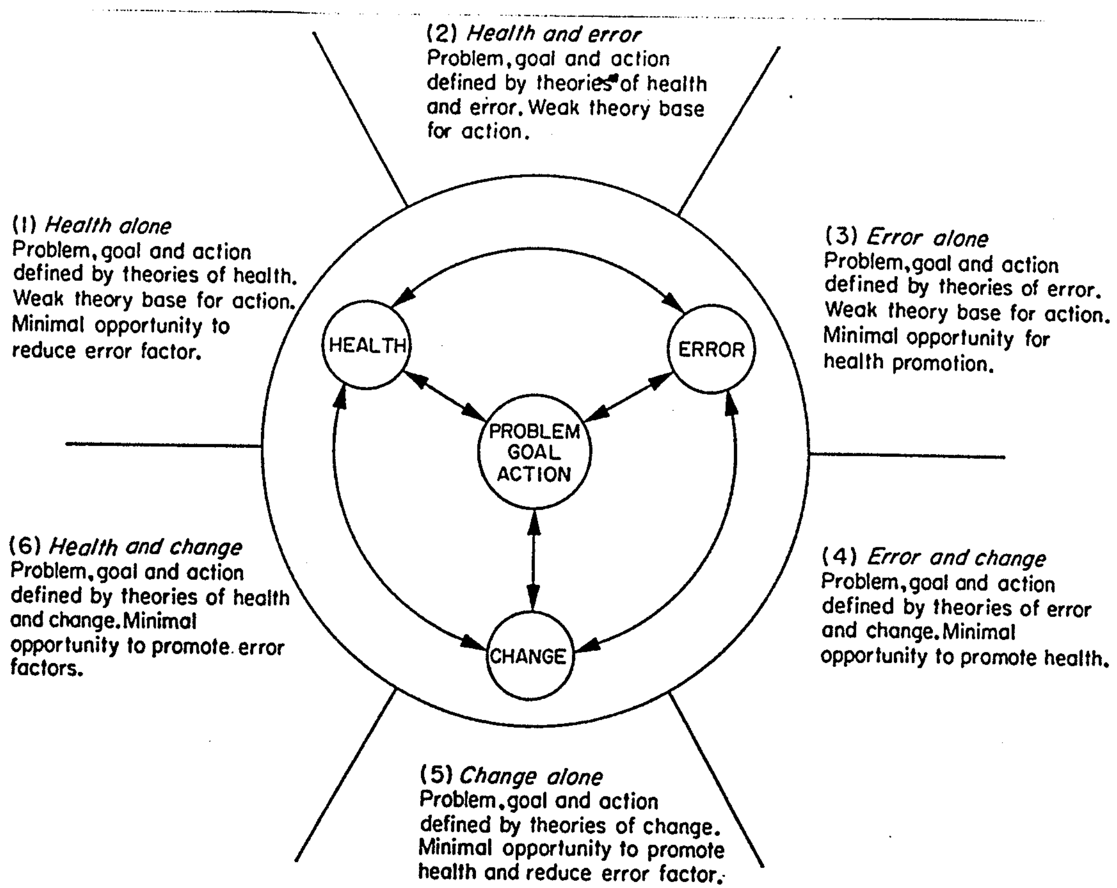


FIGURE 1 *The H-E-C framework. The figure shows that a clinician's choice in defining problems, goals and actions is determined by three major theory domains—health, error and change. Selective or uneven attention to the theory domains leads to predictable consequences in clinical judgement, as shown in 1–6 outside the circle. The range and flexibility of the clinician's judgement are increased as his/her range and depth of knowledge of all domains is increased.*

H-E-C Framework (Kristjanson, Tamblyn, & Kuypers, 1987)

APPENDIX C: Pilot Study

Permission to Release Name, Explanation of the Pilot Study/Disclaimer, Consent

Request for Permission to Release Names of Potential Panel Members

(Used by Victoria Hospital Clinic Nurses when approaching women)

Lynda Balneaves is a registered nurse and Masters' student from the Faculty of Nursing, University of Manitoba. She is doing a research project about the beliefs and practices of women with breast cancer.

Information given is strictly confidential. Whether or not you decide to participate will in no way affect the care you receive.

Ms. Balneaves would like to talk to you and tell you more about the study so that you can decide if you would like to participate. Would it be alright with you if I give Ms. Balneaves your name so that she can explain the study to you?

(If agreeable, the name of the woman is given to the researcher and the nurses thanks them).

(If the woman declines, the nurse thanks them for their time).

Explanation of Pilot Study to Potential Panel Members

(Used by the researcher when approaching potential panel members by phone).

Hello, my name is Lynda Balneaves and the clinic nurse <u>(name of nurse)</u>, gave me your name as being willing to hear more about a research study I am doing. I am a registered nurse and Masters' student at the Faculty of Nursing, University of Manitoba. I am conducting a research study as part of my thesis on the beliefs and treatment practices of women with breast cancer. Phase one of the study involves pilot testing a questionnaire which explores the beliefs and treatment practices of women with breast cancer. This purpose of the pilot test is to make sure the questionnaire is appropriate for use with women with breast cancer.

Your participation would involve answering seven questions about the questionnaire's items. You will also be asked to list any items which you feel should be included on the questionnaire that is not listed. It is expected to take about 45 minutes to complete all aspects of the pilot test of the instrument.

Your participation is voluntary and will in no way affect the care you receive. You may withdraw from the study at any time by simply telling me that you wish to do so. The information you provide will be confidential because your name will not be listed on the pilot study's forms.

Do you have any questions about the study or about your participation in the study?

Would you be interested in participating in this study?

(If yes, then make any appointment to meet at a place of convenience)

(If no, "Thank you for taking the time to listen to me.")

Consent Form - Pilot Study

The Beliefs and Practices of Women with Breast Cancer who Use Alternative/Complementary Therapies

I ____________________, agree to participate in the pilot study of the project, "The beliefs and practices of women with breast cancer who use alternative/ complementary therapies". The purpose of the pilot test is to assess the appropriateness of a survey exploring the beliefs and practices of women with breast cancer.

The results of the pilot test will be used to revise the questionnaire so that it addresses beliefs and treatment practices found important by women with breast cancer.

The study is conducted by Lynda Balneaves, Master's study at the Faculty of Nursing, University of Manitoba.

The pilot study has been approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba and the Victoria General Hospital.

My participation involves answering seven questions about the questionnaire which will take approximately 45 minutes to complete. I understand that my participation is voluntary and that I may withdraw from the study at any time by simply telling the researcher. I understand that my decision to participate or not participate will in no way affect the care I receive.

The information I provide will be confidential because my name will not be on the questionnaires. Findings from the research may be published. I also grant permission for Ms. Balneaves to have access to my medical chart in order for her to record information about my disease.

Consent Form - Pilot Test (cont'd)

The Beliefs and Practices of Women with Breast Cancer who Use Alternative/Complementary Therapies

Answering some questions may arouse sad feelings about my illness. Otherwise no known risks are involved with participating in this study. The study offers no direct benefits to participants. I understand that I will receive answers to any questions about the study at any time.

The researcher can be reached at . . The researcher's advisor is Dr. Linda Kristjanson, who can be reached a .

____

Name (please print)

____

Signature

____

Date

Pilot Study Forms (Example)

Pilot Study Forms

1. Clarity of Items:

Clarity Instructions

This questionnaire is made from answers people with cancer gave to an interviewer's questions about their beliefs and treatment practices. You are being asked to rate the overall questionnaire on its clarity since you also are a person with cancer.

a) Read each item on the list as you answer the question on the response sheet. Beside each item number on the response sheet circle C (clear) or U (unclear) to indicate whether the item is clear to you.
b) Write any comments in the space provided beside each response.
c) After you finish you may discuss your comments with the researcher.

Thank you for your help

LIST OF ITEMS
SET _____

5a. I believe they can cure cancer.

6d. It was caused by smoking.

6o. It was caused by multiple factors.

7k. Are more important than alternative/complementary therapies.

RESPONSE SHEET: CLARITY

SET:______
DATE:_____
SUBJECT #:________

Circle One:

	C (clear)	**U (unclear)**	**Comments**
5a.	C	U	____________________
6d.	C	U	____________________
60.	C	U	____________________
7k.	C	U	____________________

Pilot Study Forms

2. Apparent Internal Consistency:

Consistency Instructions

This questionnaire is made from answers people with cancer gave to an interviewer's questions about their beliefs and treatment practices. You are being asked to look at questionnaire's items and tell if they seem to belong together. You will be given several sets to rate, but only one list at a time.

With each list of questionnaire items is a right half-page response sheet with questions on it for your answers about the set of items. Read the entire set of items on the list first. After you finish reading the entire set of items, answer question (A) at the top of the right half-page response sheet. Then answer question (B) for each item in the set. Answer by circling the response you choose under question (B). Add any comments you want to explain your answers.

LIST OF ITEMS
SET _____

8a. ACTs are helpful.

8b. It is wise to use ACTs.

8c. ACTs will cure my cancer.

8d ACTS will prevent the spread of my cancer.

8e. ACTs will bring about a remission of my cancer.

2. Apparent Internal Consistency (cont'd):

RESPONSE SHEET: CONSISTENCY

SET:______
DATE:_____
SUBJECT #:________

A. Do these items generally belong together? (circle one)

YES **NO**

B. Does each item belong in the set? Answer by circling Y (Yes) or N (No) beside each item number for this set.

	Circle One		
	Y (Yes)	**N (No)**	**Comments**
8a.	Y	N	____________________
8b.	Y	N	____________________
8c.	Y	N	____________________
8d.	Y	N	____________________
8e.	Y	N	____________________

Pilot Study Forms

3. Content Validity:

Content Validity Instructions

This questionnaire is made from answers people with cancer gave to an interviewer's questions about their beliefs and treatment practices. Since you also have cancer, you are asked to look at the questionnaire items and tell if they seem to measure various aspects of beliefs and treatments.

You will be given one set (one list of items) at a time to rate. Attached to each set is a response sheet with a label and definition. For each label, definition and set of items, four questions will be asked. The four questions are:

a. In general, does the label and definition fit the whole set of items? Answer once for the entire set on the response sheet under question A.
b. For each item, does it belong to the label and definition? You will answer Y (yes) or N (no) next to each item number on the response sheet under question B.
c. Save this question until you finish A and B. Is each item unique? Answer Y (yes) or N (no) to the far right of each item number on the response sheet under question C.
d. Is anything left off the list that you think should be there?

LIST OF ITEMS
SET _____

8a. ACTs are helpful.

8b. It is wise to use ACTs.

8c. ACTs will cure my cancer.

8d ACTS will prevent the spread of my cancer.

8e. ACTs will bring about a remission of my cancer.

Pilot Study Forms

3. Content Validity (cont.):

RESPONSE SHEET: CONTENT VALIDITY

SET:______
DATE:______
SUBJECT #:_________

LABEL: Beliefs about Alternative/complementary Therapies.
DEFINITION: Thoughts and feelings expressed by cancer patients about the effect of alternative/complementary therapies on the body, the efficacy of the therapies and how the therapies work.

A. Read the label and definition above. Then read all items in the set. In general, does the label and definition fit the whole set of items? Answer once for the entire set (circle one).

YES **NO**

B. For each item does it belong to the label and definition? Circle **Y** (yes) or **N** (no) next to each item number on this response sheet, under B below.

C. Is each item unique? Circle **Y** (yes) or **N** (no) next to each item number on this response sheet, under C below.

Item	**B. Does this item fit the label and definition?**			**C. Is this item unique?**	
8a.	**Y N**	______________	8a.	**Y N**	______________
8b.	**Y N**	______________	8b.	**Y N**	______________
8c.	**Y N**	______________	8c.	**Y N**	______________
8d.	**Y N**	______________	8d.	**Y N**	______________
8e.	**Y N**	______________	8e.	**Y N**	______________

D. Is anything left off the list that you think should be there?

____

____

APPENDIX D - Phase Two (Oncology Clinics)

Permission to Release Name, Explanation of the Study, Consent

Request for Permission to Release Names of Potential Subjects

(Used by Clinic Nurses when approaching women)

Lynda Balneaves is a registered nurse and Masters' student from the Faculty of Nursing, University of Manitoba. She is doing a research project about the beliefs and practices of women with breast cancer.

Information given is strictly confidential. Whether or not you decide to participate will in no way affect the care you receive.

Ms. Balneaves would like to talk to you and tell you more about the study so that you can decide if you would like to participate. Would it be alright with you if I give Ms. Balneaves your name so that she can explain the study to you?

(If agreeable, the name of the woman is given to the nurse researcher and the therapist thanks them).

(If the woman declines, the therapist thanks them for their time).

Explanation of Study to Potential Subjects

(Used by the researcher when approaching potential subjects in person or by phone)

Hello, my name is Lynda Balneaves and the clinic nurse/therapist gave me your name as being willing to hear more about a research study I am doing. I am a registered nurse and Master's student at the Faculty of Nursing, University of Manitoba. I am conducting a research study as part of my thesis on the beliefs and treatment practices of women with breast cancer. I would also like to hear any other experiences you have had during your illness which you feel are important. I am especially interested in any alternative/complementary cancer therapies you have been involved in or considering. These are therapies that you consider to be not part of your medical treatment.

The study consists of four questionnaires which look at your beliefs about cancer and the treatments you have had and your future plans about treatment. The first questionnaire looks at your beliefs and treatment practices. The second tool asks how much control you would like to have when making treatment decisions. These third questionnaire asks you about your quality of life and symptoms you are experiencing right now. The last questionnaire includes questions about yourself such as age and education. Altogether, the questions should take about one hour to complete.

Explanation of Study to Potential Subjects (cont.)

(Used by the researcher when approaching potential subjects in person or by phone)

The information you provide will be confidential because your name will not be listed on the questionnaires. You may refuse to participate in the study or stop answering questions at any time you wish without affecting the care you receive.

Would you be interested in participating in this study?

(If yes, then make appointment to meet at a place of convenience)

(If no, "Thank you very much for taking the time to listen to me. "

Consent Form - Questionnaires

The Beliefs and Practices of Women with Breast Cancer who Use Alternative/Complementary Therapies

I ______________________ agree to participate in the questionnaire portion of the study, "The beliefs and practices of women with breast cancer who use alternative/complementary therapies". The purpose of the study is to gain an understanding of the beliefs and practices of women with breast cancer and their experiences with both conventional and alternative/complementary therapies.

The results of the study may be helpful to health professionals caring for breast cancer patients because it may provide information about how they might improve the care they give and improve communication between caregivers and patients.

The study is conducted by Lynda Balneaves, Master's student at the Faculty of Nursing, University of Manitoba.

The study has been approved by the Ethical Review Committee of the University of Manitoba Faculty of Nursing, the Manitoba Cancer Treatment and Research Foundation, Victoria General Hospital, and the St. Boniface Hospital Research Committee.

My participation involves answering four questionnaires which will take approximately 60 minutes to complete. I understand that my participation is voluntary and that I may withdraw from the study at any time by simply telling the researcher. I understand that my decision to participate or not participate in the study will in no way affect my care. I understand and give permission to Ms. Balneaves to have access to my medical chart in order to obtain information regarding my illness.

Consent Form - Questionnaires (cont'd)

The Beliefs and Practices of Women with Breast Cancer who Use Alternative/Complementary Therapies

The information I provide will be confidential because my name will not be on the questionnaires. Only a report of grouped data will be provided to the participating agency. Findings from the research may be published.

Answering some questions may arouse sad feelings about my illness. Otherwise, there are no known risks involved with participating in this study. The study offers no direct benefits to participants. I understand that I will receive answers to any questions about the study at any time.

The researcher can be reached locally at: (. The researcher's advisor is Dr. Linda Kristjanson ( ).

____

Name (please print)

____

Signature

____

Date