Complementary and Alternative Medicine and the Experience of Breast Cancer: A Phenomenological Study

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Complementary and Alternative Medicine and the Experience of Breast Cancer:

A Phenomenological Study

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This thesis for honors recognition has been approved for the Department of Nursing.

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Dedication

To my family. Your support has meant everything.
Acknowledgments

I wish to express my sincere gratitude to everyone involved in making this thesis a reality. Primarily, I want to thank the participating women for sharing such a personal and difficult experience as breast cancer. Their descriptions have helped me understand better the central role of caring in the nursing profession. Also, their inspiring enthusiasm for life reassured my belief in the strength of the human spirit in the face of adversity.

Thank you to Joni Walton Ph.D. for taking on the elaborate and demanding task of research advisor and reader. Her encouragement to take on this thesis project was key in my academic development. Thanks to her feedback and sharing of her academic expertise I was able to bring this project to completion.

I am also indebted to Kim Garrison as reader of this thesis and to phenomenology researcher John Ries Ph.D. who broadened my understanding of phenomenology.
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Abstract

About 1 in 8 women in the United States develop breast cancer, according to a National Cancer Institute report (Center for Disease Control, 2003). Some women use Complementary and Alternative Medicine (CAM) to help them cope with breast cancer and cancer treatment. Although CAM use is especially prevalent among cancer patients and is increasing in the overall U.S. population, few studies address the reasons behind CAM use in cancer patients. The purpose of this phenomenological thesis was to explore the experience of three women who used CAM while going through traditional treatment for breast cancer. Colaizzi’s method was used to analyze the data. Findings included five main themes: coping with stressors, overcoming negativity, evaluating limitations of traditional medicine, taking an active role, and alleviating side effects.
CHAPTER 1

Breast Cancer and CAM therapies

Few things provoke as much fear in a woman as a breast cancer diagnosis. This fear is supported by the fact that in the United States each year breast cancer affects 1 in 8 and kills 39,400 women (National Cancer Institute [NCI], 2003). Breast cancer threatens every aspect of a woman’s wellbeing, physiological, psychological, social, spiritual, and even her very own identity as a woman. The multiple stressors associated with cancer forces patients to draw on coping mechanisms.

To help them cope with cancer, a significant and increasing number of cancer patients are choosing to use Complementary and Alternative Medicine (CAM) in conjunction with traditional treatment (Bennett & Lengacher, 1999; Shumay, Maskarinec, Gotay, Heiby, and Kakai, 2002). However, why CAM use is increasing and prevalent among cancer patients is neither well studied nor understood.

Generally, patients who use CAM do not disclose their use to traditional practitioners. The reason behind this lack of disclosure as well as knowledge about the attitudes of general practitioners towards CAM is poorly documented. Yet, in order to promote a working and caring relationship between health care providers and cancer patients who use CAM, these issues must be addressed. Gaining some understanding of what cancer patients go through is critical for health care providers because cancer patients often receive health care at times when they are most vulnerable and in need of empathic support.

It is difficult to imagine the stomach-sinking feeling of palpating an abnormal mass during a monthly self-breast exam or the anxiety of waiting for clinical results. It is
even more difficult to imagine the fear and shock accompanying a cancer diagnosis. However, a breast cancer diagnosis is only the beginning of a complex and difficult experience with far ranging implications. After diagnosis, there is still the decision about the type of treatment to follow. There are still the costs and the side effects of such treatment and individual challenges that only those with the actual experience of cancer can describe in their totality. Clearly, trying to understand the experience of breast cancer is a challenge, a challenge undertaken by phenomenological studies such as this.

**Purpose**

Greater understanding of patients' experience empowers health care providers to provide more empathic care and engage in more effective communication, both of which are critical in the development of a caring relationship (Schwerin, 2004; Kunvk & Olson, 2001). Cancer patients regard a caring relationship with health care providers as critical.

A group of oncology patients cited caring and similar traits such as individualization, rapport, and attentiveness as hallmarks of quality nursing care in one study (Radwin, 2000). Similarly, the physician’s caring attitude was the most important component of the cancer diagnostic interview in a study comprising a group of one hundred breast cancer patients (Roberts, Cox, Reintgen, Baile & Gibertini, 1994). Even information giving was rated as secondary to the physician’s caring attitude in this study.

In addition to a caring attitude, effective communication is key in the formation of an optimal working patient-health care provider relationship. The need for communication about CAM use is not being met, according to some studies. Given its prevalence, it is unsettling that a majority of patients do not tell their health care providers about their CAM use (Ben-Arye, Frenkel, & Margalit, 2004).
Because the ultimate way to understand cancer is direct experience, without actually having lived through cancer or a similar chronic illness, health care providers are limited in their ability to relate to breast cancer patients at a personal level. Here lies the importance of qualitative studies such as this. The purposes of this phenomenological study were as follows: (a) to identify key aspects of the experience of breast cancer, (b) identify CAM therapies used by participants, and (c) to describe the factors that prompted the participants to use CAM. Information from this study adds to the knowledge about breast cancer patients who use CAM therapies in addition to traditional treatment.

Pathophysiology of Breast Cancer

Breast cancer has different stages and can be noninvasive (in situ) or invasive (Hart, 1999; Weaver, 2002). The most common types of cancers are ductal and lobular. Ductal carcinoma originates in the epithelial cells lining the mammary ducts. If the cancer remains inside the duct it is noninvasive. Once it spreads to surrounding tissue, the cancer becomes infiltrating ductal carcinoma, the most common pathologic type of breast cancer, accounting for 79% of breast cancer cases (Ignatavicius & Workman, 2002). A biopsy is the only way to determine if a suspicious lesion is malignant or benign (Hart, 1999).

Survival of breast cancer and treatment plan determination is influenced by numerous factors. Prognostic factors include the tumor’s size, hormone receptor status, rate of growth, cell abnormality, whether the tumor is confined to a specific area of the breast, axillary nodes involvement, menopausal status of the patient, age, and additional medical conditions (Weaver, 2002).
Prevention

The main form of breast cancer prevention is regular screening using self-breast exams and mammograms. A mammogram provides greater accuracy than a self-breast exam (American Cancer Society, 2003) since a lesion usually cannot be palpated until 5-9 years after the onset of the cancer (Ignatavicius & Workman, 2003). Yet, mammograms fail to detect cancers in about 10% to 15% of patients (Weaver, 2002). Other methods of early detection are digital mammography, computer assisted diagnosis, ultrasounds, magnetic resonancy imaging, positron emission tomography scan, and thermo-scans. Ductal lavage is a new method that determines increased risk. This method is based in detecting changes in milk duct cells (Weaver, 2002).

Due to advances in medicine it is possible to treat cancers at earlier stages than in the past. Today, patients’ long-term survival rate is about 86%. Even with metastatic cancer, for which there is no cure, new systemic therapies prolong survival (Weaver, 2002).

Etiology and Risk Factors

Although there exist rare cases of breast cancer in men (Weaver, 2002), breast cancer mostly affects women. The cause of breast cancer remains largely unknown, but age is the single most important factor identified (Hart, 1999). Most breast cancer cases occur in women over 50 years of age (Center for Disease Control [CDC], 2003). In fact, “96% of breast cancer deaths reported during 1996-2000 occurred in women ages 40 and older” (American Cancer society [ACS], 2003, ¶ 10). Another risk factor, family history of breast cancer in a first-degree relative, is associated with a 2-fold risk increase of
CAM Use by Women With Breast Cancer

developing the disease (ACS, 2003). However, a surprising 90% percent of affected patients do not have a familial history of breast cancer (CDC, 2003).

In different degrees, there are multiple factors associated with an increased risk of breast cancer. Mutations in the specific genes BRCA1 and BRCA2 have been found to increase the risk of breast cancer (Ignatavicius & Workman, 2002). A number of additional risk factors fall under prolonged estrogen exposure, primarily early menarche, late menopause, use of birth control pills in the teens and for longer than 5 years, and not having children or bearing children after age 30 (Hart, 1999). Environmental and lifestyle risk factors include exposure to ionizing radiation, high alcohol intake, obesity, and high fat diet. Less understood factors are race, exposure to toxins, a history of fibrocystic changes, and tobacco use (Hart, 1999). Interestingly, the risk associated with obesity is dependent on the menopausal status of the woman. After menopause, being obese places a woman at a higher risk. The opposite is true for women who have not reached menopause, among whom thinner women are at a higher risk of developing breast cancer (Weaver, 2002).

Impact on Patient

Ethical impact. Ethical difficulties exist in regard to cancer and CAM use. Some traditional practitioners may support or oppose CAM therapies in general. However, since there is no ample scientific research regarding CAM therapies, health care providers’ perception of CAM might be largely based on a personal opinion. Additionally, patients’ view of CAM might be opposite to that of health care providers. These contrasting opinions might result in conflict and be detrimental to the treatment outcome. Balancing the need to protect patients from potentially harming CAM therapies
with the need to consider the role that CAM therapies can play in promoting coping with cancer is a challenge health care providers face.

The consideration of a prophylactic mastectomy brings up another ethical issue in relation to breast cancer. Although a prophylactic mastectomy reduces the risk of cancer by about 90% (Weaver, 2002), physicians’ decision to recommend this therapy must be handled with extreme care. Although a highly successful intervention in preventing breast cancer, a prophylactic mastectomy might be too drastic of a measure against breast cancer to be offered as an option in other than extremely few selected cases.

*Psychological and social impact.* Breast cancer has great psychological and social impact on a person’s life. Many women face fear and uncertainty when confronted with a breast cancer diagnosis (Ödling, Norberg, & Danielson, 2002). “I thought I’d been given a death sentence,” said one woman about her breast cancer diagnosis (Hinson, 2000, p. 2).

In cases where a mastectomy is performed, the psychological impact of losing a breast and the strong alteration it produces in physical appearance is difficult to measure. According to a surgical nurse, when she changed a patient’s dressing after a mastectomy, the woman screamed out loudly, leaving a lasting impression on the nurse (Ödling, et al. 2002).

Although certainly a difficult experience for anyone, it is important to note that a breast cancer diagnosis does not affect all women equally. Psychosocial adaptation takes different forms for individual women and occurs in different stages (Livneh, 2000). According to different studies, there are three main coping dimensions: (a) emotion focused, (b) problem-focused (Lazarus & Folkman, 1984; Billings & Moos, 1981), and
(c) avoidance-oriented dimension (Parker & Endler, 1992). Similarly, multiple coping styles have been identified. Some of the most frequently researched coping styles among cancer patients are as follows: “a) internal vs. external perceptions of control, b) optimism vs. pessimism or helplessness, and d) approach vs. avoidance” (Livneh, 2000, p. 41).

Positive reinterpretation is a coping style associated with better psychosocial adaptation to cancer (Berckman & Austin, 1993). It is inspiring that amidst the difficulties some women describe positive outcomes from their experience with cancer, declaring that their diagnosis brought them closer to friends, and affected their lives at a spiritual level (Hinson, 2000).

The meaning attributed to the cancer affects psychosocial adaptation even more immediately than engagement in a particular coping style. In a study, women who described their breast cancer with negative meanings at a follow up assessment had higher levels of depression and anxiety than women who described it with a more positive meaning (Degner, Hack, O’Neil, & Kristianson, 2003). In this study, most of the 1012 participating women chose the more positive meanings such as “challenge” (57.4%) or “value” (27.6%) to describe cancer. Relatively few women chose more negative meanings such as “enemy” (7.8%) or “irreparable loss” (3.9%).

_Economical impact_. Breast cancer directly puts great financial stress on breast cancer patients and their families. Besides costs involving hospital bills, cancer treatment, and expenses previous to the diagnosis, loss of wages can result in a financial crisis for the patient and her family (Cancer Care, 2003).
Although it is a fact that the cost associated with cancer treatment is significant, it is practically impossible to determine an average cost for this treatment. There are multiple variants involved in determining cost of cancer treatment such as the insurance policy, cancer stage, type(s) of chemotherapy (different combinations are used), and type of surgery (i.e., lumpectomy, mastectomy, or reconstruction) according to a spokesperson at the Saint Peter’s Hospital Cancer Treatment Center in Helena, MT (personal communication, February 1, 2005). Additionally, a patient may or may not receive radiation (Cancer Treatment Center, personal communication, February 1, 2005). According to a woman who received breast cancer treatment, the overall cost of her treatment was $35,000 (Personal communication, February 1, 2005). Because of their prevalence, spending on CAM therapies is also significant.

CAM therapies out-of-pocket expenditures were estimated at $27 billion in 1995 (Richardson, 2001). Patient demand is also driving an increasing number of managed care organizations and insurance providers to offer some kind of CAM coverage (Pelletier, Astin & Haskell, 1999).

*Traditional Treatment*

*Surgery.* Treatment for breast cancer can be either local or systemic. Local treatment entails surgery and radiation therapy. Types of surgery include lumpectomy (removal of a tumor and tissue margins) and mastectomy, which might be either simple (breast is removed) or modified radical (the breast and axillary lymph nodes are removed) (Weaver, 2002).

*Radiation.* Radiation is implemented mainly in two forms: as teletherapy (external radiation source), or as brachytherapy (radiation source is implanted near tumor mass).
External beam radiation therapy is implemented together with surgery for early stage breast cancer, and might also be implemented after a mastectomy (Weaver, 2002). Brachytherapy radiation is delivered through a catheter. There are indications that brachytherapy reduces patient complications when compared with other types of radiation. Additional forms of radiation therapy include a portable electron beam driven-device, intraoperative radiation, and three-dimensional radiation. To treat cancer that has spread beyond the breast, radiation and surgery are not sufficient. Chemotherapy is implemented in addition to local forms of treatment (Hart, 1999).

Chemotherapy. Chemotherapy is a systemic treatment. This therapy involves combinations of medications to fight cancer cells throughout the body. Concurrently with chemotherapy, hormonal therapy (e.g., tamoxifen) is often prescribed. Targeted therapies are new forms of chemotherapy, which do not impact normal cells and therefore have fewer and milder side effects. These therapies involve antibodies that attack tumor cells only (Weaver, 2002).

The types of chemotherapy used most commonly affect all rapidly growing cells in the body, including noncancerous cells, and are associated with multiple side effects. Surgery and radiation also have significant side effects. Cancer patients report that CAM use is linked to ameliorating side effects of cancer and traditional treatment (Badger, Braden & Mishel, 2001).

Complementary and Alternative Medicine

CAM information resources. In the United States the two main governmental agencies carrying out CAM research related to cancer are the OCCAM (Office of Cancer Complementary and Alternative Medicine) within the National Cancer Institute (NCI)
and the NCCAM (National Center for Complementary and Alternative Medicine). Both the NCI and the NCCAM are part of the National Institutes of Health (NIH). The NIH is one of the eight agencies under the Public Health Service (PHS) in the Department of Health and Human Services (NCCAM, 2003). OCCAM’s exclusive focus is CAM therapies in relation to the diagnosis, prevention and treatment of cancer whereas the NCCAM develops and supports CAM research in general (NCI, 2004).

*What is CAM?* Defining CAM poses multiple challenges. The NCCAM defines CAM as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (NCCAM, 2004 ¶ 2). However, this is a changing definition since as therapies are proven to be safe and effective, they may be added to conventional treatment. For example, once considered CAM, patient support groups are now an option available within traditional treatment (NCCAM, 2004).

*Complementary vs. alternative medicine.* Complementary forms of treatment are used in addition to traditional treatment (e.g., chemotherapy, radiation, or surgery) and alternative therapies are used to replace traditional treatment (NCCAM, 2003). However, the distinction between complementary and alternative and the definition of CAM itself are not black and white. A therapy might be categorized as complementary or alternative but how it is used is ultimately an individual decision. Difficulties in defining CAM pose a challenge for finding information, conducting, and evaluating CAM research studies.

*CAM Classification*

It is impossible to provide a clear succinct definition of CAM. An incredible variety of therapies are considered CAM methods. The NCCAM divides CAM into five
separate groups (NCCAM, 2004). However, in this classification there are overlaps of therapies. The five main groups include the following: (a) alternative medical systems, which are built upon complete systems of theory and practice such as traditional Chinese medicine, (b) mind-body interventions such as meditation, prayer, and art therapy, (c) biologically based therapies, such as “herbs, foods, and vitamins” (NCCAM, 2004, ¶ 10), (d) manipulative and body-based methods; for example, chiropractic manipulation and massage, and (e) energy therapies, such as qigong, therapeutic touch, and magnetic fields (NCCAM, 2004).

Nurse’s Role

From providing education to offering professional and understanding care, nurses have a direct effect in the outcome of cancer treatment. Because of their significant role, nurses must be committed to promoting the best possible outcome for patients.

Nurses hold key positions to aid patients and families to cope with the stress of surgery by implementing preoperative teaching strategies (Garbee & Gentry, 2001). In order to fulfill well the role of educators, nurses need to promote their own education and be aware of medical advances that can affect patients. This awareness can be demanding due to the great amount of research done related to breast cancer treatment (Weaver, 2002).

In addition to addressing physical needs, the provision of empathic care is another important role of nurses. This aspect of care is especially significant from the patients’ point of view. Oncology patients cited attentiveness, individualization, rapport, and caring, as part of eight hallmarks of quality nursing care in one study (Radwin, 2000). Additional markers of nursing excellence were professional knowledge, continuity,
coordination, and partnership. Furthermore, to provide empathic care it is important for nurses to be aware of the treatments women with breast cancer might receive and their side effects (Jordan & Delunas, 2001).
CHAPTER 2

Review of Literature

Traditional medicine has evolved to heights that would have astonished its earliest founders in Classical Greece roughly two thousand years ago. Yet, knowledge related to the time from diagnosis to treatment and recovery with its implications from patients’ point of view is a long haul not thoroughly studied, especially as it relates to CAM use. The greater knowledge health care providers have about the experience of CAM use and the reasons patients seek these therapies, the better equipped they are to understand and care for these patients (Salmenperä, Suominen, Lauri & Puukka, 2001).

Due to client demand, especially among cancer patients, CAM is slowly but persistently making its way into patient care (Henderson & Donatelle, 2004; Ben-Arye, Frenkel & Margalit, 2004; CancerWeb Project, 2001). This increase in CAM has several implications. This review of literature highlights issues surrounding CAM use.

CAM Controversy

Debate surrounds CAM. Disagreement related to CAM ranges from safety to efficacy issues. Although many CAM therapies pose little or no risks (e.g., relaxation techniques), the efficacy of many CAM therapies remains without ample scientific support (Moyad, 2001) creating valid concerns related to CAM use.

Herbal therapies and dietary supplements are a primary source of concern because of potential interactions with traditional drugs (Richardson, 2001). Also, the manufacturing of herbal therapies and dietary supplements is not subject to the same strict regulations required of traditional drugs (Abebe, 2003). Consequently, dietary, herbal, and, biopharmacologic CAM therapies are a major focus of CAM research in an
effort to prevent interactions (Richardson, 2001). Besides the risk of interactions, these CAM therapies might be the emphasis of CAM research due to their similarities with traditional treatment. Dietary, herbal, and biopharmacologic therapies resemble traditional treatment (i.e., drugs) more closely than other CAM therapies (i.e., meditation). The research methods used to investigate the efficacy as well as the side effects and interactions of traditional drugs readily apply to these CAM therapies.

Substituting traditional cancer treatment with CAM is also a source of concern. By choosing to prevent and treat cancer with CAM alone, patients can put themselves at great risk (Simpson, 2003). Delaying traditional diagnosis and treatment decreases a woman’s chance of survival (Facione, Giancarlo & Chan, 2000). Some of the women delayed mammograms or Western treatment by their use of traditional Chinese medicine in one study of 45 Chinese-American women (Facione, Giancarlo & Chan, 2000).

The professionalism of CAM providers was also a source of concern for patients in one study. A significant 40% of the women felt that CAM providers practiced simply for the financial gains in this study that involved 216 breast cancer patients (Salmenperä et al., 2001).

**Prevalence of CAM Use**

The estimated number of visits made to CAM providers was greater than the number of visits to all primary care medical doctors nationwide in 1990. The estimated 425 million visits to CAM providers surpassed the 388 million visits to all US primary care physicians in the same year (Eisenberg, Kessler, Foster, Norlock, Calkins & Delbanco, 1993). A later study showed that more than 40% of Americans had used at least one complementary therapy in 1998 (NCCAM, 2002).
these studies plainly show the significance of CAM use in the US. Already, CAM therapies are increasingly being offered in mainstream hospitals (Schenider, 2002). According to the American Hospital Association, about 15% of U.S. community hospitals in 2000 offered CAM therapies; almost double the amount two years earlier (Schenider, 2002).

CAM use is even more prevalent among cancer patients than in the general population (Henderson & Donatelle, 2004; Bennett & Lengacher, 1999; Shumay, Maskarinec, Gotay, Heiby, and Kakai, 2002). Sixty-three percent of the cancer patients used at least one nontraditional therapy in a NCI study (Sparber, Bauer, Curt, Eisenberg, Levin, Parks et al., 2000). This study had a convenience sample of 100 adult cancer patients.

Although in all the studies reviewed CAM usage was above 30%, there are high variations. Discrepancy in percentages might be attributed to methodological issues, such as the use of inconsistent CAM definitions (Gözüm et al., 2003; Moyad, 2001).

Cancer patients who use CAM are characteristically female, less than 65 years of age, more highly educated, and with larger incomes than nonusers (Jordan & Delunas, 2001; Lengacher et al., 2002). Additionally, women who use CAM are more likely to have undergone chemotherapy treatment according to one study (Lengacher et al., 2002).

CAM Therapies Used by Cancer Patients

Vitamin and mineral supplementation, prayer and spiritual healing, regular use of antioxidants, herbs and health foods, support groups, and massage at least once after diagnosis were the prevalent CAM therapies used among a group of breast cancer
CAM Use by Women With Breast Cancer

patients (Lengacher et al., 2002). The sample in this study consisted of a convenience sample of 105 predominantly Caucasian women.

Prayer, humor, and support group attendance were the therapies with the highest use incidence in a rural cancer population (Bennett & Lengacher, 1999). In this group of 53 patients, 87% were using at least one complementary therapy. Given the high prevalence of CAM use in this study, it is interesting to note that 40% of the respondents said that they would definitely not try acupuncture and none of the respondents were currently receiving this treatment.

Dietary therapies were considered the most effective CAM form against breast cancer by 41% of the women in one study (Salmenperä et al., 2001). Other therapies thought to be useful were prayer (39%), immunotherapy (use of an injection made from patients’ own tissue) (26%), and vitamin therapies (25%) (Salmenperä et al., 2001).

Herbal treatment in patients with cancer is prevalent among certain cultural groups (Gözüm et al. 2003; Simpson, 2003; Lam, 2001). A high percentage of Chinese women used herbs for prevention and treatment of breast cancer in two studies (Simpson, 2003; Lam 2001). Chinese herbal treatment includes more than 40 different herbs. Most times, herbs are used in mixtures and rarely as single agents (Beinfield & Komgold, 2003). One herb that has been used for thousands of years in China to stimulate the immune system and that has received particular attention in the West is astragulas membranaceus (Gözüm et al., 2003). Currently, this herb, known in China as Huangchi is being studied to test its use in ameliorating effects of chemotherapy treatment (Donnelly, 2003).
Similarly, herbal therapy was the most prevalent CAM therapy used by patients with cancer in a Turkish study. In this study, 41% of the respondents used a herb called stinging nettle leaf (*urtica dioica*) to complement traditional cancer treatment (Gözüm et al., 2003).

**Complementary Role of CAM**

Most patients who use CAM do so in a complementary form (Sparber, Bauer, Curt, Eisenberg, Levin, Parks et al., 2000; Lengacher, Bennett, Kip, Keller, LaVance, Smith et al. 2002; Canales & Geller, 2003; Henderson & Donatelle, 2004; Ben-Arye, Frenkel & Margalit, 2004). Also, it seems that many breast cancer patients support the integration of CAM into traditional treatment. A majority (57%) of breast cancer patients thought that CAM should be integrated with conventional treatments to treat breast cancer in one study (Salmenperä et al., 2001). Since CAM therapies often used by cancer patients such as prayer and humor have no known side effects (Bennett & Lengacher, 1999; Moyad, 2001) these therapies can be beneficial as a complement to traditional treatment (Moyad, 2001).

CAM therapies used to decrease stress and increase quality of life might be the most promising in complementing traditional treatment (Moyad, 2001; Sparber & Wootton, 2001). Stress and anxiety were the top main conditions for which specific CAM therapies were considered beneficial according to a survey of professional CAM organizations (Long, Huntley & Ernst, 2001). Other conditions that were believed to benefit most from specific CAM interventions were “in order of frequency, headaches/migraine, back pain, respiratory problems (including asthma), insomnia, cardiovascular problems and musculoskeletal problems” (Long, Huntley & Ernst, 2001,
p. 178). An example of a relaxation technique widely used by nurses and supported by research is therapeutic touch (Moore, 2005; Moyad, 2001; Sparber & Wootton, 2001). No risks are associated with this therapy (Moore, 2005). Furthermore, therapeutic touch addresses physical, psychological, and spiritual stress (Kelley, 2002).

CAM also generally takes a complementary role among cultural groups with strong CAM use (Simpson, 2003; Facione, Giancarlo, & Chan, 2000; Lam, 2001). In one study most of the women (who were Chinese) diagnosed with breast cancer felt that Traditional Chinese Medicine (TCM) played a large but complementary role in managing symptoms of breast cancer and promoting recovery. Most of the participants (n=20) “believed in and encouraged the use of TCM practices as complementary therapies, primarily for managing symptoms and maintaining health” (Simpson, 2003, p. 838). The TCM therapies women used in this study for breast cancer were qigong (chee-gong) and herbs. In a similar study, Chinese participants felt that TCM and traditional medicine complemented each other well because the strengths of one form of treatment could help the weaknesses of the other (Lam, 2001).

Reasons for CAM Use

To decrease side effects of traditional treatment. Cancer patients identify alleviating side effects of traditional treatment as one of the main reasons for CAM use (Badger, Braden & Mishel, 2001; Sparber et al., 2000). Side effects of traditional treatment are a significant part of the cancer experience, as shown by the numerous studies addressing this issue (Wengström, Häggmark & Forsberg, 2001; Garbee & Gentry, 2001; Ream, Richardson & Alexander, 2002; Donovan & Ward, 2005).
Sixteen side effects of breast cancer treatment were identified in a study. These side effects included “skin irritation, swelling, nausea, change in appetite, constipation, difficulty concentrating, fatigue, pain, difficulty sleeping, diarrhea, depression, vomiting, sore arms(s), hair loss, anxiety, and sore mouth” (Badger, Braden, & Mishel, 2001, p. 570).

Surgery, radiation and chemotherapy have specific side effects. Side effects of surgery include loss of breast tissue with subsequent scarring. Following a mastectomy, psychological effects might also include loss of body image (Ignatavicius & Workman, 2002). Common side effects of radiation include dryness, peeling skin, redness, and fatigue (Weaver, 2002). Additionally, turgor deterioration and skin thickening can be long-term side effects (Hart, 1999). Side effects of chemotherapy include alopecia, nausea and vomiting, mucositis, and skin changes. Chemotherapy also results in different degrees of immunosupression, anemia, and thrombocytopenia (Ignatavicius & Workman, 2002).

Nausea, depression, and fatigue are especially significant side effects of cancer treatment, representing a large portion of research in the experience of cancer (Maunsell, Brisson, & Deschenes, 1992; Munkres, Oberst, & Hughes, 1992 as cited in Badger, et al., 2001; National Cancer Institute, 2004; Garbee & Gentry, 2001; Richardson & Alexander, 2002; Donovan & Ward, 2005). Some studies indicate that these side effects are not managed well in traditional treatment.

Although the mean reported score of fatigue was 6.48 on a scale of 0-10, 56% of women receiving chemotherapy for gynecologic cancers reported never receiving recommendations for managing fatigue in one study (Donovan & Ward, 2005).
To increase control/participation. Uncertainty and its associated control loss is a major part of the experience of women with breast cancer (Hakhoe, 2004). Increasing control through use of CAM therapies is identified as a reason for CAM use in two studies (Sparber et al. 2000; Jordan and Delunas, 2001). Wanting to become an “active participant in care” can enhance coping by allowing the patient some control over the illness experience and affecting stress adaptation positively (Jordan & Delunas, 2001, p. 112).

Because one of our basic needs as humans is to have a sense of control over our lives (Shapiro & Astin, 1998) the loss of control associated with illness can be a frightening experience. An illness like breast cancer disrupts control over daily life, future, and even one’s own body (Shapiro & Astin).

A significant negative correlation between uncertainty and quality of life was identified in a study, involving 103 breast cancer survivors (Sammarco, 2003). This study used the Mishel Uncertainty Illness Scale, which is amply used in the nursing literature to study control loss (Sammarco).

To increase quality of life. Patients use CAM to increase their quality of life and strengthen their ability to cope with cancer (Canales & Geller, 2003; Henderson & Donatelle, 2004; Sparber et al. 2000; Moyad, 2001). Although few, if any, CAM therapies are proven to increase survival rates in breast cancer patients, the perceived effects of CAM in increasing quality of life are significant (Moyad, 2001).

Perception of low risk and illness prevention. The perception of low risk associated with CAM therapies and prevention of further illness were additional factors identified by cancer patients (Henderson & Donatelle, 2004; Henderson & Donatelle,
Some patients perceive that they have "nothing to lose" by trying CAM therapies because these therapies are not perceived as harmful (Badger, Braden & Mishel, 2001, p. 63). Prevention of further illness through boosting of the immune system by CAM was also identified as a reason for CAM use in one study (Badger, Braden & Mishel, 2001).

*Cultural influence.* CAM use is strongly associated with a Chinese cultural background (Facione et. al., 2000). Types of TCM used in breast cancer are qigong, herbs, acupuncture, acupressure, and moxibustion (Beinfield & Korngold, 2003). Positive aspects of Chinese medicine identified by Chinese-American women in one study in comparison with Western medicine was that it was less expensive, or patients could be seen right away instead of waiting for an appointment (Facione et. al., 2000). Additionally, Chinese medicine was seen as a more natural approach than traditional medicine, reestablishing harmony in the energy within the body in a similar study (Lam, 2001).

Women in both studies also cited perceived strengths of traditional treatment. The main identified advantages of traditional treatment were that it provided a faster recovery (Facione et. al., 2000; Lam, 2001), was better to treat some diseases such as flu, and was more convenient to use than TCM (Lam, 2001). However, traditional medicine was also perceived as potentially weakening because of the side effects of drugs or surgery (Lam, 2001).

The concept of qi is elemental to TCM. Qi (also spelled Ch’i) is believed to flow within the human body along a series of interconnected channels called meridians (Beal, 2000). Qi is considered as "life energy" or "vital force" and many TCM therapies are
used to restore qi to the body, mind, and spirit (McCaffrey & Fowler, 2003). Illness in traditional Chinese medicine is considered to be the result of imbalances in the movement of qi within the body.

*Lack of Disclosure About CAM Use*

In general, few patients mention their CAM use to traditional health care providers according to many studies (e.g., Henderson & Donatelle, 2004; Gözüm et al. 2003; Lengacher et al. 2002; Sparber et al., 2000, Salmenperä et al., 2001, Eisenberg et al., 1993). The low prevalence of discussion between health care providers and cancer patients about the use of CAM therapies is a problem. In addition to concerns related to interaction between CAM and traditional medicine, ineffective communication regarding CAM use can potentially hinder the development of a working and caring relationship with health care providers.

Only 26% of the cancer patients had discussed the use of complementary therapies with their physician and only 6% with the physician and nurse or with the nurse only in one study (Salmenperä et al., 2001). In another study, 46.5% of the cancer patients using CAM therapies discussed CAM use with their health care professionals (Gözüm et al., 2003). In the general US population, 72% of respondents did not mention their CAM use with traditional medical doctors in a 1990 survey (Eisenberg et. al, 2003).

CAM discussion with physicians was particularly low regarding traditional and ethnic medicines in one study of women with breast cancer (Lengacher et al., 2002). Of 12 people in this study who used these therapies (out of a sample of 105), none discussed them with their physician.
In another study, 57% of cancer patients reported that their physicians did not ask about CAM therapies (Sparber et al., 2000). However, for a significant percentage (62%) of the patients in the study it was important to talk to their physicians about CAM. Interestingly, most of the patients using CAM (82%) believed that physicians would most likely support their CAM use. This study was based on a sample size of 100 cancer patients. In a contrasting study, 76% of physicians responding to a survey said they asked their patients about CAM use (Milden & Stokols, 2004). This study had a sample number of 45 physicians in California.

Nurses’ Perceived Barriers to Effective Communication

There are few studies related to communication between nurses and breast cancer patients. Nurses identified stress and lack of time as barriers to effective communication in one study (Ödling et al., 2002). Some nurses mentioned uncertainty about the patients’ desire to talk, and uncertainty of how to respond as barriers to effective communication. This study indicated that nurses want to communicate with patients and consider it extremely important. The patients’ need to talk and receive information was the most important patient need identified by 31 nurses on a surgical ward taking care of breast cancer patients. However, there were few self-experienced examples of implementing ways to meet this need to talk (Ödling et al., 2002).

Health Care Providers’ Attitudes Towards CAM

Nurses show a significant interest in CAM therapies (King, Pettigrew, & Reed, 2000). Some nurses employ CAM in their own lives and with patients (King et al., 2000). However, nurses express lack of time as a deterrent to implementing CAM therapies in
their nursing practice they considered beneficial (e.g., art, exercise, humor, relaxation) (Hessig, Arcand & Frost, 2004).

Prayer (81%), diet (74%) and herbal products (41%) were the main CAM therapies used by nurses in a study (King et al., 2000). In this study, authors surveyed a random sample of 467 registered nurses living in the State of Ohio. Diet (38%) and prayer (30%) were the CAM therapies used by these nurses most frequently with their patients.

*Perceived Negativity from Health Care Providers*

Cancer patients perceived a negative opinion from traditional health care providers regarding CAM therapies in one study (Salmenperä et al., 2001). About half of the participants felt that physicians and nurses had negative opinions of CAM (57% and 40% respectively) in a Finnish study (Salmenperä et al., 2001). The sample in this study included 216 breast cancer and 190 prostate patients. The authors in this study concluded that negative attitudes among health care providers towards CAM might cause patients to feel guilty about using these therapies and therefore conceal this information from physicians and nurses. Yet, the ability of nurses to discuss CAM use with patients in a nonjudgmental manner is of critical importance. By opening up discussion about CAM use, nurses are better able to assess patients’ coping skills and decision-making ability (Sparber et al., 2000).

*Knowledge About CAM*

Although there are an increasing number of studies related to the knowledge of health care providers about CAM therapies, studies about patients’ knowledge level regarding CAM are nonexistent or extremely rare. CAM knowledge of health care
providers has direct influence in the provision of accurate information and appropriate referrals for CAM therapies upon patients' requests.

Patients' expectations of CAM knowledge among health care providers are not met according to some studies. A high percentage (83%) of patients felt the healthcare providers should be able to provide information on CAM therapies in one study, but this information need was not met (Salmenperä et al., 2001). Unfortunately, the literature points out that as CAM interest increases, even among traditional practitioners, the availability of professional education about CAM remains low (Sohn & Loveland, 2002).

Nurses' professional education about CAM was lower than their interest in numerous studies (Hessig, Arcand & Frost, 2004). Although 83% of nurse practitioners recommended CAM to their patients, only 24% reported formal nurse practitioner education as a source of knowledge about these CAM treatments in one study. Over 60% of the nurse practitioners relied on personal experience as well as lay and professional journals for knowledge related to CAM (Sohn & Loveland, 2002).

Nursing students also seem to have limited knowledge in spite of positive opinions of CAM therapies as shown in a study done in Turkey (Uzun & Tan, 2004). A high percentage (64.5%) of nursing students desired CAM to be integrated in the nursing curriculum and used in clinical practice (62.3%). The sample included 276 nursing students.

Sixty-one percent of physicians did not feel sufficiently knowledgeable about CAM safety or efficacy in one study (Milden & Stokols, 2004). A high percentage (81%) of the physicians in this study wanted to receive more education on CAM modalities.
These were results from a survey mailed to a random sample of California physicians. The response rate (about 25%) was low and included 51 physicians.

The relatively low knowledge level of nurses in spite of increased interest, implicates the possibility of some nurses practicing outside the American Nurses Association Standards of Clinical Nursing Practice by providing inappropriate CAM referrals. (King et al., 2000). These standards indicate that making appropriate referrals is part of nurses’ accountability for client care and responsibility for continuity of care.

Nurses are in the position of encouraging patients to discuss their use of CAM therapies with health care providers, and providing accurate information about resources regarding CAM. In order to fulfill this role, the literature shows that nurses need to become more knowledgeable in regards to CAM. The lack of knowledge regarding CAM among nurses indicates the need to incorporate CAM themes into educational curriculum. However, CAM knowledge is not low only among nurses and nursing students.

Summary

Even though the use of CAM therapies is significant within the cancer population, sound research regarding CAM use by breast cancer patients is limited, especially within the nursing literature. CAM use among breast cancer patients indicates that CAM is used in a complementary form and as a way to promote coping (by decreasing stress and lessening side effects of traditional treatment) and to increase control over the illness experience. The existing research concerning CAM highlights the need for effective communication between health care providers and patients. The fact that patients are more likely to conceal their CAM use from health care providers more often than not is a sign that steps should be taken to create more effective communication about CAM. It is
also important for nurses to assess the reasons a particular patient uses CAM to identify unrealistic expectations of either CAM or traditional treatment.
Methodology

Design

Given the complexity, subjectivity, and unpredictability of human experience, gaining a complete understanding of it seems beyond reach. Fortunately, phenomenology, a qualitative methodology, gives nursing research a systematic approach to analyzing reality, phenomena, or “things” that make up experience, in this case, the experience of patients with breast cancer who use CAM methods. With phenomenology, it is possible to begin to understand what women with breast cancer go through. Because any experience affects directly only the person with the experience, it is difficult to “know what it is like” unless we ourselves have direct experience with breast cancer. Moreover, experience is highly personal and dependent on the individuals’ past experiences, beliefs, and values.

Clearly, using phenomenology to arrive at the description (Husserlian phenomenology) or interpretation (Heideggerian phenomenology) of phenomena is easier said than done. The challenges of understanding phenomenology itself and its different approaches remain. As a philosophical practice, phenomenology is extremely extensive and complicated. However, a basic understanding of phenomenology is critical to placing a research study within the appropriate phenomenological framework, and for the study to be even referred to as phenomenological research.

Phenomenology is a relatively modern movement within the discipline of philosophy. Prior to the development of phenomenology as a method, Immanuel Kant wrote about the defining aspect of the human mind structure to experience what is perceived as reality (i.e., phenomena). According to Kant, humans have a limited
rationality because that which is outside the perceptive capabilities of the human structure is unknowable (J. Ries, personal communication, November 5, 2004).

With the purpose of studying meaning following a rigorous scientific format Edmund Husserl first introduced “phenomenology” as a method in 1900 (Leininger, 1984). Husserl, the father of phenomenology, introduced the elusive concept of bracketing as a way to obtain a “pure seeing” (J. Ries, personal communication, November 5, 2004). Bracketing demands that the researcher suspends his or her own beliefs and interpretations in order to portray an experience just as the participant perceives it. For bracketing to be effective, the phenomenological researcher must go ‘back to the things themselves’ as Husserl stated and avoid interference of personal biases (as cited in Wall, Glenn, Mitchinson, & Poole, 2004, p. 20).

Following Husserl, Heidegger and others expanded the concept of phenomenology by addressing the inescapability of interpretation. For Heidegger, a “pure seeing” is unattainable and the best an interviewer can do is limit the effects of preconceptions by becoming aware of them (J. Ries, personal communication, November 5, 2004). Bracketing, for Heidegger, does not serve the purpose of getting rid of presumptions but it is instead a process of recognition of those assumptions; therefore, Heidegger’s hermeneutical approach does not contradict the use of bracketing. An interviewer doing phenomenological research will always bring his or her own world to the interview, but the more conscious this intrinsic limitation is, the less likely it is to produce biased findings. Heidegger’s phenomenology is referred to as interpretive phenomenology because it seeks to take somebody’s description of experience and gain an understanding of it through guided interpretation (Priest, 2004). In this study, the
researcher monitored her own limitations in addressing interviews with a unique perspective, the result of past experiences and attempted to interfere with the process of the interview at a minimum.

*Purpose of bracketing.* This critical process aids the researcher in becoming aware of previous experiences, beliefs, and attitudes that might bias the research course. However, how bracketing is actually carried out is not well defined, and there are no set number of steps or guidelines to follow (Priest, 2004). Bracketing instead of a clear guideline is rather a developmental skill and a "psychological orientation towards oneself (Priest, p. 5)."

*Avoiding bias.* Considering these limitations, in this study, a conscious effort was made to avoid biased results. Bracketing was practiced while doing the interviews by engaging in active listening and refraining from letting the researcher’s experience interfere with the participant’s descriptions. The researcher attempted to carry out the interviews in a neutral attitude and form in order to allow participants to express their experience as freely and independently as possible from the interviewer’s preconceptions. The researcher used open-ended questions such as “tell me about your use of CAM” and “What was that like?” Following is a description of the researcher’s experience in relation to CAM use in an effort to identify preconceptions, which might interfere with the study.

*Bracketing of Nayabei Vanwoerkom.* The researcher implements CAM methods in her own life and is aware of potential bias to support CAM practices in others. The three CAM methods used are yoga, qigong and Vipassana meditation. The researcher has
practiced all three modalities for about three years, focusing primarily in Vipassana meditation.

The researcher perceives the practice of this meditation technique invaluable. Personal perceived benefits from this technique include greater sensitivity to changes in one’s body, greater patience with oneself and others, mind and body relaxation, and a gradual acceptance of reality as experienced through the framework of the mind and physical body. It is personally perceived as a challenging practice that requires discipline, but which has strong benefits.

Procedure

Participants. The criteria to participate in this study were to have undergone traditional treatment for breast cancer and have used at least two types of CAM as defined by the NCCAM for two months or longer. The three women who formed the purposive sample of this study were Caucasian and between 50 and 60 years old. They used CAM while receiving traditional treatment (surgery, chemotherapy, and radiation) for breast cancer. All three women had consults with and received treatment from a naturopathic doctor, primarily in the form of nutritional supplements and acupuncture.

Participation was voluntary and the women were contacted through naturopathic clinics from the area and by word-of-mouth. The interviews were held in the women’s houses or in the college, whichever they expressed as their preference.

Ethical considerations. Adherence to confidentiality and the establishment of a trusting relationship with participants were ethical aspects taken into consideration. For all the interviews, informed consent was obtained. The consent form stated the purpose and risks of this kind of study and the confidential nature of the interview. The
participants’ names were omitted from the transcribed interviews, which were identified only by a code number. In the discussion, the pseudonyms “Mary”, “Judy” and “Alice” identify the participants to conserve confidentiality. Also, the importance of a trusting relationship between the interviewer and the participants was considered. Presenting the purpose of the study and answering the participant’s questions honestly helped in establishing trust.

**Design.** Data were collected through open-ended semi-structured interviews recorded on audiotape. Demographic and clinical data was recorded in a short questionnaire. This data included the following: age, marital status, educational level, race, traditional treatment underwent, and main CAM therapies used. After transcribing the interviews, emerging reasons to use CAM were found, along with the perceived benefits or downsides of those therapies.

**Data analysis.** The data were translated into themes using Colaizzi’s method. This method specifies steps to follow in obtaining, analyzing, and verifying research data. The final step of verifying one’s findings with the participants and to modify the descriptions according to their comments if necessary characterizes Colaizzi’s method from other phenomenological methods (Priest, 2004).

**Steps in Colaizzi’s method** (Fain, 2004, p. 231):

1. Describe the lived experience under study.
2. Collect participant descriptions of the lived experience.
3. Read all participants’ descriptions of the lived experience.
4. Extract significant statements.
5. Articulate the meaning of each significant statement
6. Aggregate the meanings into clusters of themes.

7. Write an exhaustive description.

8. Return to participants for validation of the exhaustive description.

8. Incorporate any new data revealed during validations into a final exhaustive description.

Limitations

Since the results of many CAM therapies are often based on patients’ perceptions, outcomes are subjective and difficult to quantify. Indeed, “CAM cancer research faces several methodological difficulties in the aspects of study design, setting, recruitment, inclusion criteria, and blinding” (Ben-Arye, Frenkel & Margalit, 2004, p.54). Given the personal nature of the experience of breast cancer in relation to CAM use, phenomenology is a highly fitting research method.

Simultaneously, phenomenology as a method has general limitations such as difficulty in replicating a descriptive study of experience, its subjectivity, possibility of researcher’s biases interfering with the study, and the fact that this research is based on the participants’ ability to recall past events (Barritt, Beekman, Blecker, & Mulderij, 1982). Earlier, the bracketing process was addressed in an effort to decrease the interference of the author’s experiences with this project.
CHAPTER 4

Results

Although traditional medicine was considered necessary and important, the participants perceived real value in CAM and associated its use with increased ability to cope with the multiple stressors of cancer and cancer treatment. Although it was especially difficult for the participants to describe the effect of CAM therapies used to relieved spiritual distress, these CAM therapies were perceived to have intrinsic value.

Coping with Stressors

*Coping with spiritual distress.* Spiritual distress related to fear of dying was a major challenge for the participants. As they confronted a potentially terminal illness, the women expressed finding greater spiritual meaning in their lives and developing a sense of connection with themselves, others, the environment, and a higher power. The participants also expressed developing greater awareness and appreciation of the present moment.

*Coping with diagnosis and difficult feelings.* For the participants, the initial diagnosis as well as the treatment brought difficult emotions to cope with including shock and disbelief, fear, anxiety, and anger. Fear was one of the first elements in the experience of breast cancer.

Alice became afraid when a mammogram showed calcifications and she was asked to return to the clinic in 3-6 months to repeat the test. For Mary, fear an anxiety had an effect in coping and being able to retain information from the diagnostic interview. However, this information conveyed by the physician was critical because Mary needed to make quick decisions regarding treatment. To cope, she had a friend accompany her to
doctor appointments and take notes that she could review after the appointment to help her make decisions.

Awareness of her increased risk of breast cancer did not ameliorate the shock of the diagnosis for Judy. Although her mother had died of cancer, the diagnosis came as a complete surprise. According to the participants, other sources of anxiety were treatment administration and the financial impact of cancer treatment.

*Coping with side effects.* Other significant side effects of cancer and traditional treatment included anxiety, muscle pain and numbness, and nausea. However, one the side effects that disrupted the women’s lives the most was fatigue.

*Overcoming Negativity*

*Desiring enhanced communication with traditional practitioners.* A desire for greater communication with traditional practitioners was present among all the women. In different forms, the participants expressed their hope for greater engaged listening and communication of caring from traditional practitioners.

*Perceived negativity from traditional practitioners.* The participants also mentioned communication difficulties with traditional providers regarding CAM use. They described communicating about CAM use with traditional health care providers as challenging and felt that traditional practitioners in general felt negatively about CAM use.

*Evaluating Limitations of Traditional Medicine*

The women shared the feeling that medical treatment was limited in knowledge and interventions of breast cancer. For Alice and Judy, diagnosis of the cancer as well as
determination of the appropriate treatment was inconsistent across different traditional practitioners. This inconsistency decreased their confidence in traditional treatment.

Taking an Active Role

Increasing quality of life. CAM use was related to a sense of greater wellbeing among the women. Judy perceived the options given by the naturopathic doctor as a positive complementation to traditional treatment that helped her “feel better.” For her, CAM use was related to choosing things in her life that felt “right” for her and made her happy. The women perceived CAM as useful in providing additional support in coping with breast cancer.

Self-empowerment. Self-empowerment was a way to take an active role in the experience of breast cancer and all the uncertainty associated with it. The initiative of the participants to incorporate CAM use into their treatment was related to promoting a better outcome and regaining normalcy and control. Due to a limited number of options within traditional treatment and the sense of being “told what to do”, the participants perceived CAM use as strengthening and helpful in their ability to “make it through” cancer treatment.

Alleviating Side Effects

The women felt that traditional treatment is necessary but harsh on the body with significant side effects. They sought different CAM modalities to help manage the side effects of traditional treatment and cancer. CAM was generally seen as a “positive” and strengthening option although there were variations in the perceived benefits and applications of some CAM therapies.

All the women shared their use of supplements with oncologists to prevent
interactions. Mary felt that chemotherapy and the antioxidants she used actually “enhanced one another.” It is important to note that not all the women found the same therapies beneficial. Mary and Alice deemed visualization, which all women used, helpful, but Judy was uncertain if this CAM intervention provided significant benefits.

*Types of CAM Used by Participants*

The participants used a wide variety of CAM therapies. All the women had consults with and received treatment from a naturopathic doctor mainly in the forms of nutritional supplements and acupuncture. The first participant, Mary, used dietary supplements, acupuncture, energy therapies (qigong, reiki, and therapeutic touch), a solution prepared by a Native American man, and massage. The second participant, Judy, used supplements, acupuncture, massage, and prayer. Alice used supplements (antioxidants, vitamins E and C, and selenium), herbs (*arnica montana*), acupressure, acupuncture, reiki, visualization, prayer, massage, and magnet therapy.
CHAPTER 5

Discussion

The participants in this study perceived CAM use of certain therapies as completely compatible with traditional treatment and beneficial in helping them cope with breast cancer and cancer treatment. There were three main reasons identified by the participants in deciding to use CAM: evaluating the limitations of traditional medicine, taking an active role, and alleviating side effects of cancer and traditional treatment. Just as the side effects of cancer and traditional treatment were significant in the participants’ experience, managing those side effects was also a significant reason for using CAM. CAM use was distinctly characterized by a “taking charge” stance through which the women perceived increased quality of life and self-empowerment.

Coping With Stressors

Clearly, the participants’ experience of breast cancer was complex and included all areas of their lives. Stressors perceived as significant in this study, namely spiritual distress, anger, fear, anxiety, fatigue, muscle pain and numbness, and nausea, were similar to those identified in other studies that describe patients’ experience with breast cancer. According to the American Cancer Society, the concerns patients with breast cancer and survivors most often express are the following:

- Fear of recurrence, chronic and/or acute pain; sexual problems; fatigue; guilt for delaying screening or treatment, or for doing things that may have caused the cancer; changes in physical appearance; depression; sleep difficulties; changes in what they are able to do after treatment; and the impact of cancer on finances and loved ones (American Cancer Society, 2002, ¶ 12).
Although a life-saving intervention, a mastectomy can have detrimental effects on a woman’s identity. Becoming aware of the change in physical appearance after a mastectomy was a shock-provoking experience for Alice. However, the significance of her lost breast became especially apparent after she had reconstructive surgery.

According to Alice, the first thing she did, unplanned, almost as an automatic reflex, when the anesthesia wore off, was to look at her chest. Having two breasts again gave her a sense of completeness. She described her experience as follows:

I said 'oh I've got two again, I'm back!' and I remember saying that and then just kind of going back into the fog . . . it just didn't occur to me until that moment, just how much my breasts actually meant to me, to realize that having two again, having cleavage again, made me sort of whole again.

Spiritual distress, which was closely associated to fear of dying, was a significant aspect of the participants’ experience. As in this study, fear of dying was characteristic of spiritual disequilibrium in a phenomenological study involving women with breast cancer (Coward & Kahn, 2004). However, in Coward and Kahn’s study, in addition to fear of dying, a sense of aloneness was characteristic of spiritual disequilibrium.

Resolution of spiritual distress involved what Alice called “spiritual housekeeping”, the development of a sense of connection with self, others, and a higher power. Other studies identify this sense of connection as beneficial in coping with spiritual stress (Coward & Kahn, 2004; Albaugh, 2003). According to the participants, some CAM therapies, primarily prayer, promoted resolution of spiritual disequilibrium.

In contrast to this study, other studies did not highlight focusing in the present moment as a key factor in the resolution of spiritual distress among breast cancer patients.
patients. For the women in this study, focusing on the present moment was primary in coping with the uncertainty and fear of death related to cancer. All three participants expressed the importance of appreciating what they were able to do in the present and enjoying life also in the present. Judy expressed, “It's important, what I do today, each day, because I might not be here in two days.” Similarly, Mary found relief from spiritual distress and anxiety by focusing in the present moment.

As her mind dwelled in the uncertainty and fear associated with the cancer and the question “am I going to die?” Mary challenged herself to change her thinking patterns. She found that uncertainty vanished in the present moment. Concentrating in her ability to care for herself and enjoy life in spite of the cancer and the uncertainty of the future helped her cope with spiritual distress. Mary described her experience eloquently:

Everything imaginable came to my mind, and the worst things, never the good things, never . . . I thought 'you know what? I don't like this, I don't like that too much negativity.' I thought ‘all right, you are going to sit down, and you're going to change your thought patterns’ . . . every thought that came in, ‘What if this, what if that?’ and I said '[Mary], what if? What do you know right now? Is it a what if? What do you know right for this minute, what for this day?’ So I said, ‘Well, the sun's out, I'm a little tired’. ‘Well, can you scratch your head?’ ‘Yeah’, ‘Can you dress yourself? ‘Yeah,’ ‘Can you care for yourself?’ ‘Yeah’ ‘So, what is the big deal!’ and I began that way and what happened is when I began to think ‘am I going to live? Am I going to die?’ I always go back to the present, the now, and that took all that away for me, and I was better able to cope with what was going on.
In addition to spiritual distress, stressors deemed significant by the participants were anger, fatigue, fear, anxiety, muscle pain and numbness, and nausea. For Mary, receiving treatment was perceived as invasive and anxiety provoking. She said, “When I began chemotherapy, absolutely, there was anxiety, oh man... some people have shunts put into them... and you’re all hooked up to the IVs and all this stuff is running into your body.”

Anger was another significant aspect of the experience with cancer. In a phenomenological study, the experience and expression of anger among breast cancer patients was linked to helplessness and a desire to increase control (Garrison, 1995). Interestingly, in the current study, a desire to increase control was strongly liked to CAM use.

Although anger was a major feeling in the experience of cancer, sometimes the source of this anger was difficult to locate. According to Mary, her anger was directed “at the cancer.” She felt angry because she could not find a reason for the cancer being in her body. In Judy’s case, she felt angry because she was diagnosed with breast cancer in spite of rigorously having followed medical advice to decrease her risks. Her diagnosis of cancer was associated with a feeling of betrayal that decreased over time. Also, because her mother died after the cancer recurred, Judy disliked being referred to as a survivor. She expressed her feeling as follows: “My mom survived the surgery but seven years later she didn't survive, and you know, it's like ‘at what point are you a survivor?’... It may come back still.”

Given its subjectivity, it might be easy to disregard fatigue as a minor side effect. However, as expressed by the participants, fatigue was truly detrimental to all aspects of
their lives. Mary prized her self-reliance before the cancer diagnosis and found difficult to cope with her lack of energy. House chores took a toll on her. She was able to cope by accepting help from her friends in cleaning her house and found this support comforting and extremely helpful.

At the time of her chemotherapy treatment, Alice was also working full time making coping with fatigue even more difficult. She scheduled her chemotherapy treatment on Fridays to recover over the weekends. However, she expressed, “there were a couple of times I probably shouldn't have been there on Monday.”

Overcoming Negativity

The women in the study perceived general negativity from traditional providers regarding CAM use and shortcomings in communication of a caring approach. However, literature regarding breast cancer patients’ perception of traditional practitioners’ attitude towards CAM is not readily available.

In Alice’s case, even though she perceived she had a good relationship with the oncologist and held him in high esteem, she felt it was better to avoid disclosing her CAM use to avoid raising negativity and opposition from him. Mary described her perception of the health care provider’s reaction to her use of supplements as follows: “I’m sure they thought I was nuts!” Similarly, Judy mentioned that physicians would “roll their eyes” when she described the supplements she was taking. However, Judy also felt that one physician was accepting of her CAM use. This physician wrote her a prescription for massage and supported her use of supplements.

All the participants hoped for better communication with physicians. Judy felt that oncologists used active listening sparingly. She said, “In terms of sitting there and putting
up with me, I mean, they [oncologists] do that [laughter].” However, she felt that “real listening” did not occur frequently.

The participants attributed health care providers’ limited use of active listening and emotional support to the excessive demands put on them to do much in little time. Mary perceived the lack of time of traditional providers as detrimental to their ability to listen and offer understanding care. She felt that because of the strenuous demands placed on them, physicians’ main focus was to “get things done.” Mary expressed, “They [medical doctors] are so engrossed in ‘we gotta get this done and I gotta do this, this, and this’ and they are pretty much overworked . . . big time.”

The perception of the women in this study is congruent with identification of the need for better communication between breast cancer patients and physicians in other studies (McWilliam, Brown & Stewart, 2000). However, in one study, CAM use was not correlated with perceived negativity or dissatisfaction with traditional treatment. Almost all of the women in this study “reported high levels of trust in their physicians and were very satisfied with how much their doctors listened to them and with their overall conventional medical treatment for breast cancer” (Henderson & Donatelle, 2004, p. 58). Although studies on communication between nurses and breast cancer patients are few, stress and lack of time were self-reported barriers of nurses to effective communication in one study (Ödling et al., 2002).

To Mary, the use of touch and listening to convey caring were extremely important and added a spiritual dimension to the relationship with health care providers. However, according to Mary, communication involving active listening and the use of
touch was seldom experienced. This hope for better communication with physicians was connected to a strong sense of vulnerability. She described her experience as follows:

I guess it's like I might have been a little child that fell down, got a real bad scrape, and I wanted to be held, I wanted to be told that I was going to be okay, and I wanted to be loved, and hugged, and, and, and just kind of cuddled over, and you don't get that from a medical doctor, at least I didn't.

According to Mary, naturopathic doctors and nurses employed touch more often than traditional doctors to communicate a caring attitude. To Mary, her friends’ ample expression of caring in the form of active listening and touch “was worth its weight in gold.”

Evaluating Limitations of Traditional Medicine

Studies do not specifically cite patients’ perceived limitations of traditional medicine as a reason for CAM use. However, in the current study, all the women cited limitations of traditional medicine, including challenges in communication, as a reason for complementing their treatment with CAM therapies. The participants perceived that traditional medicine did not have “all the answers” and that by using CAM therapies, they could increase their chances of survival.

Their perception of inconsistency among different traditional practitioners regarding diagnosis and treatment of breast cancer shook Alice and Judy’s confidence in using traditional treatment exclusively. According to Judy, the provider who evaluated the mammogram felt that she had cancer. However, the provider who did the ultrasound said, “No, there’s nothing here.” An additional health care provider said, “I think we can wait and see.”
In Alice’s case, the cancer was missed numerous times in diagnostic tests. She felt that although care providers have cancer patients’ best interest in mind, cancer is “much an unknown.”

_Taking an Active Role_

This study’s finding that CAM use is related to taking an active role and enhancing coping is supported by the literature (Sparber et al., 2000; Jordan and Delunas, 2001). An internal locus-of-control is generally linked to better psychological adaptation to cancer and lower depression (Livneh, 2000). In contrast, disengagement strategies such as denial and problem avoidance are associated with maladaptive coping (Livneh, 2000).

Taking an active role was identified as a major reason for increased use of CAM among the general population in a _Journal of the American Medical Association_ study. Cited reasons for the increased popularity of CAM were as follows: “a rise in the prevalence of chronic disease, an increase in public access to health information, reduced tolerance for paternalism, an increased sense of entitlement to a quality of life, declining faith that scientific breakthroughs will have relevance for personal treatment of disease, and an increased interest in spiritualism” according to Jonas V. in a 1998 article (p. 1616 as cited in Henderson & Donatelle, 2004).

CAM therapies are also identified as a strong tool in increasing quality of life (Henderson & Donatelle, 2004). However, in a contradicting study, CAM use was correlated with greater psychosocial distress and worse quality of life among women after surgery of breast cancer according to an article by Burstein et al. in a 1999 article (as cited in Sparber & Wootton, 2001).
Control loss was a significant issue in the women’s experience in this study partly because of the few options of treatment available. Judy perceived traditional treatment as rigid. She said, “It’s surgery- chemo- radiation, you know, and there was no talk of options.” CAM use increased the women’s range of options.

The women perceived CAM use as empowering since these were therapies they sought out and initiated themselves. Along an increased sense in control, there was an increased sense of responsibility. Referring to her CAM use, Judy expressed, “I feel like I do what I think is good for me, and if it turns out to be wrong, I did the best I could.”

Alice also expressed this sense of ownership of her own health. When the breast cancer reoccurred, she decided to use antioxidants against the oncologist’s advice. During the first cancer treatment, she stopped using antioxidants, as the oncologist advised, but during the second treatment she felt differently. She said “It all boils down to this is my body and be it right or wrong I'm going to try to do the best thing for myself.” Mary also “took charge” of her treatment by asking the traditional and the naturopathic doctors to work together and share information related to her treatment to promote a better outcome.

Alleviating Side Effects

Alleviating the side effects of cancer and cancer treatment found in this study, namely fatigue, muscle pain and numbness, nausea, spiritual distress, anger, fear, and anxiety, were strong reasons to use CAM. The perceived significance of side effects of traditional treatment for cancer patients is prevalent in the literature (Wengström, Häggmark & Forsberg, 2001; Garbee & Gentry, 2001; Ream, Richardson & Alexander, 2002; Donovan & Ward, 2005). Alleviating side effects of traditional treatment is one of
the main reasons cancer patients identify for using CAM according to numerous studies (Badger, Braden & Mishel, 2001, p. 63; Sparber et al., 2000).

CAM use may help nurses strengthen the interventions for reducing nausea according to one study (Badger, Braden, & Mishel, 2001). According to the authors, because there are few community-based oncology support programs that give access to pharmacologic agents, alternative therapies can become a helpful part of intervention procedures. Since an alarming 60% of patients who undergo chemotherapy treatment continue to experience nausea and vomiting in spite of the use of antiemetic drugs (Collins & Thomas, 2004), it is important to consider the role of CAM therapies in ameliorating this side effect.

Herbal medications, Chinese medicine, qigong, and visualization were CAM therapies used by women with breast cancer to aid recovery from radiation treatment in a qualitative study (Wengström, Häggmark & Forsberg, 2001). However, studies provide limited support in the effectiveness of antioxidant supplements to reduce risk of breast cancer recurrence and breast cancer-related mortality among postmenopausal women (Fleischauer, Simonsen, & Arab, 2003).

Therapies recommended by the naturopathic doctor helped Alice find relief from a chemotherapy related oral fungal infection. Lymphedema, muscle pain, and numbness were additional side effects targeted by CAM therapies. Massage, acupuncture, and qigong were used to relieve these side effects. All the women in this study used lymphatic manual drainage, a specific form of massage. Manual lymphatic drainage is beneficial in the treatment of lymphedema according to one study (Williams, Vadgama, Franks & Mortimer, 2002). Acupuncture was also used by Mary to deal with radiation-
induced fatigue and by Alice to decrease nausea after surgery.

However, Judy felt unsure if the acupuncture was the reason behind her relief of numbness in her arm or whether her arm was finally gaining back sensation on its own. She did point out that “after that second acupuncture treatment it [sensation in her arm] was noticeably different.” Judy also felt uncertain if the supplements she took through all the time she received chemotherapy made a difference or not. She felt that she “had nothing to judge it by” since she took them throughout her treatment.

Acupuncture is effective in the management of chemotherapy-associated nausea and vomiting and in controlling pain associated with surgery according to a panel of experts at a NIH Consensus Conference in 1997 (NCCAM, 2004). The effectiveness of acupuncture and acupressure in reducing chemotherapy-associated nausea is supported by numerous studies (Collins & Thomas 2004; Dibble, Chapman, Mack & Shih, 2000). Acupuncture involves stimulation of anatomical points on the body by inserting thin metallic needles in the skin (NCCAM, 2004). Acupressure and acupuncture are similar therapies. However, acupressure involves the use of the hands, fingers, and/or thumbs to apply pressure in specific points along meridians (Beal, 2000). Both acupuncture and acupressure are used in traditional Chinese medicine to restore energy balance, or qi balance, within the body (Collins & Thomas, 2004).

The participants did not deem all therapies equally helpful. Although both Mary and Alice found visualization helpful, Judy did not. Alice felt certain about the benefits of prayer and visualization. She said, “There's no doubt in my mind that prayer is significant.” At the same time though, she expressed that it was difficult to “measure” the benefits of prayer. Judy used prayer in her life but did not find visualization helpful after
trying it a few times. She felt that it was relaxing, but wondered if it was significantly beneficial.

Mary used visualization, touch therapy, and reiki therapy to help her decrease anxiety. She visualized the cancer encapsulated by oxygen and expelled during exhalation. She felt this technique was helpful in decreasing her anxiety before traditional treatment appointments. Alice used a similar form of visualization by focusing in the cancer “being destroyed, beaten back, replaced by healthy tissue.” She felt that this form of visualization was “strengthening, supportive, and spiritually uplifting.”

Although all the women perceived benefits from CAM use, differences in perceived benefits highlight the individuality of patients in choosing CAM. According to Judy, if another “serious illness” occurred, she felt sure she would request CAM treatment from the naturopathic doctor. At the same time, she felt that the decision to use CAM was highly personal and that individual patients must decide on their own if CAM is “right” for them. This statement expresses the importance of considering the individuality of patients in relation to CAM use and coping. One study pointed to the importance of carrying out individual assessments in relation to coping strategies (Wengström, Häggmark & Forsberg, 2001).

Summary

Chemotherapy, radiation, and surgery are life saving forms of treatment for breast cancer. Over the years, these interventions in addition to more widely available screening have saved countless numbers of women’s lives. At the same time, as the women in this study concluded, traditional medicine is limited in what it knows and can do about breast cancer.
Exploring CAM methods to enhance traditional treatment and to complement areas where traditional treatment might offer limited support can enhance women’s coping abilities by encouraging an approach coping style as opposed to an avoidance style. Keeping in mind that further research regarding some CAM therapies, especially biologically based therapies, is needed to establish their safety, CAM therapies aimed at promoting spiritual and emotional coping are promising.

Most certainly, cancer treatment solely based on CAM therapies, ignoring the value of the life-saving interventions of traditional medicine, is imprudent. However, rigid skepticism to the point of completely dismissing the potential of some CAM therapies to enhance quality of life is unsuitable.

About eight years ago, integrated medicine, the combination of traditional medicine and complementary therapies was considered the future of health care according to Shrifffs, 1996 (as cited in King et al., 2000). This prediction seems to be realizing, especially in the area of chronic illnesses (Underwood, 2002). As prevalence studies show, CAM use is here to stay.

It is the responsibility of health care providers as well as of the general public to become knowledgeable about commonly used CAM therapies and to increase communication related to CAM to promote a positive outcome. However, it is predominantly traditional health care providers’ duty to offer sound information to patients and to suggest appropriate CAM referrals.

Potential and Future Research

CAM as a single unit is an incredibly broad group. Specific studies related to the effects and characteristics of individual CAM therapies are needed. Furthermore, more
research is needed in the area of communication between traditional practitioners and patients related to CAM use. This research would help practitioners gain insight into how to provide optimal health care for patients who use CAM.
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