

Complementary and Alternative Therapy Use During Treatment of Breast Cancer

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ABSTRACT

CAMILLE LAMBE: Complementary and Alternative Therapy Use During Treatment of
Breast Cancer

(Under the direction of Dr. Barbara Germino)

Complementary and alternative medicine (CAM) is used often by women having treatment for breast cancer and has been studied extensively in European American, educated, affluent women. However, it is poorly understood in poor, uneducated, rural and African American women. Studies of folk medicine, spirituality and those few studies with ethnically diverse samples indicate that CAM is also used in these groups. The process by which women make decisions to use CAM during and after breast cancer treatment has not been clearly described.

The aims of this study were to characterize CAM use during treatment for breast cancer in a sample of African American and Caucasian women; to examine precipitating and influential factors in Caucasian and African American women's choices to use CAM during breast cancer treatment; to describe the process and timing of decisions to use CAM; and to clarify the use of CAM for treatment of breast cancer related issues as compared to the use of CAM for maintaining and improving health.

This exploratory descriptive study used a cross sectional design and multiple methods including a card sort, individual interviews and quantitative measures. A convenience sample of 19 African American and European American women participated, all of whom were CAM users and were receiving or recovering from breast cancer treatment. The women

in the sample were generally educated beyond high school, were varied in age and income as well as type of residence (urban/rural).

The results of this study indicate the importance of participant definitions of CAM. African American women in the sample reported higher use of CAM treatments than the European American women both for managing side effects of treatment and for their general health. The types of CAM treatments used by African American and Caucasian women were different. Having breast cancer motivated all the women to engage in a type of life review to search for reasons for having breast cancer and to affect adoption of healthy lifestyle choices in the form of CAM. These women used a process of deciding about CAM use that was shaped by people they considered to be experts, a variety of other information sources, their health beliefs and their own personal experiences with the CAM treatment. The decision to use CAM therapies involved weighing the pros and cons and trying out CAM therapies for their effectiveness.

The importance of faith and spirituality, especially but not exclusively for African American breast cancer patients, was supported by these findings. Prayer was the CAM therapy chosen most often by all of the women in the sample. The study raises questions about literature indicating that women do not discuss CAM use with their health care providers. In fact, the findings indicate the importance of providers as a resource for patients considering CAM during treatment of breast cancer and the need for study of precise doses of CAM and conventional treatment given concurrently.

DEDICATION

From the time I can remember breast cancer has been a part of my life and a part of my family. The women in the clan of the one-breasted women (Williams, 1992) are truly courageous and they have honored me with their stories. I dedicate this work to them.

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Chapter I

The Problem

The use of complementary and alternative medicine (CAM) is reported to be increasing in the United States (Eisenberg et al., 2001) and worldwide (Kimby, Launso, Henningsen, & Langgaard, 2003). There is no agreement in the scientific literature about how CAM is defined, however. The National Center for Complementary and Alternative Medicine (NCCAM), a center within the National Institutes of Health, has identified 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 (National Center for Complementary and Alternative Medicine, 2004). Other definitions used in the literature include lists of selected treatments and therapies (Eisenberg, Kessler, & Foster, 1993) as defined by researchers; holistic approaches to health and illness (Montbriand, 1994); unconventional therapies provided by unlicensed practitioners (Druss & Rosenheck, 1999); licensed physicians' integration of unconventional therapy with conventional care (Dalen, 1998); or any nontraditional therapy adopted by a person for relief of a particular problem, symptom, or concern (Low Dog, Riley, & Carter, 2001). All of these varied definitions complicate and limit knowledge about CAM use. According to available definitions, CAM may be prescribed by licensed or certified health care providers (Standish, Greene, Greenlee, Kim, & Grosshans, 2002) or by non-licensed practitioners of a particular kind of unconventional therapy (Mathews, 1992), or it may be self-initiated (Bushy, 1992). Individuals may self-prescribe CAM (Eisenberg et al., 2001) following information from the Internet (Satterlund,

McCaul, & Sandgren, 2003) or following influences from friends and family (Crocetti et al., 1998) or fellow members of a support group (Henderson & Donatelle, 2004). Because control of care rests in part with the patient, all of these influences are important in the adoption of CAM treatments. A CAM treatment, for purposes of this study, is defined as any non-conventional, non-biomedical strategy that the patient initiates while receiving or recovering from conventional biomedical therapy for breast cancer, regardless of the source of information about CAM or the influencing persons or resources.

Cancer is a diagnosis that prompts patients not only to seek biomedical treatment but also to investigate CAM. Women have been found to be more likely than men to use CAM (Arcury, Preisser, Gesler, & Sherman, 2004). Newly diagnosed breast cancer patients are also more likely than other cancer patients to use CAM (VandeCreek, Rogers, & Lester, 1999). Breast cancer patients are also more likely to adopt CAM after their diagnosis than other cancer patients (Boon, Brown, Gavin, Kennard, & Stewart, 1999). Survey data indicate that from 40 to 70% of women with breast cancer use CAM during treatment (Alferi, Antoni, Ironson, Kilborn, & Carver, 2001; Burstein, Gelber, Guadagnoli, & Weeks, 1999; Morris, Johnson, Homer, & Walts, 2000)

Breast cancer patients have been reported to use CAM from the time of diagnosis (Alferi et al., 2001), through treatment with chemotherapy (Shen et al., 2000) or radiation therapy (Kolcaba & Fox, 1999), and during advanced breast cancer (Mathews, Lannin, & Mitchell, 1994). They report using CAM for well-being (Moschen et al., 2001), for relief of symptoms associated with their cancer (Rees et al., 2000), and for relief of side effects of treatments including surgery (Ashikaga, Bosompra, O'Brien, & Nelson, 2002), radiation therapy (Lengacher et al., 2002), chemotherapy (Maskarinec, Shumay, Kakai, & Gotay, 2000), and

hormonal therapy (Canales & Geller, 2003). Complementary therapy use increases among patients with breast cancer as treatment intensifies (Shen et al., 2002), which may increase the chances that the patient will experience interactions between their conventional treatment and the CAM they use (Izzo & Ernst, 2001). We know little about these interactions and their effects on cancer morbidity and mortality.

Although some authors advocate the beneficial effects of CAM during cancer chemotherapy (Bougnoux et al., 1999; Carlsson, Arman, Backman, & Hamrin, 2001; Conklin, 2000; Heggie et al., 2002; Messina & Loprinzi, 2001; National Center for Complementary and Alternative Medicine, 2004), others urge caution in its use (Boyle, 1997). The conventional medical community has expressed major concerns about the use of CAM. Some authors are concerned that patients will use CAM rather than conventional biomedicine for cancer treatment. Others worry about drug interactions with CAM that may interfere with treatment effectiveness. Still others indicate that CAM use may intensify the toxicities of conventional treatment. Studies of CAM use during cancer show that only a small number of patients completely withdraw from all conventional biomedicine (Montbriand, 1998). Instead, most patients combine CAM with their biomedical regimen (VandeCreek et al., 1999), perpetuating provider concerns about interactions with conventional therapy.

Some forms of CAM, specifically antioxidants (Labriola & Livingston, 1999; Lamson & Brignall, 1999), St. John's wort (Werneke et al., 2004), and essiac (Kumar et al., 2002), have been cited as having actions that interfere with the effectiveness of chemotherapy drugs. A larger body of literature, mostly case studies, includes reports of the additive effects of CAM to the complications of cancer treatment, including postoperative bleeding (Norred &

Finlayson, 2000), acute hepatitis (Whiting, Clouston, & Kerlin, 2002), and disruption of coagulation processes (Barone, Gurley, Ketel, & Abul-Ezz, 2001).

In several reviews of the literature about interactions between herbal medicines and prescribed drugs (Drew & Myers, 1997; Erlen, 1997; Izzo & Ernst, 2001; Mahady, Fabricant, Chadwick, & Dietz, 2002; Markman, 2002; Miller, 1998), the authors found cause for concern in mixing CAM with conventional biomedicine (Erlen, 1997; Vickers, 2004). These concerns included prolonged sedation from barbiturates, as in the case of valerian; bleeding, as in the case of ginkgo biloba combined with warfarin; and rejection of renal transplant, as in the case of St. John's wort. In case study reports, kava, a natural anxiolytic, has induced fatal fulminant hepatic failure (Gow, Connelly, Hill, Crowley, & Angus, 2003), and black cohosh, an herb for hot flashes, has induced acute hepatic failure (Whiting et al., 2002). Although surveys of CAM use during chemotherapy have been done (Alferi et al., 2001; Chou, Horng, & Vargas, 2000; Lengacher et al., 2002; Meyer, Russo, & Talbot, 1995; O'Connor, 1980), there are few large, longitudinal studies of the effects and interactions of CAM with conventional breast cancer treatment.

Women with breast cancer who are most likely to combine CAM with biomedical treatment have traditionally been described as European Americans, educated, and affluent. This picture of CAM users is largely generated from the types of samples selected for study, which are dominated by patients with those characteristics. Since minority groups are rarely represented in the samples of published studies about breast cancer, little is known about the application of the traditions of CAM use within minority groups. Traditional medicine (Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003), folk medicine (Fletcher, 2000), spirituality (Roberson, 1987), and herbal medicine (Mathews, 2000) have all been described

as being used by persons from a variety of cultures in the United States. Some authors have identified these therapies as CAM (Fletcher, 2000), and the patients they study seem to use them in a complementary manner (Cuellar, Aycock, Cahill, & Ford, 2003; Powers, 1982). Research with purposive samples of ethnically diverse groups (Chou et al., 2000; Mackenzie, Taylor, Bloom, & Hufford, 2003) has generated a more diverse picture of CAM users. A sample representative of European Americans, African Americans, Latinos, and Asian groups clearly shows that CAM use is prevalent in all of these groups, but the types of therapies used varies from group to group (Lee, Lin, Wrensch, Adler, & Eisenberg, 2000), perhaps based on cultural traditions.

The process by which breast cancer patients come to a decision about using CAM therapy is also unclear. Lack of diversity in study samples limits reports of decision-making about CAM use in breast cancer patients. Many of the studies sample mostly European Americans, well-educated women (Boon et al., 1999; Mathews, 2000; Rees & Bath, 2001; Seegers et al., 1998; Truant & Bottorff, 1999), and few studies have focused on the decisions that women make during treatment (Matthews, Sellergren, Manfredi, & Williams, 2002) or how they are made.

Since adjuvant treatment is so vital to the potential success of biomedical therapy for breast cancer, adding another therapy that is unregulated is of particular concern. The role of complementary therapy, with its potential for drug toxicity, possible interactions with conventional therapies, and prevalence of use during toxic conventional biotherapy, makes the decisions women come to about CAM particularly important. Without insight into the processes women use to decide about CAM use, intervention and education for this group of women lack foundation (Moschen et al., 2001). The limitations of existing studies; the

potential for problems in interactions of conventional treatment and CAM; and the lack of systematic information about how and when women with breast cancer decide to use CAM all supported this study of a more diverse sample of women during adjuvant therapy for breast cancer as they decide whether or not to include complementary therapy in their treatment.

The aims of this study were:

1. To characterize CAM use during treatment for breast cancer in a sample of African American and European Americans women from both urban and rural settings in the South.
2. To examine precipitating and influential factors in the choices of European Americans and African American women to use CAM during treatment for breast cancer.
3. To describe the process and timing of decision making that women use in choosing CAM during breast cancer treatment.
4. To clarify the use of CAM for treatment of breast cancer–related issues as compared to CAM use for self-care and healthy lifestyles.

Chapter 2

Review of Literature

The complementary and alternative therapy (CAM) movement has become pervasive in the United States, with CAM being added to conventional treatment regimes by patients with breast cancer (DiGianni, Garber, & Winer, 2002; Gray, Fitch, Goel, Franssen, & Labrecque, 2003; Lengacher, Bennett, Kip, Berarducci, & Cox, 2003). Researchers demonstrate high CAM use in cancer patients (Vickers, 2004), in women in general (Patterson et al., 2002), and in breast cancer patients specifically (Maskarinec et al., 2000), but the variability in definitions of CAM makes the scope of CAM use unclear. Researchers have defined CAM as a list of treatments, a holistic philosophy, or as a series of domains. When authors use a list to define CAM therapies, treatments used by particular ages and ethnic groups may be inadvertently omitted. When researchers use a holistic definition of CAM, health maintenance behaviors are included in CAM definitions. Using a series of domains, particular treatments may be included in one domain for one report and in another domain in another report.

Decision-making is an important element in the use of CAM treatments because it provides an avenue for providers to intervene with patients. The decision-making process has been poorly described in the literature about CAM and breast cancer. The ways in which the elements of decision-making interact in women making the choice to use CAM or to reject CAM are unclear in women with breast cancer.

Descriptions of CAM use and decision-making that include African American women are largely absent in the breast cancer literature. Traditional medicine, folk medicine, and spirituality have been documented heavily in the literature about the African American community and the health care that they use (Abrums, 2000; Fields, 2001; Woodard & Sowell, 2001) but are absent in the literature about CAM in breast cancer. Forms of CAM used by African American women may be included in surveys of breast cancer patients, but often the sample surveyed includes few African American women. Authors who have studied multiethnic samples of breast cancer patients have found that European Americans and African American women both use CAM, but each group uses a different combination of therapies (Factor-Litvak, Cushman, Kronenberg, Wade, & Kalmus, 2001; Lee et al., 2000).

Difficulties in Defining Complementary Therapy: Historical Background

The modern concept of CAM has its origins in the United States during the early 1960s. With the advent of the new age movement and self-help and wellness interest groups, patients became more involved with their medical care and their health. During this period ("Unproven methods," 1967), cancer patients began hearing about cures and treatments for cancer from outside the United States (Seligmann, 1977b). The conventional medical establishment, however, voiced concern that cancer patients would forsake proven treatment for expensive unorthodox cures (Cramp, 1982). These unorthodox treatments and medicines included botanicals such as laetrile from South America (Seligmann, 1977a), treatments such as acupuncture from China (Reston, 1971), and practices such as yoga from India (Decker, 1999). Users of CAM were portrayed by the medical community as dissatisfied, desperate patients with no hope left (American Cancer Society, 1982). Although the popular press

touted CAM as revolutionary and providing hope for patients with incurable illnesses (Reston, 1971; Seligmann, 1977b), the conventional medical press was skeptical (Hubbard, 1966).

In an early survey of CAM use in cancer treatment (Cassileth, Lusk, Strouse, & Bodenheimer, 1984), the authors described the prevalence of CAM use and presented a definition of CAM. They defined CAM as “treatments and methods deemed by established medicine to be unproven, unorthodox, ineffective, or fraudulent” (Cassileth, Lusk, Strouse, & Bodenheimer, 1984, 105). In their study, they interviewed 660 patients and found that 51% reported using CAM at the same time they used conventional cancer treatment. The authors collected information about CAM treatments from their respondents and created a list that they used to define CAM treatments. However, the sample they studied was narrowly drawn, including mainly European Americans, educated, and affluent women. Researchers have used the methods and therapies of this report in CAM definitions from that time to the present.

Differences in CAM Definitions

Use of a List to Define CAM

The most quoted survey of CAM use (Eisenberg et al., 1993) drew from a largely European Americans sample of 1,539 members of the public and was a phone survey. These authors found that 34% of their sample used CAM. They defined CAM with a list generated from their pilot work and simply asked the respondents if they did or did not use specific therapies. Essentially, the researchers defined CAM in this study by the therapies they asked about and by the people whom they questioned. These authors defined CAM as “a list of 16

commonly used interventions neither taught widely in U.S. medical schools nor generally available in U.S. hospitals” (Eisenberg et al., 1993, 246). These were therapies that were included in the earlier (Cassileth et al., 1984) list in addition to others. This list has become the standard definition for current research describing CAM use.

Other authors have utilized the author-defined list as a way to study CAM (Arcury et al., 2004; Ashikaga et al., 2002; Consumer Reports, 2000; Cushman, Wade, Factor-Litvak, Kronenberg, & Firester, 1999). The problem with this method, however, is that the samples surveyed to create these lists have been narrowly drawn and do not include members of multiple cultures that also use CAM (Lengacher et al., 2002; Navo et al., 2004). Even when a list is provided to a set of subjects that includes multicultural modalities such as traditional and folk medicine, there has been low use reported when the sample was narrowly drawn (Eisenberg, 1998). That is, the study population in the original Eisenberg study was 82% European Americans, 9% Black, 6% Hispanic, 1% Asian, and 2% other. The researchers asked about some therapies that reflected cultural diversity, such as folk remedies and prayer, but because of the low proportion of respondents from minority groups, the authors came to the conclusion that CAM users are young, non-Black, highly educated, and affluent (Eisenberg et al., 1993). The findings of other studies dispute these conclusions (Frate, Croom, Frate, Juergens, & Meydrech, 1996; Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000), concluding that African Americans and indigent patients were indeed frequent CAM users. The primary difference in these studies was the diversity in the samples.

In reports of an ethnically diverse sample of women from New York (Cushman et al., 1999; Factor-Litvak et al., 2001), the authors asked about the use of CAM for women’s

health concerns. The authors found unique types of CAM used by Hispanic and African American women (Cushman et al., 1999). The second study in this series (Factor-Litvak et al., 2001) combined the individual types of CAM for analysis. This report found no differences in the ethnic groups regarding CAM use. However, by grouping the individual modalities used by the women, the potential richness of CAM use information was lost. The authors' conclusions failed to capture the unique systems of healing used by the women in their diverse sample.

Use of Holistic Philosophy to Define CAM

Other researchers have defined CAM as a holistic approach to health (Montbriand, 1994, 1995a, 1995b, 1998). Holism is a broad concept, encompassing both illness and health. It focuses on the interrelatedness of parts and emphasizes the organic or relation between parts and wholes (Merriam-Webster, 1967). In the context of holism, the experience of cancer is only a portion of the patient's concern, and other body systems weigh equally in attention and importance. Prevention behaviors such as diet and exercise are included (Kinney, Rodgers, Nash, & Bray, 2003) in CAM lists when subjects are asked about the amounts of CAM they use. Another element in the holistic approach to health is the belief that there are things that are "good for you" and substances that are unhealthy. CAM users are more likely to maintain a low-fat diet and exercise more frequently (classified as CAM in some studies) than non-users (Politi, Rabin, & Pinto, 2006). Some breast cancer patients describe biomedical treatments for cancer as potential toxins (Downer et al., 1994) that may be harmful to their bodies (Montbriand, 1998). Many studies report that patients use CAM to detoxify their bodies from the effects of conventional cancer treatment (Cassileth et al., 1984; Gotay & Dumitriu, 2000; Marbella, Harris, & Diehr, 1998; Shen et al., 2002).

Distinguishing between therapies for general health and those aimed specifically at breast cancer (Alferi et al., 2001; Astin, Pelletier, Marie, & Haskell, 2000; Balneaves, Kristjanson, & Tataryn, 1999) is important because it gives clues about motivation for CAM use. Many surveys of CAM utilization within the breast cancer literature include health promoting behaviors such as diet and exercise (Chou et al., 2000; Sparber et al., 2000; VandeCreek et al., 1999) as CAM. Often these approaches are seen as holistic healing and focus on the whole person rather than cancer and the side effects of its treatment. Although special diets and limited exercise have been advocated for some side effects of breast cancer treatment (Djuric et al., 1998; Schwartz, 2000), the distinctions made between CAM used for cancer and its side effects and those strategies used for general holistic health are important in the overall reporting of CAM use. Unless CAM definitions can be refined, measuring CAM use will continue to be based on imprecise definitions that are inconsistent across studies, threatening the validity of the construct. The belief that a healthy body is more or less likely to promote the growth of a cancer is beyond the scope of this study.

A survey by Barnes, Powel-Griner, McFann, and Nahin (2004) provides an example of making this distinction. The survey includes the element of prayer in the list of CAM treatments. However, the researchers specify that the prayer must be for cure of the cancer or the alleviation of one of its side effects (Barnes et al., 2004). This method is in contrast to a study by VandeCreek et al. (1999) that included prayer and exercise in the list of CAM treatments without any indication of the reasons for their use. The authors did not ask about the reasons for CAM use, and it is unclear from their results whether the CAM the women used was for routine health maintenance or if it represented an attempt by the breast cancer patients to deal with their cancer.

Domains as a Way to Define CAM

The National Center for Complementary and Alternative Medicine (NCCAM) has also defined CAM. This center in the National Institutes of Health was established in 1991 to investigate the use and effects of CAM and to educate the public about it. The NCCAM identifies CAM as a group of diverse medical and health care systems, practices, and products not presently considered to be part of conventional medicine (National Center for Complementary and Alternative Medicine, 2004). Early studies outline therapies that were considered CAM (Hauser, 1991) because they were outside conventional medicine, but this list has changed as a variety of therapies have become more mainstream. Early reports define acupuncture and acupressure as unproven and unconventional (Reston, 1971), but current medical practice incorporates therapies such as acupuncture and massage (Bredin, 1999; Dibble, Chapman, Mack, & Shan, 2000; Harris, Hugi, Olivotto, & Levine, 2001; Rydholm, 1999) as potential adjuncts to cancer care. As more and more conventional providers use CAM strategies (Standish et al., 2002), conventional medical schools are expanding to incorporate the principles of CAM into their curricula (Spiegel, Stroud, & Fyfe, 1998). The NCCAM provides definitions with examples to guide classification of CAM modalities (see Table 1). This series of domains is most useful in the analysis portion of a study and may be a useful way to organize disparate types of CAM.

Alternative medical systems.

The domain alternative medical systems reflects practices of ancient cultures such as traditional Chinese medicine (Simpson, 2003) or Ayurvedic medicine (Ashikaga et al., 2002). These systems of healing became fashionable in the United States in the 1960s and were popularized in the new age and women's movements (Boston Women's Health Book

Collective, 1984). They reflect the health beliefs of the culture of origin. An alternative medical system may employ treatments from several other domains. Traditional Chinese medicine is an example of an alternative healing system that may include the biological therapy of herbs, the energy healing of acupuncture, and the mind-body therapy of meditation. A patient may subscribe to a particular modality from an alternative medical system without adopting the entire system of health beliefs. But many health beliefs are culturally derived, and the practices associated with them are quite prevalent (McCoy, 1997).

Traditional medicine (Hufford, 1997) and folk medicine (Mathews, 1987) are also examples of culturally based alternative medical systems. Each of these systems employs a series of therapies reflective of their culture of origin, but the literature seldom describes their uses as fully as other alternative systems. Some studies of minority populations have classed traditional and folk medicine as CAM (Bushy, 1992; Fletcher, 2000), and elements of these culturally based systems have been included in lists of CAM (Arcury et al., 2004; Gotay, Hara, Issell, & Maskarinec, 1999). Arcury et al. (2004) described an alternative healing system in North Carolina. They surveyed 1,059 rural mountain dwellers and reported the use of a system they classify as “honey-lemon-vinegar-whiskey.” This system includes home remedies used to deal with a wide variety of symptoms and complaints. Arcury et al. reported that this system was the form of CAM most frequently used by their subjects. This information is important because the patients reported blending these home remedies with conventional biomedicine. Work by Gotay et al. (1999) described a culturally distinct system used by Hawaiian cancer patients, including unique therapies not found in other studies of CAM such as seaweed, marijuana, and the Healing Mass, a native ceremony from Hawaii. A North Carolina study of women with breast cancer (Mathews et al., 1994) describes the

forms of CAM used by European Americans and African American women (including traditional medicine and Rootwork, a belief in the power of spells and potions) and the interaction between the women's use of CAM and the conventional biomedical system they encounter as their cancer progresses. The report makes the distinction between the different systems of care and when each was used by breast cancer patients. This application of the alternative medical system, as outlined by the NCCAM, is useful because it shows the importance of a cultural system to decision-making and provides insight into the motivation of the women to adhere to their alternative medical system while using conventional biomedicine.

Mind-body interventions.

Mind-body interventions are based on the belief that the mind and body are linked and that each affects the other (Targ & Levine, 2002). Advocates of these interventions may be proponents of the stress theory of illness (Brown & Carney, 1996) and seek to improve health by stress reduction. Many surveys of CAM use report that patients believe cancer is caused by stress (Bowman, Deiming, Smerglia, Sage, & Kahana, 2003) and that the CAM they use is aimed at stress reduction (Truant & Bottorff, 1999). In like fashion, they may also believe that illness can be cured by the power of the mind (Cushman et al., 1999).

Shumay, Maskarinec, Gotay, Heiby, and Kakai (2002) found that 82% of their respondents had used mind-body interventions. They described this CAM domain as including religious healing, meditation, guided imagery or hypnosis, support groups, relaxation, and psychological counseling. This is consistent with the NCCAM definition (National Center for Complementary and Alternative Medicine, 2004). These authors classified support groups as a form of mind-body therapy. For the past 30 years the American Cancer Society (ACS) has

advocated support groups for breast cancer patients (McMillian, Tittle, & Hill, 1993; Smith, 1998). Data support the beneficial effects of support group attendance for breast cancer survival (Davidson, Pennebaker, & Dickerson, 2000; Spiegel et al., 1998). The women who attend support groups and their conventional providers may or may not see their attendance as a type of complementary therapy. Reports of the prevalence of CAM use that include support group attendance (Alferi et al., 2001; Astin, 1998; Henderson & Donatelle, 2004) may be misleading about the frequency of use of CAM treatments unless this element is defined.

Biologically based therapies.

Another NCCAM domain, biologically based therapies, encompasses a wide variety of treatments classified as “natural,” including vitamins, minerals, and other naturally occurring products such as shark cartilage and various herbal preparations. These may be ingested as extracts, pills, or injections; they may be inhaled, taken as enemas, or used topically. Biologically based therapies are not regulated by the Food and Drug Administration (FDA, 2004) but are classified as nutritional supplements and are regulated by the Dietary Supplement and Health Education Act of 1994 (Ramsey, Ross, & Fischer, 2000). The lack of FDA regulation and the potential for harm have been criticisms of CAM by the conventional medical community (Jonas & Levin, 1999). An Australian study (Drew and Myers, 1997) described adverse effects related to regulation of some biologically based therapies. The extrinsic effects that they describe have concerned conventional providers for many years (Perharic et al., 1994) and can confuse and taint results of studies of CAM treatments. When an author describes an adverse effect of a biologic therapy, it may actually reflect the process used by the seller of the therapy rather than the intended CAM treatment itself. The CAM

treatment may not provide the anticipated outcome, but the result may have little to do with the proposed CAM treatment. Although investigation of CAM modalities is ongoing, beliefs that CAM treatments are impure may affect the patient's decision-making and provider acceptance of CAM therapies.

Table 1:

Definitions and Examples of NCCAM Domains

| NCCAM Domain | Definition | Examples |
|-------------------------------------|--|---|
| Alternative Medical Systems | Therapies built on a complete system of theory and practice. | Chinese Medicine, Ayurveda, Naturopathy, Folk Medicine, Traditional Medicine. |
| Mind-Body Interventions | Therapies use a variety of techniques to enhance the mind's capacity to affect bodily functions. | Meditation, Prayer, Mental healing, Faith healing, Art, Music. |
| Biologically Based Therapies | Therapies use substances found in nature. | Herbs, foods, vitamins, dietary supplements, herbal products. |
| Manipulative and Body-Based Methods | Therapies based on manipulation and/or movement of one or more parts of the body. | Chiropractic, Osteopathy, Massage. |
| Energy Therapies | Therapies use energy fields and include biofield therapies, of the human body, and Bioelectric-based therapies, involve the use of electromagnetic fields. | Qi Gong, Reiki, Reflexology, Therapeutic Touch, Magnetic fields, Alternating current, or direct current fields. |

(National Center for Complementary and Alternative Medicine, 2004)

Manipulative and body-based methods.

Manipulative and body-based methods employ a wide variety of treatments to promote relief of symptoms or for a general state of wellness. They may include a variety of techniques like massage or spinal manipulation. Conventional biomedical providers have expressed concern about the practices in this domain because some practitioners lack formal preparation for practice and hold varieties of licensures and certifications (Richardson, 2000). At times, both the provider of the therapy and the CAM therapy provided may be unregulated by state or local agencies. Researchers have visited health food stores and been advised by clerks about CAM use and treatment (Gotay & Dumitriu, 2000; Mills, Ernst, Singh, Ross, & Wilson, 2003). Some CAM providers such as osteopaths are required to attend rigorous educational programs and pass licensing exams, but other CAM providers may be permitted to practice without regulation (Graedon & Graedon, 1999).

The practice of chiropractic is one of the most common forms of CAM (Consumer Reports, 2000) and is a good example of the preparation of many CAM practitioners. Chiropractors complete many years of education. They are licensed by the state in which they practice and are certified by the National Board of Chiropractic Examiners (Jonas & Levin, 1999). Many studies of CAM use in breast cancer patients demonstrate high use of massage (Alferi et al., 2001; Ashikaga et al., 2002; Balneaves, Kristjanson, & Tataryn, 1999; Boon et al., 1999). The education of the practitioner must be taken into account in the evaluation of the outcome of CAM therapies. The results of studies that teach patients to employ CAM therapies for themselves (Molassiotis, Yung, Yam, Chan, & Mok, 2002) must also be judged differently than studies with interventions provided by educated, certified, and licensed practitioners (Harris et al., 2001). Many authors do not define the specifics of the

therapy provided in trials or the qualifications of the providers of manipulative and body-based methods.

Energy therapies.

Energy therapies are aimed at the energy fields in the patient's body (i.e., traditional Chinese medicine's manipulation of Chi by acupressure) or at an energy field acting on the patient (i.e., magnetic field application to the patient). In evaluations of energy therapies, researchers had particular difficulty applying the randomized experimental controlled trial to these therapies. Some CAM Researchers with manipulations of energy has abandoned traditional tenets of research, losing credibility with conventional biomedical providers. There are numerous examples (Jacobson, Workman, & Kronenberg, 1999) of quality research in CAM treatments with energy therapies. Detailed explanations of the physiology involved in acupuncture (an energy therapy) summarize research about the therapy and explain the way in which it activates small nerve fibers that override pain sensations and promotes endorphins for pain relief (Stux & Hammerschlag, 2001). Energy therapy has demonstrated efficacy when used for side effects associated with breast cancer treatment (Dibble et al., 2000).

Stephenson, Weinrich, and Tavakolil (2000) reported a clinical trial of reflexology, another energy therapy, using established research principles to provide useful information for practice. In this study, the authors used the energy theory as the basis for their study and demonstrated that reflexology could be used to reorganize and re-circulate energy through blocked pathways to blocked organs. This study provided information about the actions of reflexology and documented the potential for pain relief in cancer patients. This is an example of a study of a CAM treatment demonstrating efficacy and fulfilling the standards of

rigor for research by providing reliable information about these tools for relief of cancer pain and anxiety. Similarly, a report on the use of yoga with breast cancer survivors showed that the intervention group who used yoga after treatment had more improvement in psychosocial variables than the treatment control group (Culos-Reed, Carlson, Daroux, & Hatley-Aldous, 2005).

Summary of Definitional Issues

In studies that use a list to measure CAM use, the list provided to the subjects may be limited in scope and fail to measure wider use of CAM by specific cultural groups. In studies of CAM use in which the NCCAM domains were used as a basis for definitions of CAM (Barnes et al., 2004; Bennett & Lengacher, 1999; Shumay et al., 2002) the domains may provide structure for instrument development and discussions of findings, but they do not succeed in comprehensively defining CAM. Using the holistic approach to defining CAM may help to collect information about CAM treatments used for overall health rather than those aimed at complementing conventional biomedicine for breast cancer. The definition of CAM remains controversial and clouded in the literature. Surveys of CAM fail to take into account the cultural basis for complementary therapy, draw samples that are narrow, and generalize about CAM use. The study of CAM requires different methods than studies of conventional biomedicine (Ai et al., 2001; Fugh-Berman, 1997; Kronenberg & Fugh-Berman, 2002; Tagliaferri, Cohen, & Tripathy, 2001). The definition of a particular CAM must be quantified with descriptions of its use and prevalence, especially as it applies to breast cancer patients in active therapy as doses are defined in conventional trials. The consequences of interactions between CAM and conventional biotherapy and the potential

benefits of using CAM therapies are too important to neglect precision in the study of CAM treatments.

Complementary Therapy Use in Patients With Breast Cancer

Women with breast cancer are one of the largest groups of CAM users. Survey data show that women are more likely than men to use CAM (Norred, 2002); that breast cancer patients are more likely than other cancer patients to use CAM (Kimby et al., 2003); and that using CAM prior to a cancer diagnosis predisposes breast cancer patients to continue CAM use (Henderson & Donatelle, 2004). After a woman develops breast cancer, she is more likely to use CAM if her cancer or her treatment is toxic or she becomes sicker than other breast cancer patients with treatment and disease (McPhail & Smith, 2000). However, studies have mainly limited their inquiries to affluent, educated European Americans and have ignored minority patients with breast cancer who also use CAM. The reports of CAM use rarely link symptoms and side effects to particular CAM treatments for which they are used. The literature describes what forms of CAM some patients use but fails to describe specifically when and why they use particular therapies.

Gender Differences in CAM Use

Women are more likely than men to use CAM. Eisenberg's (1998) survey of 2,055 adults showed that 42% of the respondents used CAM and that more women than men used CAM. The author found that study participants made more total provider visits to CAM providers than to primary care physicians and estimated that 15 million adults, or 18.4% of all prescription drug users, combined prescription drugs with herbal remedies and/or high-dose vitamins (Eisenberg, 1998). Barnes et al. (2004) used data from the National Health

Interview Survey (NHIS) of 2002 to report the prevalence of CAM use. Their supplemental questionnaire asked about a list of 27 types of CAM and found that 75% of the total sample studied was using CAM. Women reported higher use of CAM therapies than men in this study, with the mind-body domain the most commonly used. A study of Native Americans from the Milwaukee Indian Health Center explored use of traditional healers, which the authors defined as CAM (Marbella et al., 1998). Older women were more likely to seek help from healers than were younger male patients. The 150 respondents were interviewed about types of healers they had seen and also the ceremonies and rites in which they had participated. The results of this study showed how the women in this ethnic group combined their strong system of traditional medicine with conventional biomedicine. In a study of data from the 1995 National Comparative Survey of Minority Health Care of the Commonwealth Fund, again, more women than men used CAM (Mackenzie et al., 2003). The authors used a telephone survey conducted in six languages to study 3,789 persons' CAM use. These authors found that 43% of the respondents had used CAM in the past year. CAM use differed across ethnic groups, with different groups using different CAM combinations. A study from rural South Carolina (Oldendick et al., 2000) also found women more likely to use CAM than men (55% vs. 49%). In this telephone survey, the investigators defined CAM as 23 therapies that were generally considered complementary or alternative. This study provided valuable information about CAM use in rural residents of the South. The authors found that a high percentage of participants used self-help groups to treat "other" health problems, which the authors reported represented participation in cancer survivor groups. Arcury et al. (2004) used data from the Mountain Accessibility Project (MAP) to study 1,059 adults in Appalachian North Carolina. The investigators reported that more women than men used

CAM. The most widely used forms of CAM reported by this sample were home remedies (46%), most often the “honey-lemon-vinegar-whiskey” treatment. The women in this sample had developed home remedies to deal with a variety of health problems, but the authors do not explain this alternative medicinal system further. It is not clear what prompted the patients to use this form of CAM versus consulting a biomedical provider (Arcury et al., 2004). In each of the studies cited, the authors found that women were more frequent users of CAM than men. The reports fail to distinguish the types of CAM used by women as compared to men and fail to identify the conditions that cause women to seek CAM.

In summary, according to surveys of the public, CAM is used more often by women than men (Barnes et al., 2004; Eisenberg et al., 1993; Eisenberg, 1998), by patients visiting outpatient clinics (Boutin, Buchwald, Robinson, & Collier, 2000), in ethnically diverse samples (Mackenzie et al., 2003; Marbella et al., 1998), and in rural populations (Arcury et al., 2004; Oldendick et al., 2000). With this predisposition to use CAM, it follows that when women develop cancer they may incorporate CAM into a treatment regime.

Frequency of CAM Use by Breast Cancer Patients

Cassileth et al. (1984) interviewed 660 cancer inpatients and found that breast cancer patients were most likely to combine unorthodox and conventional therapy than other groups. This study was important in that it showed heavy CAM use by cancer patients in general and by breast cancer patients in particular. Nearly half of the patients reported combining CAM with conventional therapy. The sample was composed of European Americans, affluent patients. A more recent telephone interview study of men and women with breast, colon, and prostate cancer (Patterson et al., 2002) not only found a higher incidence of CAM use (70%) in women than in men but also found that breast cancer patients used alternative therapy

significantly ($p < 0.01$) more often than those with colon and prostate cancer. Subjects in general used CAM largely for general health and well-being (a holistic approach); for treatment of their cancer; and for other diseases. Another important finding in this study was that the more types of conventional therapies the patients had received for their cancer, the more likely they were to use CAM. The patients reported that CAM improved their feelings of well-being. Other reports mirrored these results (Navo, et al., 2004; Sollner et al., 2000). Of 1,168 Hawaiian patients responding to a mail survey, one in four had used at least one form of CAM since the time of their diagnosis (Maskarinec et al., 2000). The women with breast cancer were twice as likely to use CAM as the men or women with the other cancers (gastrointestinal or prostate cancer). When a sample of older cancer patients with breast, lung, colorectal, or prostate cancer was studied, investigators found that breast cancer patients were more likely to use CAM than patients with the other diagnoses ($p < 0.05$) (Wyatt, Friedman, Given, Given, & Beckrow, 1999).

Studies of CAM use by cancer patients consistently describe heavy use of CAM by breast cancer patients as compared to patients with other types of cancer. However, these studies fail to apply a consistent definition of CAM, survey mostly European Americans patients, and neglect to describe the reasons breast cancer patients report for using CAM. Many unanswered questions remain about the common use of CAM by women with breast cancer. For example, are there side effects of treatment or physical effects of breast cancer that are more amenable to CAM treatments than those that occur in other types of cancer? This study examines these issues to provide a clearer basis for future intervention and education.

CAM Use Prior to Breast Cancer Treatment

A strong predictor of CAM use for breast cancer patients is prior use of CAM. Adler and Fosket (1999) found that CAM use before diagnosis continued after the patients found out that they had cancer. In this study, the main reason patients reported for CAM use was to treat their breast cancer. The authors followed the patients over time with interviews and found that CAM use varied with time, but the prior CAM users continued to use complementary therapy throughout treatment and afterward. Boon et al. (1999) also found that breast cancer survivors were more likely to have decided to use CAM during treatment if they had used CAM before their diagnosis. In this study, during participation in focus groups, women described searching for treatments that would enhance their chances of survival. CAM was seen as a safe and harmless method and a way of being proactive for their health. Prior CAM use also provided a basis for women's decision-making (Truant & Bottorff, 1999). In the initial period of deciding about treatment and supplemental therapy, the women in this study relied on the CAM they had used prior to their diagnosis. After conventional treatment had begun, the women reassessed their CAM choices and added more CAM or reduced the CAM they were using. These women constantly reassessed their CAM use and continued to use CAM after conventional treatment was completed. Prior CAM use may serve as a proven coping skill that women continue to use during diagnosis and treatment of breast cancer. The women who experience benefits of CAM use may also see CAM as a way to deal with new stresses of breast cancer. The studies cited reflect the way some women's prior CAM use carries over to the time that they receive a cancer diagnosis. However, the samples from which these conclusions are drawn are mainly limited to European Americans women. Little information is available about how minority women who have strong traditions of faith (Ford, 2001), prayer (VandeCreek et al., 1999), and the use of herbal

medicines (Frate et al., 1996) deal with these stressors after they are diagnosed with breast cancer and whether they use CAM after their diagnosis.

International studies of patients with breast cancer also show CAM use during all phases of treatment. In a British study of patients with all stages of breast cancer, Rees et al. (2000) found that 31% of breast cancer patients had used CAM. An Italian study of 242 women from the Tuscan Cancer Registry found high CAM use in newly diagnosed breast cancer patients (Crocetti et al., 1998). Canadian breast cancer survivors (Boon et al., 2000) also reported high (67%) CAM use. In an Austrian study of 117 early stage (stages 0-2) breast cancer patients (Moschen et al., 2001), 47% of the sample reported CAM use. A German study followed women for 3 years after diagnosis and found that 36% of the women continued CAM use (Nagel, Hoyer, & Katenkamp, 2004). This European sample was referred to CAM practices most often by their physicians. Participants in the international studies used CAM to boost the immune system, increase quality of life, prevent cancer recurrence, and minimize treatment-related side effects.

Use of CAM by Breast Cancer Patients Throughout Process of Illness

Studies of CAM use throughout the breast cancer experience document that women are likely to incorporate CAM into their care at the time of diagnosis, during treatment, at the time of recurrence, and during advanced cancer (Canales & Geller, 2003; Ganz et al., 2002; Shen et al., 2002). Some studies (Boon et al., 1999) have noted the role that CAM plays in the woman's ability to cope during treatment, but the cues that cause her to select a particular CAM strategy at a particular time in the trajectory of her illness are poorly understood.

Breast cancer patients themselves report CAM use at all stages of their illness. In Burstein et al. (1999), 66% of the women used CAM. Many had used CAM before their diagnosis

while others added CAM after their breast cancer surgery. More than half of the CAM users had Stage I breast cancer and had undergone a lumpectomy rather than a mastectomy.

Lengacher et al. (2002) found that two thirds of the patients reported using some form of CAM after their diagnosis. These patients were being treated with chemotherapy and radiation and were heavy users of CAM (vitamins, 53%; art therapy, 64%; music therapy, 73%; and prayer 98%). Prior chemotherapy and radiation therapy predicted CAM use ($p < 0.1$). Women undergoing stem cell transplant, a very toxic treatment, for advanced breast cancer also reported high use (73%) of CAM (Shen et al., 2002). They used CAM to boost their immune system and treat their cancer.

Ganz et al. (2002) studied the quality of life for long-term breast cancer survivors 5 to 10 years from treatment and asked about CAM use. The authors found that the survivors used multiple forms of CAM, such as vitamins and herbs. Another survivor study found a majority of breast cancer survivors were still using CAM 3 years after their treatment was complete (Henderson and Donatelle, 2004). The reasons the survivors described for continued CAM use included to remain free of cancer, to enhance quality of life, to feel more in control, to reduce stress, and to strengthen their immune system. Boon et al. (2000) found that 67% of the survivors in their sample used CAM after being treated with surgery, radiation, and chemotherapy. Again, the most common reason given for using CAM was to boost the immune system, but the women also reported using CAM to improve quality of life, prevent cancer recurrence, feel in control, treat side effects of treatment, stabilize their current condition, and compensate for failed medical treatments.

Long-term survivors (2 to 28 years from diagnosis) have reported using CAM for long-term treatment side effects such as lymphedema, pain, and menopausal symptoms (Ashikaga

et al., 2002; Canales & Geller, 2003). Survivors report using a variety of CAM modalities and gave a variety of reasons for their use: acupuncture for pain, dietary changes for reduction in fats, massage for lymphedema, and herbs for menopausal symptoms. A report of a study funded by the American Cancer Society found that breast cancer survivors believed that CAM use would prevent cancer recurrence (Hann, Baker, Denniston, & Entrekin, 2005).

Reasons for CAM Use During Breast Cancer

A review of the biomedical literature between 1975 and 2002 found the main reasons given for CAM use were to boost the immune system, to improve quality of life, to prevent recurrence of cancer, to provide control over life, and to treat breast cancer and the side effects of treatment (Nahleh & Tabbara, 2003). As demonstrated in studies of women at various stages of breast cancer, women with breast cancer report various reasons for incorporating CAM into their self-care. Some reasons focused on health maintenance, while others dealt with specific symptoms of treatment. Yet another group saw CAM as a way to cure their cancer. A study by Boon et al. (1999) found that CAM was used mainly for survival and to be proactive in an attempt to prevent further illness. Curing cancer in these women's view involved boosting the immune system to fight cancer. In a multiethnic sample of breast cancer patients from California, Adler and Fosket (1999) found many of the same results. They reported that a sample of women representing 7 ethnic groups used CAM for control of their cancer and to strengthen their antibodies. The majority of these patients used CAM before treatment, during treatment, and after treatment was complete.

Toxicity from treatment has been found to be a predictor of CAM use in studies of breast cancer patients. In a study by Chou et al. (2000) of a multiethnic sample of patients either being treated or in follow-up for breast cancer, 58% reported CAM use to improve health,

prevent cancer recurrences, and to deal with the side effects of cancer and its treatment.

Receiving chemotherapy was the strongest predictor of CAM use in this study. Other authors have found that toxicities associated with chemotherapy administration and both acute and chronic side effects of treatment are strongly implicated as factors in women using CAM (Boon et al., 2000; Burstein et al., 1999; Lengacher et al., 2002; Whittemore & Grey, 2002).

Use of complementary therapy within the African American community.

Few investigators have consciously sought samples representing diverse ethnic groups of women with breast cancer. Most of the groups studied are European Americans and tend to be educated and affluent, limiting the generalizability of information from these reports to the broader population of women with breast cancer. Evidence for this lack of generalizability is provided in the few studies with diverse samples where there are striking differences in the amount and types of CAM used by ethnicity.

Fletcher (2000) described a rich tradition of the use of folk medicine within the African American community. African slaves brought this tradition to the United States, and the African American community used folk medicine both to preserve their culture and to deal with day-to-day health problems. Modern-day folk healers enable African Americans to preserve cultural traditions and to reduce the costs of health care (Struthers & Nichols, 2004). Family and community leaders within this system of care are sources of health information and are seen as healers within the African American community. In a study of complementary therapy practices of breast cancer patients in New York City, Cushman et al. (1999) found that African American breast cancer patients continued to use the folk medicine practices they had learned from their grandmothers in the rural South. A study from rural

Mississippi (Frate et al., 1996) documented a high incidence of folk medicine use. The majority of the patients surveyed were African American (78%). These authors defined folk medicine as plant-derived and found heavy use of lemon, aloe, castor, turpentine, tobacco, and garlic. This list of therapies is important as it defines therapies included in the classification of folk medicine. A study from rural North Carolina (Arcury, Bernard, Jordan, & Cook, 1996; Arcury et al., 2004) also found high use of folk medicine such as turpentine-kerosene-gasoline. Their list of therapies was similar to those defined in Mississippi, but their sample was composed of mostly rural European Americans.

A qualitative study of African American women with advanced breast cancer (Mathews et al., 1994) showed that spirituality in the form of prayer and attendance of church services was prominent in African Americans and an important aspect of the African American healing tradition. These authors described the way the women used their spirituality to blend the biomedical model with their concept of God as healer and protector. The women in the studies described above used folk remedies and spirituality as forms of complementary medicine. In these instances, folk remedies can be classified as biological treatments and spirituality as a mind-body therapy using the NCCAM classifications (NIH, 2001).

Cuellar et al. (2003) asked rural elders (143 European Americans and 40 African American) from Mississippi about CAM use. The authors of the study defined CAM therapies as reiki, chelation, hypnosis, and naturopathic medicine, and also included prayer and folk medicine. Because the authors included forms of CAM used by both African Americans and European Americans it is not surprising that the investigators found no difference in CAM use between the European Americans and the African Americans. Inquiry

into CAM use must include culturally relevant types of CAM to adequately describe the CAM experience.

Bethel Ann Powers (1982) used a case study to illustrate the influence of folk medicine in the African American community. Her description of the two systems complementing each other shows how members of the African American community blend conventional biomedicine with folk medicine. The patient in the case study, VJ, consults a conventional healer and a traditional healer, a root doctor. A root doctor is a healer who has received a gift of healing, passed down from family members or in mystical ways such as a miraculous birth or a distinctive birthmark (Mathews, 1987). Conventional biomedical providers may also be seen as healers (Mathews et al., 1994). The cultural influences of religion, traditional healers, and home remedies are important aspects of health within the African American culture and must be included in any inquiry about CAM use in this segment of breast cancer patients.

In studies of CAM use where samples of breast cancer patients have significant minority representation, authors have found high rates of CAM use in each ethnic group. Mackenzie et al. (2003) found all minority groups, which included African Americans, Latinos, Asians, and Native Americans, using CAM. Each group used different combinations of CAM treatments, but all used CAM therapy of some kind. Lee et al. (2000) reported similar results from a study of breast cancer patients. About half of the women in that study used CAM, but the types of CAM varied with their ethnic group. African Americans in the sample were most likely to use mind-body therapy in the form of spiritual healing, while European Americans were more likely to use biologic therapies or dietary therapies. When African Americans in surveys of CAM use were asked about the things they did to improve their health, they reported religion, home remedies, and traditional healers to be important. These modalities

must be included in inquiries about CAM, and a mixed ethnic sample is vital to generalize to the wider population of breast cancer patients.

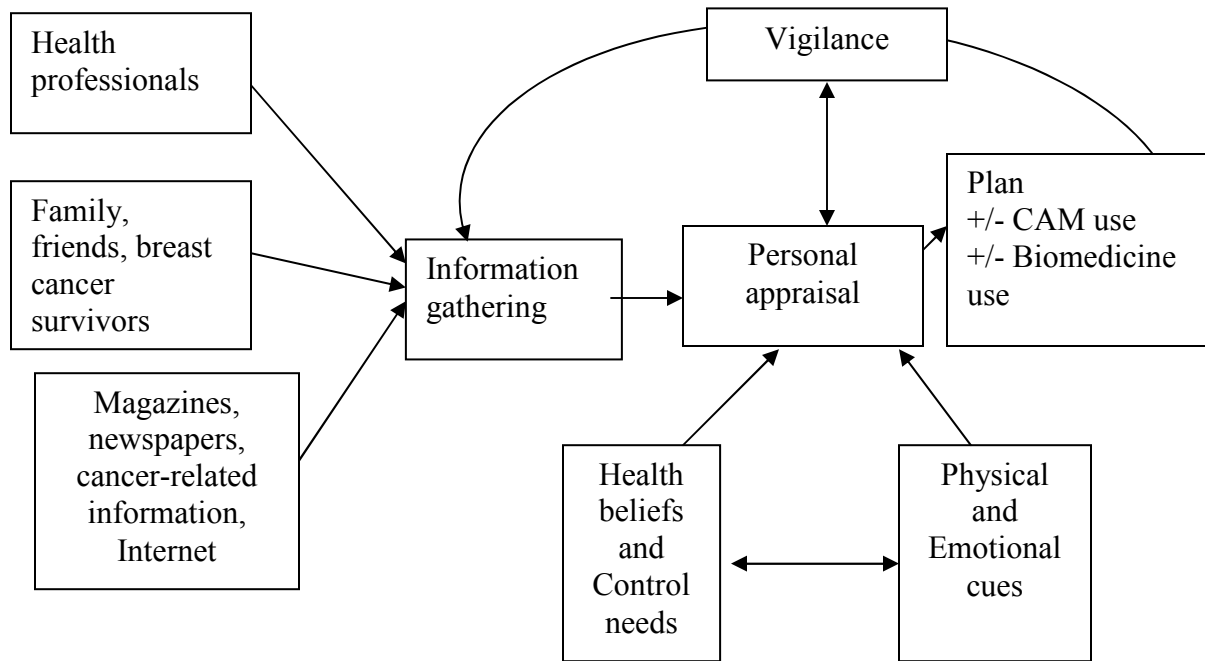
Decision-making for CAM

Although several models have been proposed to describe the decision to use CAM during breast cancer, they are difficult to apply over the course of breast cancer, through treatment to advanced disease, and are based primarily on data from the dominant cultural group in this country. Figure 1 represents the current state of the literature about CAM use in breast cancer. This alternative model is dynamic and can be applied over the entire breast cancer experience with women of varying cultural groups.

The literature documents that women with breast cancer use CAM from the time of diagnosis through terminal care. This model proposes that women with breast cancer engage in a process of personal appraisal before diagnosis, through treatment, and after treatment. This appraisal is influenced by their health beliefs (including culturally based beliefs), physical and emotional cues about the meaning of cancer, and the information that the woman gathers from her external environment.

Figure 1.

Model for Decision-making in CAM Therapy.



Health beliefs and physical and emotional cues influence each other. For example, the patient with significant toxicity from treatment may have less confidence in the conventional biomedical provider who prescribed her chemotherapy than in the folk healer who provided a CAM therapy that relieved her symptoms. Once a woman appraises her situation and settles on a plan, she may choose to use CAM exclusively, to use CAM in combination with biomedicine, or not to use CAM at all. Women who use CAM exclusively make up a very small group of women (Montbriand, 1998). In addition, personal appraisal may influence women with breast cancer to become more vigilant about cancer and their health. Vigilance motivates the woman to seek additional information about her breast cancer and CAM and also triggers her personal appraisal to reevaluate her plan and perhaps modify it. She

modifies her plan as beliefs, cues, and information change through appraisal. Personal appraisal may either increase or decrease her level of vigilance and, in turn, CAM use. The more physical cues—either positive or negative—she has and the stronger health beliefs she has about the usefulness of CAM, the more likely her personal appraisal will increase vigilance and the need for information gathering about CAM. Personal appraisal is the process by which women choose to include or exclude CAM from their care. Each woman's plan is fluid and individual and is modified as her appraisal dictates.

Information Gathering—Sources of Information

From the time of diagnosis of breast cancer, most women seek information to understand cancer and its treatment. In their qualitative study of decision-making over the life cycle, Brown, Carroll, Boon, and Marmoreo (2002) found that information seeking was essential for decision-making about the use of complementary medicine in breast cancer. They concluded that an overriding theme in studies of women's decision-making was the need to find reliable and accurate information in order to make sense of the decision before them. This is a part of decision-making about CAM for women with breast cancer. Information gathering may be the first step in the process of deciding to use CAM. For some women, the lack of credible information about CAM determined that they would not use it (Boon et al., 2000). So, although the woman seeks information, the information that she finds or fails to find and her appraisal of the quality or reliability of that information may affect her decision-making about CAM use (Chou et al., 2000; Cushman et al., 1999; Paltiel et al., 2001).

Health professionals.

Patients frequently consult health care providers for information about CAM (Canales & Geller, 2003; Moschen et al., 2001). Breast cancer patients sometimes rely on their providers

as sources of conventional treatment information and also information about CAM (Edgar, Remmer, Rosberger, & Fournier, 2000; Shen et al., 2002). However, some patients reported that their reluctance to use CAM was due to negative reactions from their providers (Boon et al., 1999; Chou et al., 2000) and that some providers actively discouraged CAM use (Burstein et al., 1999). Other breast cancer patients reported using CAM because their experience with biomedicine had been negative (Montbriand, 1998).

Family and friends.

Family and friends influence decision-making by breast cancer patients. In a study by Crocetti et al. (1998), pressure from relatives was reported to be one of the most powerful reasons the women gave for choosing CAM. The women valued family and friends as information sources (Boon et al., 1999), sounding boards (Moschen et al., 2001), and systems of support (Rees & Bath, 2001). In the African American community, older female relatives give information about CAM to breast cancer patients and pass on traditional medicine practices (Cushman et al., 1999). Women in breast cancer support groups are also an important information source for breast cancer survivors (Canales & Geller, 2003; VandeCreek et al., 1999). In one study, attendance at a support group positively influenced the likelihood that a woman would choose CAM (Alferi et al., 2001).

Media.

Another source of information that breast cancer patients report using in their decision-making is the media. Women actively look for information in the library (VandeCreek et al., 1999) or on the Internet (Crocetti et al., 1998). Many women undertake a program of reading (Canales & Geller, 2003) and personal study to draw conclusions about CAM from the

information they find. When they find insufficient information to support a choice of CAM, they are less likely to adopt its use (Shumay et al., 2002).

Demographic variables.

Demographic characteristics also have been demonstrated to have a positive relationship with CAM use. Their place in the model is unclear, but they seem to be part of the context within which women process information. Demographic characteristics that appear to predispose breast cancer patients to use CAM include young age (Adler & Fosket, 1999), more education (Ashikaga et al., 2002), higher income (Burstein et al., 1999), Christian religion (Alferi et al., 2001), being married (Downer et al., 1994), and having insurance (Lee et al., 2000). However, without more studies that sample a more heterogeneous group of CAM users, the role of these demographic characteristics remains unclear. For example, reports of information gathering in different ethnic groups (European Americans, Japanese, and non-Japanese cancer patients) found that the three groups sought different types of information from different sources (Kakai et al., 2003).

Personal Appraisal

Personal appraisal is the process each woman with breast cancer uses to sort through the information she gathers. Influenced by her health beliefs, emotional and physical cues, experiences with biomedicine, history, culture, support systems, treatment, and information she gathers from resources, she will formulate a personal plan. Each woman has a distinct set of factors that influences her personal appraisal, influences that vary in importance to the woman during diagnosis, treatment, and follow-up. In a model described by Crocetti et al. (1998), women decided about CAM based on personal experience. They utilized information from family, friends, and practitioners, but the most important influence was their own

experience. Other authors (Balneaves & Long, 1999; Bowman et al., 2003) describe a similar process. Lazarus and Folkman's (1984) theory of stress and coping first described appraisal. According to these authors, stress occurs when a situation (stressors) in the relationship between person and environment is determined by the person to be a threat or a challenge. Using cognitive appraisal, a person evaluates the significance of cancer stressors in terms of personal well-being (primary appraisal) and available resources for coping (secondary appraisal). The appraisal process is modified by the unique characteristics of the person or the environment (Folkman & Moskowitz, 2000). Coping is any attempt to mediate the cancer stressors by changing the meaning of the threat or changing the environment. Reappraisal involves reevaluation or change in an earlier appraisal of a stressor based on new information or effective coping strategies (Dowling, Hockenberry, & Gregory, 2006). In a focus group study by Canales and Geller (2003), the participants responded to the life-threatening illness of cancer by using appraisal, blending biomedicine with CAM to take care of themselves. Their beliefs about cancer as a life-changing event framed their adoption or rejection of CAM. Boon et al. (1999) described a process like appraisal in their model as an evaluation of the pros and cons of using CAM and building a treatment protocol, a highly individualized process. They found that the patient assumed responsibility for choosing from multiple options available to them. The work from which this model is drawn is based on a sample of affluent, European Americans women. It does not reflect the strong influence within the African American community of cultural health beliefs related to the meaning of physical symptoms (Mathews et al., 1994) or African American women's distrust of information given to them by conventional biomedical practitioners (Phillips, Cohen, & Tarzian, 2001).

Truant and Bottorff (1999) described the process of settling on a plan as hand-picking complementary therapies that fit and getting a personal regimen in place. The appraisal phase either may conclude with incorporation of CAM into the plan or may increase the woman's vigilance to prompt her to collect more information and reassess her plan. Regardless, these processes need to be clarified in samples that are more heterogeneous.

Factors Affecting Personal Appraisal - Health beliefs and control needs.

Health beliefs and control needs are very influential in women's decisions to choose CAM for breast cancer. A Canadian study found that CAM users feared recurrence and death from their breast cancer more than non-CAM users (Rakovitch et al., 2005). One of the strongest factors in determining CAM use during breast cancer treatment has been identified as prior CAM use (Burstein et al., 1999; Crocetti et al., 1998; Rees et al., 2000). Women who believe that CAM can benefit them and have used it successfully before their cancer diagnosis will continue CAM after diagnosis and add more CAM therapies (Adler, 1999) during treatment.

Women who use CAM report using it for beliefs directly related to their cancer, including faith in CAM to enhance survival (Downer et al., 1994), to detoxify from treatment (Shen et al., 2002), to aid conventional therapy (Moschen et al., 2001), to prevent recurrence (Alferi et al., 2001), and to boost their immune system (Boon et al., 2000). Indirect effects are more related to health maintenance, including beliefs that they have nothing to lose and that CAM is harmless (Boon et al., 1999), reduces stress (Truant & Bottorff, 1999), improves health (Patterson et al., 2002), increases quality of life (Paltiel et al., 2001), and makes them stronger (Astin et al., 2000).

Culture has a strong influence on health beliefs. Several studies with European Americans and African American samples note that the two cultures differ in their health beliefs about cancer (Ashing-Giwa, 1999; Barroso, McMillan, Casey, Gibson, & Kaminski, 2000; Champion & Scott, 1997), including the belief that cancer is a death sentence; the role of luck in cancer incidence; or women's perceived susceptibility to breast cancer. Within the small number of samples of African American patients who have been studied, there was a strong belief in the benefit of CAM, in the form of herbal remedies and spiritual healing (Fletcher, 2000; Lannin, Mathews, Mitchell, & Swanson, 2002).

Women who use CAM exhibit the need for ultimate control of their plan. They also take part in decisions concerning conventional biomedicine treatment (Hack, Degner, & Dyck, 1994) and report additions of CAM to optimize their overall health (Beaver et al., 1996). Balneaves, Kristjanson, and Tataryn (1999) found that women who used CAM were more likely to prefer an active or collaborative role in decision-making about their care. Adopting CAM provided the women with a feeling of control in other reports of CAM use (Boon et al., 2000; Montbriand, 1995b).

Factors Affecting Personal Appraisal - Physical and emotional cues

The use of CAM seems to be influenced by emotional and physical cues. Women with more emotional distress in the form of anxiety (Downer et al., 1994), depression (Burstein et al., 1999), fear of recurrence (Edgar et al., 2000), and somatic complaints (VandeCreek et al., 1999) are more likely to use CAM. The question of motivation is unclear. Do women use CAM because of these emotions or are women with these emotions more likely to use CAM? Previous investigators administered questionnaires or scales to measure these variables, and so the sequencing of the cue and the CAM use is unclear. Physical distress is also linked to

CAM use. Women with cytotoxic chemotherapy (Boon et al., 2000; Ganz et al., 2002), extensive surgery (Shen et al., 2002), treatment side effects (Ashikaga et al., 2002), and more advanced disease (Burstein et al., 1999) were more likely to use CAM. Having had more therapy leads to increased symptom burden (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Ganz et al., 2002). In studies of CAM use, women taking Tamoxifen were less likely to use CAM than women whose disease required cytotoxic intravenous chemotherapy (Balneaves, Kristjanson, & Tataryn, 1999; Chou et al., 2000). If the woman's breast cancer required an axillary dissection (Ashikaga et al., 2002), an indication of a more extensive cancer, or if the pathology showed positive lymph nodes (Alferi et al., 2001), another indication of extensive disease, she was more likely to use CAM.

Cytotoxic chemotherapy and extensive surgery are more likely to produce treatment side effects, and the women who reported treatment side effects were also more likely to use CAM. The sequence of side effects/CAM use is also unclear. The literature reflects that women who use CAM have more nausea and vomiting (Lee et al., 2000; Shumay et al., 2002), swelling (Canales & Geller, 2003), pain (Alferi et al., 2001), physical distress (Crocetti et al., 1998), and limited physical functioning (Ashikaga et al., 2002). Women with more advanced breast cancer were also more likely to use CAM regardless of race (Burstein et al., 1999; Mathews et al., 1994; Paltiel et al., 2001; Patterson et al., 2002). The literature is clear that the more distressing physical cues the woman receives, the more likely she is to use CAM. The input in the process of personal appraisal by health beliefs and physical and emotional cues may affect the information gathering and the value given to that information.

Vigilance

Vigilance is the heightened state of awareness that women develop in response to the things they learn, the things they believe, and the emotions and feelings they experience after their diagnosis with breast cancer. Vigilance also leads women to seek out new information about breast cancer or CAM. When the patient has increased vigilance, physical and emotional cues become more meaningful than when vigilance is lower. In a model for decision-making by Balneaves and Long (1999), the authors combine the stress and coping theory of Lazarus and Folkman (1984) with the conflict-theory model of Janis and Mann (1977) to describe decision-making in breast cancer. They examine the complexity of decision-making during breast cancer and emphasize the importance of embedding the conflict of deciding about treatments for breast cancer within the life stress of the total breast cancer experience. High-quality decision-making is defined by vigilant information processing utilizing behavioral and cognitive processes. Vigilance may be heightened in women with breast cancer for many reasons, such as experiencing physical symptoms, learning new information about breast cancer or CAM, losing confidence in the health care provider, or hearing or reading about a new biomedical advance being made in breast cancer. The woman appraises change as it applies to her and her personal preferences, and then she may reformulate her personal plan. Vigilance is the impetus to seek assistance for symptoms. Lack of vigilance causes the woman to minimize symptoms. It is alluded to in the model built inductively by McWilliam et al. (2000) that describes the way providers and patients communicate. They found that when patients felt vulnerable or out of control, they sought information to deal with their feelings of vulnerability. Negative interactions with biomedical providers caused the women to seek information elsewhere: from CAM providers, family, and friends. The women in their study described their information seeking

as meeting a need to regain control over their body. Control is also a part of the proposed exploratory model and is instrumental in personal appraisal, feeding into the amount of vigilance. The higher the patient's vigilance, the more likely they are to modify their personal plan because they are more attentive to cues, beliefs, and information.

Summary

The components of the model for decision-making about CAM in patients with breast cancer interact in a recursive fashion. The model is not static, and the elements of the model redefine themselves as the woman with breast cancer progresses from diagnosis through treatment to follow-up. She may be diagnosed, be treated, and live for many years without breast cancer. The CAM that she uses at the time of her diagnosis will be modified as her life progresses. If the patient's breast cancer returns, she may incorporate different types of CAM in response to her personal appraisal, her level of distress, and the information she finds useful to her plan. The sources of information the breast cancer patient with recurrent disease uses may be different from the ones the woman who experiences a remission of her disease uses. As the cancer experience becomes more remote, the woman's vigilance may diminish depending on her perceived risk of recurrence, which may be modified by her past history. The more frequently cues occur, the more heightened her vigilance. Personal appraisal is at the heart of the model. Through appraisal, the plan for CAM use is developed and modified. To do this, the woman receives information from the outside in light of her health beliefs, cultural influences, and personal cues. Personal appraisal is the black box within which outside influences are processed. The results of the woman's personal appraisal are a plan to incorporate CAM or not and continual vigilance. Vigilance is the heightened state of awareness that women develop in response to the things they learn, their life experiences, the

things they believe, and the emotions and feelings they experience after their diagnosis of breast cancer. One woman in the Canales and Geller (2003) study said, “I learned to become my best advocate ... I really learned that you have to trust yourself” (p. 16). The interplay between the elements of this model defines an experience of decision-making during breast cancer that acknowledges the cultural diversity of the breast cancer experience.

Chapter 3

Study Methods

CAM use was studied in a sample of European Americans and African American women receiving treatment for breast cancer. The investigation synthesized individual interviews and quantitative data from selected questionnaires to provide a rich description of women experiencing treatment for breast cancer who decided to use CAM, and the process of their decision-making. Although CAM use has been described in some populations of women with breast cancer, this study expands the scope of descriptions of CAM use to include African American and rural women.

Design

This is an exploratory descriptive study that used a cross-sectional design, recruiting and collecting data at one point in time from women currently receiving breast cancer treatment. The study was designed to combine qualitative and quantitative data to elicit a rich description of the decision to use CAM during treatment for breast cancer and the factors that influenced that decision.

Methods

The study used three methodological approaches, individual interviews, a card sort and selected quantitative instruments. A qualitative approach, using individual interviews, generated descriptions of CAM decisions by European Americans and African American women to provide in-depth information about CAM decision-making and a private forum to

explore unique forms of CAM use accounting for patient's issues with disclosure.

Quantitative data were generated from instruments measuring the particular types of CAM used; for treatment toxicities; and influences important to group members in the selection of CAM, as well as demographic and treatment information.

Individual interviews were used in this study to clarify the elements of decision-making about CAM, as they are useful to explore motivations in depth (Kerlinger, 1986). By conducting individual interviews, meanings can be clarified in a private, flexible atmosphere. Disclosure is an issue in the study of CAM use in breast cancer (Adler & Fosket, 1999), so, in the privacy of an interview, it may be more comfortable for women to discuss. An interview can delve into the types and motivations for CAM use more easily than other forms of data collection (Boon et al., 2000; Montbriand, 1999). Interviews have been used successfully to investigate CAM use (Brown & Carney, 1996; Crellin & Philpott, 1989; Shumay, Maskarinec, Kakai, & Gotay, 2001), CAM decision-making (Shen et al., 2002; Tasaki, Maskarinec, Shumay, Tatsumura, & Kakai, 2002), and with African American samples (Baldwin, 1996; Henderson & Donatelle, 2003). Therefore, the individual interviews provided a depth and richness to the information about CAM use and the forces that influenced women to adopt CAM.

The Sample

The sample for the study was a convenience sample of European Americans and African American women who were currently receiving treatment for breast cancer. Other inclusion criteria were:

- Aged 18 and above

- Stage II-IV breast cancer
- Patients with breast cancer currently receiving or had received in the past chemotherapy, hormonal therapy, or radiation therapy
- Able to speak and read English

Women were recruited from the population of breast cancer patients who had used CAM in the past or who expressed an interest in using CAM. Although less common, breast cancer may occur in young women. Several studies report that young age is a positive factor in CAM use (Ashikaga et al., 2002; Boon et al., 2000; Gray et al., 2003); however, older women have also been found to also use CAM (Astin et al., 2000; Navo et al., 2004; Wyatt et al., 1999). Therefore, women of any age above 18 years were included in the sample.

Women who have used CAM prior to their breast cancer diagnosis are more likely to continue CAM during treatment (Rees et al., 2000) and were a rich resource for study of CAM decision-making. Cancer treatments often have treatment-related side effects generating physical and emotional cues. These cues have been shown to increase the likelihood that women may choose to combine CAM with biomedicine (Adler & Fosket, 1999; Alferi et al., 2001). African American women are more likely to present with a more advanced stage of breast cancer (Burri, Landry, Norton, & Davis, 2004; Du & Simon, 2005; Henson, Chu, & Levine, 2003; Li, Burton, & Glass, 2001; Mancino et al., 2001). In order to ensure that there would be an equal number of European American and African Americans in the study, breast cancer patients at all stages of disease were included. Women who expressed an interest in or were currently using CAM were included in the study.

The Setting

The study took place in three different locations around North Carolina in both urban and rural settings. The interviews took place in locations convenient to participants, including an oncology clinic, a wig and prosthesis shop, a public library, a school of nursing, and private homes.

Wake County participants were recruited from the Wake County area, as the principal investigator (PI) has extensive community contacts in this setting due to clinical practice in oncology nursing and experience with cancer patients as an American Cancer Society volunteer. African American subjects were recruited primarily from the clinic population of a community hospital serving a large African American and rural population and from an African American support group organized by a former patient of the PI. European Americans participants were recruited from wig and mastectomy supply businesses in the Wake County area.

Procedures

Pilot Study

After Institutional Review Board (IRB) review and approval, an expert panel was convened to review study materials for appropriateness of language of the quantitative instruments, the interview questions, and the feasibility of procedures for the individual interviews. As African American women had not often been included in recent research about CAM use in breast cancer treatment, the study materials were evaluated for content validity and relevance for this sample of women. The expert panel was made up of a CAM

provider; African American community members; a nurse researcher familiar with CAM use in breast cancer treatment; an oncology nurse; community contacts in Wake County; an African American faculty member from a historically Black university to provide input for recruitment and cultural issues; and an oncologist specializing in breast cancer treatment. The group was asked to review the procedures of the study for ease of participation by patients in active treatment; to assess the relevance, order, and wording of the interview questions; to comment on the language used in the quantitative measures; and to review the list of CAM treatments for completeness and redundancy. The panel was also asked to add additional items they had encountered in their experience to the working list of CAM therapies. Following review and input from the expert panel, procedures and questions were revised.

Recruitment

Community contacts and key informants were enlisted to assist in identifying potential subjects for recruitment. Community contacts included oncologists, oncology nurses, breast cancer support group leaders, CAM therapy providers, and key informants in the African American community. They introduced the study to potential participants and provided a list of names and numbers for the PI to follow-up with by phone. The PI also visited clinics and shops to recruit participants and placed posters and fliers with the permission of the community contacts. Community contacts had proven to be important sources for patient recruitment in prior studies of CAM in breast cancer treatment (Gibson, 2000; Henderson & Donatelle, 2004; Navo et al., 2004;). Special attention was given to recruitment of African American subjects, as they are often resistant to participation in studies (Fields, 2001; Matthews, Selligren, Manfredi, & Williams, 2002). Fliers and posters (Appendix A) were placed in oncology clinics, on African American radio station bulletin boards, and in

businesses selling CAM treatments, such as health food stores and wig and prostheses shops. If patients who saw these advertisements were interested in the study, they were asked to call the investigator on a toll-free number for more information. This number was linked to a mobile phone, which was carried by the PI and equipped with a voice messaging system. Snowballing and nominating recruitment were also utilized to increase study participation. In snowballing, subjects with breast cancer were asked to pass along information about the study to other patients with breast cancer whom they believed would like to participate. Nomination involved community contacts suggesting potential subjects for follow-up by the PI (Kruger & Casey, 2000). The PI recruited by telephone women who agreed to be contacted about the study.

When a woman agreed to participate in the study, she was sent an overview of the study and directions about the time and place of the interview. Each woman received a follow-up call on the day of the interview as a reminder of the meeting. At the beginning of each interview, the PI reviewed the consent form, answered questions about the study from the participant, and had her sign the consent form (Appendix B). Participants signed consent for the interview and also, if they agreed, signed consent for a follow-up interview. Each participant received a copy of the consent for her records. Interviews were arranged over the phone by the PI, at a time and location convenient to the participant.

The individual interviews lasted about 1½ hours each. Cash payment (\$20 each) was provided to the participants as an incentive for participation. The PI conducted all interviews. The interviews were audio-taped with the permission of the participants and transcribed verbatim for analysis.

Individual Interview Procedure and Card Sort

After questions were concluded and the subject's consent form was signed, the participant received a set of CAM cards and five blank cards (see Appendix C for CAM card list). The set of 81 cards listed 1 CAM therapy per card. The women sorted the cards using a card sort format to begin their discussion of their CAM use. For a card sort, between 30 and 100 cards have been found to be useful, as fewer numbers of cards do not allow for grouping of cards and more cards can be tiring and time consuming (Maurer & Warfel, 2004). The participants were asked to go through the card set and sort them into five categories: the forms of CAM they were currently using; the forms of CAM they had ever used but were not using at the time of the interview; those that they had considered but never used; those they had never used and were not considering; and those they had never heard of. Later in the session, the women were asked to separate the cards of the CAM therapies they were currently using into those they used for general health and those they used specifically for the breast cancer and its treatment. The blank cards were available for the participants to add CAM treatments not included in the card stack. This form of inquiry, a card sort, has been used successfully in past studies with breast cancer patients (Hack, Degner, & Dyck, 1994), and the results of the card sort have been analyzed using the theory of preferential choice. Bilodeau and Degner (1996) used preferential choice to examine treatment decision-making by breast cancer patients. Using the card sort was intended to both mirror a part of the patient's decision to use CAM and to stimulate discussion about how decisions about CAM are made (Bilodeau & Degner, 1996). A paper and pencil tally reflecting the distribution of the CAM cards selected by each patient was totaled and recorded on the CAM Tally Sheet (Appendix D). Using the

Interview Guide (Appendix E), patients were asked about how they had decided about the CAM therapies they were using and the factors that influenced them in their decision-making. The questions in the guide explored the words they used to describe the complementary therapies they used to deal with their breast cancer and its treatment; their personal experiences with CAM; and the barriers and facilitators to their CAM use. With each modality the influences to use or not to use CAM (Boon et al., 1999) were explored, and the women described the ways they had come to use CAM. As more interviews took place, the Interview Guide was modified to clarify the themes identified in previous interviews.

At the end of each interview, the PI wrapped up the discussion by asking for the women to add thoughts and feelings about their experiences and decisions not covered by the interview guide. The women then completed the packet of quantitative instruments. The amount of time allotted for this was approximately 20 minutes. This packet included the Breast Cancer Chemotherapy Toxicity Questionnaire (Levine et al., 1988), the Sources of Information in Cancer (Mishel, Germino, Belyea, & Stewart, 2003), and the Demographic and Cancer Treatment Form (Lengacher et al., 2003). The PI was available to assist the women in completing the forms if there were questions or if the participants had difficulty reading them. On several occasions the PI read the forms to participants due to reading levels of the participants or physical difficulties in holding the paper and pen to complete the forms related to treatment toxicities. After completion of the forms, the cash payment was distributed. The women were offered the opportunity to receive summaries of the study results at the end of the investigation.

Each interview was audio-taped and transcribed verbatim for analysis. In addition, the PI made notes as necessary during the sessions or immediately following the interview. After

the interviews were transcribed, the PI and the dissertation chair reviewed the transcripts. Analysis began after the first interview was complete and transcribed (Strauss & Corbin, 1990).

Variables and Instruments

The elements of the women's decision-making process—the patients' level of vigilance, their personal plan, their personal appraisal, their information gathering, plus their health beliefs and personal cues—were assessed by individual interviews and with quantitative instruments.

Quantitative Instruments

Quantitative measures attempt to assign objects to categories that represent the amount of a characteristic an object has (Waltz, Strickland, & Lenz, 1991). The influences on CAM decision-making have been measured using reliable quantitative measures. These influences included level of toxicity and information sources. Adding these measures to the descriptive data about the women who were interviewed helped to locate them in the population of breast cancer patients. How sick were these women? Whom did they consult about health care decisions? By providing validated measures of toxicity and sources of information about the women, this study was designed to add to information available about rural and African American women's breast cancer experiences.

Personal Cues

Personal cues are emotional and/or physical signals to women that they are having a problem that may be aided by adding CAM to their personal plan. Cues include somatic symptoms (VandeCreek et al., 1999) and/or emotional distress in the form of anxiety (Downer et al., 1994), depression (Burstein et al., 1999), or fear of recurrence (Edgar et al.,

2000). They were operationalized as responses to the modified Breast Cancer Chemotherapy Questionnaire (BCQ) (Appendix F), a 30-item questionnaire with a 7-point Likert response scale (Levine et al., 1988). The BCQ focuses on physical and emotional cues and quality of life during treatment for breast cancer. Questions addressed physical, functional, sexual, and social aspects of quality of life. When the original BCQ was compared with other measures of the quality of life (correlation coefficients with Rand Emotional [0.58], Rand Physical [0.60], and Spitzer QL [0.62]), it proved a valid and responsive measure of treatment-related morbidity over time in patients receiving adjuvant chemotherapy for stage II breast cancer (Levine et al., 1988) measured at different times in the patients' treatment cycles. The final score for the BCQ is expressed as the sum of the 30 questions, each on a 1-7 scale. Many studies of women who use CAM during breast cancer treatment report that emotional and physical distress increases the likelihood that they will use CAM (Ashing-Giwa, Ganz, & Peterson, 1999; Boon et al., 2000; Burstein et al., 1999; Crocetti et al., 1998; Gotay et al., 1999). The BCQ has documented validity when used with other cancer samples in Eastern Cooperative Oncology Group and National Cancer Institute clinical trials (Gunnars, Nygren, & Glimelius, 2001). This instrument specifically includes items about hair loss, which is an important issue for African American women (Wilmoth & Sanders, 2001). The original BCQ was designed to be administered by an interviewer but was used in this study as a questionnaire with three possible responses: "All of the time (3)," "Some of the time (2)," and "None of the time (1)." As in the original instrument, the final score for the modified BCQ was expressed as the sum of the subject's answers. Additional items were added to the BCQ by the investigator to reflect the current understanding of toxicity experienced by patients receiving treatment for breast cancer, cues that patients report lead them to use CAM

treatments (Ferrell et al., 1997), and neutropenia, a toxicity with a high incidence in African American cancer patients (Hershman et al., 2003). The resulting questionnaire had 35 items, including questions about fatigue, alopecia, feeling good about self, numbness in fingers, menopausal symptoms, depression, nausea, change in body image, positive feelings about the future, insomnia, worry, vaginal dryness, family support, alterations in smell, tearfulness, increased production of gas, low blood counts, optimism, constipation, feeling in control, mouth sores, and watery eyes. The revised BCQ was evaluated by the expert panel for content validity before the study began. Changes in format and minor content changes were made. The final questionnaire included 33 items in a modified Likert format with three possible responses: “All of the time (3),” “Some of the time (2),” and “None of the time (1).” An analysis of internal consistency was assessed when all data collection was complete by calculation of coefficient Cronbach’s alpha for the entire sample. The resulting Cronbach’s alpha was 0.827 for the 33-item Breast Cancer Treatment Toxicity Questionnaire (name for the modified BCQ).

Sources of Information

Information sources are defined as individuals, institutions, and media that provide information for women in their process of deciding about using CAM during their treatment (Rees & Bath, 2001; Wallberg et al., 2000). They were assessed using the Sources of Information Checklist (Appendix G). This is an investigator-generated 22-item checklist of sources of information to be used by patients with breast cancer and includes sources like your surgeon, friends, television/radio, and herbalists. The checklist was modeled after a similar published checklist administered to a sample of African American and European Americans prostate cancer patients (Mishel et al., 2003) and was modified for use with breast

cancer patients by adding breast cancer appropriate items (Degner et al., 1997; Kakai et al., 2003; Satterlund, McCaul, & Sandgren, 2003). This checklist was evaluated by the expert panel for content validity prior to use in the interviews, and modifications were incorporated to reflect their input. The Sources of Information Questionnaire was scored by totaling the number of checked items with higher scores reflecting use of more information sources. An analysis of internal consistency was assessed when all data collection was complete by calculation of coefficient alpha for the entire sample. The resulting Cronbach's alpha was 0.8964 for the 30-item Sources of Information Questionnaire

Complementary and Alternative Therapy (CAM)

As the construct of complementary therapy is not consistently or clearly defined in the literature, individual interviews were used to explore its meaning for the women in the study. The motivation to use a therapy not prescribed by conventional biomedicine is central to the construct of CAM. A group of CAM therapies listed on 3 x 5 index cards was the basis for the working list of CAM treatments. The list was generated from studies of breast cancer patients (Lengacher et al., 2003), studies of CAM used by the public (Eisenberg et al., 2001), studies of ethnic samples (Cushman et al., 1999; Lee et al., 2000; Marbella et al., 1998), plus therapies used in traditional and folk medicines within the African American and rural communities (Bushy, 1992; Cuellar et al., 2003; Eisenberg, 1998; Fletcher, 2000; Lee et al., 2000; Lengacher et al., 2003; Marbella et al., 1998). The compiled list was also reviewed by the expert panel, which made additions to the list to reflect current thought and practice in the clinical arena.

The Complementary Therapy Rating Scale (CTRS) by Lengacher et al. (2003) was used as the basis for the initial list. The CTRS was designed to be administered in an interview

setting, so it was modified to a card sort for ease of use by the interview participants. The CTRS list was based on the National Center for Complementary and Alternative Therapy domains of CAM treatment (Lengacher et al., 2002) and developed with input from patients, oncology nurses, oncologists, and administrators of oncology clinics.

The CTRS contains a demographic section that was separated out in this study and used to collect data from each participant on their age, race, education, stage of breast cancer, and current treatment. This form, Use of Complementary Therapy Survey for Breast Cancer—Demographic and Cancer Treatment Form (Appendix H), was distributed to subjects at the end of the interview with the other quantitative instruments. The participants were given instructions, time, and any assistance needed to complete the forms. The original CTRS has been used with breast cancer patients and in rural populations and was found to be reliable with an alpha for the whole scale of 0.86 and for the instrument subscales, ranging from 0.67 to 0.8 (Lengacher, Bennett, Kip, Berarducci, & Cox, 2003).

Elements of Decision-Making

Decision-making was defined here as the process patients use to make decisions about using or not using CAM during treatment for breast cancer. The literature reflects partial definitions of the process of decision-making (Balneaves & Long, 1999; Canales & Geller, 2003; Hack et al., 1994; Meyer, Russo, & Talbot, 1995; Hack et al., 1994; Meyer, Russo, & Talbot, 1995), and the interview questions were designed to produce data that was used to clarify the details of that process. Questions were based on the preliminary model for CAM decision-making, which was generated from the current literature. As the interviews progressed, the questions and probes were modified to better elucidate the decision-making process. A description of the process evolved as the women described their experiences and

decisions. Because of the limited amount of information about CAM decision-making during treatment, the interview questions were open-ended to provide more flexibility for information sharing (Morgan & Scannell, 1998).

Analysis

Data entry and cleaning was continuous from the beginning of the study through final entry of all the data. Data sets were assessed using descriptive statistics, scatterplots, and histograms to detect coding errors using the Statistical Package for the Social Sciences (SPSS) (Belbase & Mason, 2004; Tabachnick & Fidell, 2001). The quantitative measures, the revised Breast Cancer Chemotherapy Toxicity Questionnaire and the revised Sources of Information Questionnaire, were psychometrically evaluated using Cronbach's alpha as an index of internal consistency of the revised instruments (Waltz et al., 1991). The types of CAM used were assessed using the data gathered from the CAM Tally Sheets. Frequencies and descriptive statistics were calculated for by residence of the subjects, by racial groups, and for the total group. The individual interview transcripts and the quantitative data were analyzed separately and then synthesized to maximize the richness of the description.

Aim 1: To characterize CAM use during treatment for breast cancer in a sample of African American and European Americans women from both urban and rural settings in the South.

Descriptive statistics were computed to describe the CAM treatments used by respondents, utilizing the results of the card sort procedures. These analyses were done by ethnicity, by urban/rural residence, and for the entire sample. Interview data furnished

information about when CAM was used and what physical, psychosocial, and emotional factors characterized CAM use.

Aim 2: To clarify the use of CAM for treatment of breast cancer–related issues as compared to CAM use for self-care and healthy lifestyles.

The interview questions included requests for the women to explain the reasons for their CAM use, specifically in relation to treatment of breast cancer–related problems and self-care and healthy lifestyles. The themes from this discussion were coded and compared among the women, the ethnic groups, and the areas of residence. The card sort identified CAM therapies considered by the women related to their breast cancer and those they used for healthy lifestyles. Descriptive statistics were calculated on these differences.

Aim 3: To examine precipitating and influential factors in the choices of European Americans and African American women to use CAM during treatment for breast cancer.

Quantitative data about sources of information and treatment toxicities were combined with themes identified from individual interviews to validate that the elements of the decision-making model were indeed relevant to the women’s choices in the types of CAM selected and the extent or intensity of these factors associated with the decision to use CAM. The two ethnic groups were compared on personal cues.

Aim 4: To describe the process and timing of decision-making that women use in choosing CAM during breast cancer treatment.

The interview transcripts were analyzed to describe the timing of CAM decision-making in relation to the breast cancer diagnosis and treatment as well as other factors such as specific toxicities of treatment. The women's accounts were examined for examples of CAM selection and rejection and the logic the women used to come to these decisions. These

data were compared to the elements of the preliminary model to determine the validity of the model elements and associations, and the model was revised to reflect and describe new, more relevant concepts and associations.

Human Subjects Protection

Women participating in the interviews were in the midst of treatment with the possibility of experiencing treatment side effects such as nausea, fatigue, or low blood counts. At the time of recruitment, they were cautioned to cancel their interview if their provider had warned them to avoid crowds or infected individuals. There were no cancellations due to toxicities. Quantitative instruments were coded with subject numbers to identify the subjects. All study materials were stored in a secure location, and no subject was identified in any presentation of study findings.

Chapter 4

Results

Description of the Sample

Since there are few studies of CAM use that include African American and rural women, the subjects for this study were a convenience sample of 19 European Americans and African American women who had received or were currently receiving treatment for breast cancer. The women in the sample self-identified as European American (10) or African American (9) women. They were interviewed from December 2005 until May 2006. All of the women indicated that they used CAM at the time of recruitment. Tables 2, 3 and 4 display descriptive statistics, socioeconomic factors, and disease characteristics for the sample. Although this sample is small, it is important to note that it is unique in several ways. The sample is equally balanced between European American and African American women, and the setting for this study is a geographic area including both rural and urban locations. The examination of CAM use by demographic characteristics, cited as important in prior literature, begins to elaborate a fuller understanding of CAM during breast cancer.

Demographic Characteristics

Much of the literature about CAM use reports that younger women are more likely to use CAM (Adler & Fosket, 1999; Buettner et al., 2006; Gerber, Scholz, Reimer, Briesse, & Janni, 2006; Hann et al., 2005). The women in this study ranged in age from 35 to 67 with a mean age of 51.16 ($SD = 10.12$). The African American women in the sample ($M = 51.78$, $SD = 9.65$) were slightly older than the European American women ($M = 50.6$, $SD = 11.02$), but

the difference was not statistically significant ($t [17] = .247, p = 0.808$). More of the sample reported that they lived in an urban setting than a rural setting (68% vs. 32%). Table 2 summarizes descriptive statistics for the study sample.

Table 2
Descriptive Statistics for the Sample

| Characteristic | European Americans ($N = 10$) | African Americans ($N = 9$) | Total ($N = 19$) |
|-------------------------------------|------------------------------------|-------------------------------|-----------------------|
| Age | | | |
| Mean (SD) | 50.6 (11.2) | 51.78 (9.65) | 51.16 (10.12) |
| Median | 49 | 51 | 51 |
| Range | 35-67 | 38-67 | 35-67 |
| Residence N (%) | | | |
| Urban | 8 (57.1) | 5 (55.56) | 13 (68.4) |
| Rural | 2 (33.3) | 4 (44.44) | 6 (31.6) |

Work

Inability to work during treatment may be an indication of treatment-related toxicity during breast cancer and certainly affects the amount of disposable income available to purchase CAM. Eleven of the 19 women in the sample were not working at the time of the study. Of this group, 3 were unemployed, 3 were retired, and 5 were disabled. Most of the women who were not working were in the midst of chemotherapy treatments that occurred either weekly or every three weeks. Several of the women reported that they had jobs that required them to be physically active and were unable to do those jobs since they started

treatment. Most of the women who were employed were European American (7), even though the European American women in the study reported more treatment-related toxicity (mean toxicity score: European Americans 83.30 vs. African Americans 74.78). Perhaps as a result of not working, half of the sample reported family incomes below \$25,000/year, and only two of the women reported incomes over \$75,000/year. The African American women in the sample had lower annual incomes than the European American women with 7 of the 9 African Americans reporting incomes below \$25,000/year. Most of the literature about CAM use during breast cancer is with samples of affluent women so, while small, the diversity of incomes for the women in this sample adds to our information about CAM use.

Education

CAM users are often identified as a more educated group than non-users (Nagel et al., 2004). Education levels for this sample of women ranged from less than high school to one participant with an advanced college degree. The average number of years of education was 13.84 (range 8-18 years, $SD = 2.85$). The women differed in education by race with the mean number of years of education for the European American women of 15.3 ($SD = 1.77$) years and the mean for the African American women of 12.22 ($SD = 3.03$) years.

Religious affiliation

Faith and the role of spirituality are often associated with CAM use, and prayer is noted in many studies as an important CAM treatment (Ashing-Giwa & Ganz, 1997; Henderson, Fogel, & Edwards, 2003; Morgan et al., 2005). Although spirituality and faith were not measured directly, most of the women in this sample were members of Protestant or Roman Catholic Christian churches. Further information about the role of faith and spirituality will be discussed from the qualitative data.

Table 3

Social/Economic Characteristics for the Sample

| Social/economic characteristic | European Americans <i>N</i> (%) | African Americans <i>N</i> (%) | Total <i>N</i> (%) |
|--------------------------------|------------------------------------|-----------------------------------|-----------------------|
| Employment | | | |
| Full time | 3 (30) | 0 (0) | 3 (16) |
| Part time | 4 (40) | 1 (11) | 5 (26) |
| Unemployed | 2 (20) | 1 (11) | 3 (16) |
| Retired | 1 (10) | 2 (22) | 3 (16) |
| Disabled | 0 (0) | 5 (56) | 5 (26) |
| Education | | | |
| Less than high school | 0 (0) | 3 (33) | 3 (16) |
| High school diploma | 1 (10) | 1 (11) | 3 (11) |
| Some college | 3 (30) | 4 (44) | 7 (37) |
| Four-year college degree | 4 (40) | 0 (0) | 4 (21) |
| College past four-year degree | 1 (10) | 1 (11) | 2 (11) |
| Advanced college degree | 1 (10) | 0 (0) | 1 (5) |
| Income | | | |
| Under \$25,000 | 3 (30) | 7 (78) | 10 (53) |
| \$25,000-\$75,000 | 4 (40) | 1 (11) | 5 (26) |
| Over \$75,000 | 2 (20) | 0 (0) | 2 (11) |
| Missing data | 1 (10) | 1 (11) | 2 (11) |
| Religion | | | |
| Protestant | 7 (70) | 7 (78) | 14 (73) |
| Catholic | 3 (30) | 0 (0) | 3 (16) |
| None | 0 (0) | 2 (22) | 2 (11) |

Time Since Cancer Diagnosis

The length of time since the women's breast cancer diagnosis ranged from 2 months to 132 months ($M = 32.94$, $SD = 34.23$). One woman who had been diagnosed 132 months ago was clearly an outlier. When descriptive statistics were recalculated with her data removed, the mean time since diagnosis was 27.44 months ($SD = 25.13$), and the range was 2-84 months. Ten of the women had been diagnosed in the past year, and 8 had been diagnosed from 2 to 7 years. The European American women in the sample were more likely to be in their first year of treatment ($n = 7$ of 10), while the African American women were more likely to be more than 2 years from diagnosis ($n = 5$ of 9).

Prior Treatment

The women had received a variety of surgical treatments ranging from biopsy to mastectomy. The most common surgical intervention was mastectomy, with 9 women having undergone this surgery and 2 of those completing reconstructive surgery at the time of the interviews. Seven women had lumpectomy and 3 of the women had only had a biopsy. Postponing surgical resection reflects the current practice of neo-adjuvant treatment. When women present with aggressive breast cancer, they often receive chemotherapy prior to surgical intervention, and therefore these 3 women faced surgical intervention in the future. Fourteen of the women in the sample had received or were receiving chemotherapy. Half of the sample had received radiation therapy.

Table 4

Disease Characteristics for the Sample

| Characteristic | European Americans <i>n</i> =10 <i>N</i> (%) | African Americans <i>n</i> = 9 <i>N</i> (%) | Total <i>n</i> = 19 <i>N</i> (%) |
|----------------------|--|---|--|
| Time since diagnosis | | | |
| 2-12 months | 7 (70) | 3 (33) | 10 (53) |
| 24-84 months | 3 (30) | 5 (55) | 8 (42) |
| 132 months | 0 (0) | 1 (11) | 1 (5) |
| Surgery type | | | |
| Mastectomy | 3 (30) | 4 (44) | 7 (37) |
| Lumpectomy | 6 (60) | 1 (11) | 7 (37) |
| Biopsy | 1 (10) | 2 (22) | 3 (16) |
| Reconstruction | 0 (0) | 2 (22) | 2 (11) |
| Past treatment | | | |
| Chemotherapy | 7 (70) | 7 (77) | 14 (74) |
| Radiation therapy | 6 (60) | 4 (44) | 10 (50) |
| Hormonal therapy | 4 (40) | 3 (33) | 6 (32) |
| Current treatment | | | |
| Chemotherapy | 4 (44.4) | 5 (55.6) | 9 (47.4) |
| Radiation | 0 (0) | 0 (0) | 0 (0) |
| Hormonal therapy | 5 (62.55) | 3 (37.5) | 8 (42.1) |
| None | 1 (50) | 1 (50) | 2 (10.5) |

Current Treatment

At the time of the interview, all patients in the sample were receiving or had completed conventional treatment for breast cancer. Nine were receiving chemotherapy, and 8 were receiving hormonal therapies, and 2 had completed therapy. The women who were currently receiving chemotherapy had the lowest toxicity scores ($M = 73.67$, $SD 9.54$), while the women who had completed therapy had the highest toxicity scores ($M = 88.50$, $SD 2.12$). The patients who were receiving chemotherapy at the time of the interview were more likely to have been diagnosed less than a year and to be European American, while the patients receiving hormonal therapy were likely to be diagnosed between 2 and 7 years and to be African American. This also reflects the current practice of following cytotoxic chemotherapy with estrogen suppression for 5 years (National Cancer Institute, 2005). One of the participants had a prior cancer, a colon cancer for which she had been treated with surgery and chemotherapy. Of the 19 study participants, 8 had family members with breast cancer. The relationships of these family members to the subjects included father (1), mother (1), grandmother (3), aunts (2), and sister (1). European Americans (5 of 8) were more likely to have a family history of breast cancer.

CAM Use for Breast Cancer

In this study CAM use was measured with a card sort to allow the women as much leeway as possible in identifying the CAM therapies they were using. They were given a deck of 81 cards with 1 CAM therapy per card (see Appendix C for the list). The items on the cards were drawn from the CAM-use literature and with input from the expert panel. The women separated the cards into five stacks to identify the CAM they were currently using for their

breast cancer; CAM they were using to maintain or improve their health; CAM they had used in the past but were no longer using; and CAM treatments they did not plan to use. Each woman was also asked at the end of the card sort to identify therapies she was using that were not included in the 81 cards and to add these. The women in this study used a variety of CAM therapies not included in the card sort, such as Lutein, royal jelly, rice milk, flax seed, grape seed, Certo, Oxycise, and positive thinking (Peale, 1952). One woman used Papaw, an extract of *Asimina triloba* that belongs to the Custard Apple Family, during treatment. She began using this at the advice of her herb doctor. She described the Papaw:

It's a pill, and when I was going through my breast cancer I took it. It was just a general taker, I'd just take it with water . . . he [the herb doctor] said that once it get in my system, that 'posed to knock the cancer, you know, out of your body. . . . I know that it helped me . . . it really did help me when I was going through all the things that I was going through.

Frequencies of CAM Selection

The women's responses to the card sort were tabulated. In the card sort, the subjects selected only 53% ($n = 43$, $M = 7.79$, $SD = 5.65$) of the 81 therapies as therapies they were using for their breast cancer (see Appendix I). Nine therapies were selected frequently (by 6 or more women), including prayer (used by 9 women), traditional medicine (8 women), special diet (8 women), antioxidants (7 women), exercise, meditation, special foods, support groups, and vitamin C (all used by 6 women). It is important to note that all the women in the interviews described traditional medicine as using conventional medical providers, their oncologists. They did not subscribe to the definition of traditional medicine delineated in the literature about CAM. In the literature, *traditional medicine* is a specific type of therapy that employs a holistic approach to health (Esper & Heidrich, 2005; Mathews, 1992; World Health Organization, 2003). In several other instances the women's definitions of CAM

therapies differed from the definition of CAM therapies in the literature. The results reported here reflect these women's descriptions of CAM use as defined by them, rather than definitions of CAM therapies from the literature. As an example, when the women reported using a special diet it might have meant a low-fat diet, a diet of organic vegetables, or a diet without junk food. All were tabulated as special diets. In another instance one woman described her family's use of mistletoe. The herb mistletoe has been used in Europe and in this country to boost the immune system (Kienle, 1999; Kovacs, Hajto, & Hostanska, 1991). However, this woman was given it as a child as a tonic. She said:

I had an auntie who would take mistletoe, she would wash them real good. . . . She would take it and dice it up and put it over her greens. But she said it was for some kind of vitamins that would be in 'em, but it didn't taste right, o-o-h. No, ma'am, no, ma'am, it didn't taste right. It didn't taste right cut up in nobody's greens.

Grouping of Therapies

The individual therapies selected by the women in the sample were grouped using the National Center for Complementary and Alternative Medicine (NCCAM) domains (NIH, 2006). These domains were used to determine if there was one type of CAM treatment that was most frequently used by the women. NCCAM uses five domains to classify CAM treatments. One part of this general classification divides types of therapies into the way they are delivered. The method of delivery of a type of CAM is important to the way the women in this sample decided about CAM use (Mackenzie et al., 2003) because some women felt that a therapy that was not invasive was less potentially harmful. Grouping the therapies made examination of the methods of administration more apparent. The NCCAM classifications include *alternative medical systems*, a collection of therapies built upon complete systems of theory and practice such as Chinese medicine; *mind-body interventions*,

a variety of techniques designed to enhance the mind's capacity to affect bodily function and symptoms; *biologically based therapies*, which use substances found in nature, such as herbs, foods, and vitamins to alter body responses; *manipulative and body-based methods*, based on manipulation and/or movement of one or more parts of the body; and *energy therapies*, the manipulation of energy biofields within the body by applying pressure and/or manipulating the body. The 81 therapies listed in the card sort were sorted using these categories (Appendix I). The women in the sample most frequently used biologically based therapies, which includes vitamin C, special diet, antioxidants, and special foods. The mind-body domain was the second most frequently used CAM category. The most frequently used therapies in this domain were prayer, support groups, and meditation. In the category of alternative medical systems, the main therapy used by the women was traditional medicine, defined by them as their medical oncologist. In the manipulative and body-based methods domain, the women in this sample used exercise and massage. Only 2 of the women in the sample used energy therapies. The women in this study selected more than half of the CAM therapies available in each of the five NCCAM domains. (See Table 5 below.)

Table 5

CAM Therapies Used for Breast Cancer by NCCAM Domain

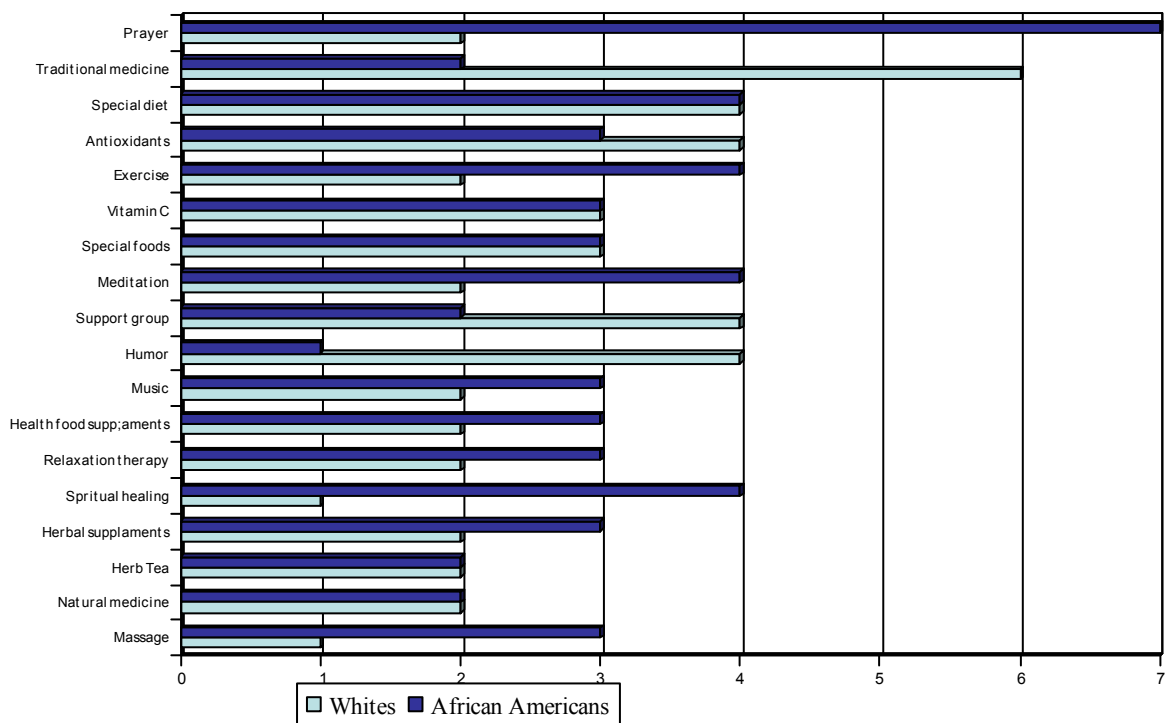
| | NCCAM Domains | | | | | |
|--|-----------------------------------|----------------------------|------------------------------------|---|---------------------|-------|
| | Alternative medical systems | Mind-body interventions | Biologically based therapies | Manipulative and body- based methods | Energy therapies | Total |
| CAM | 6 | 15 | 49 | 5 | 6 | 81 |
| therapies in the card sort | | | | | | |
| % of therapies selected from available cards (<i>n</i>) | 50 (3) | 73 (11) | 51 (25) | 40 (2) | 33 (2) | |

Ethnic Groups

Although the study sample was small, it was so evenly balanced by race that exploring race as a variable was important, particularly since the current literature describes CAM use as mainly a European American practice. In contrast to current literature (Kessler et al., 2001; Lee, 2004, 2005; Politi, 2006), the African American women in this sample used more types of CAM (76) than the European American women (72) and averaged more therapies

per woman ($M = 8.44$, $SD = 5.50$ for African American women) than for European American women ($M = 7.2$, $SD = 6.01$). The African American women used prayer, spiritual healing, meditation, special diet, and exercise. European American women used traditional medicine, support groups, humor, special diet, and antioxidants. Although the ethnic groups shared some types of CAM, there were some differences by ethnicity (see Figure 2 below).

Figure 2. Frequently used types of CAM for cancer by Race



Amount of CAM Used

In comparison to subjects in published studies about CAM use in cancer (Struthers & Nichols, 2004), our results suggest that CAM use is not just a young, well-educated, European American, affluent women's phenomenon. This sample provides information

about CAM use in breast cancer patients from other demographic groups. Both ethnic groups in this sample used CAM, although the types of CAM they used were different. The amount of CAM that the women used was also examined. Heavy CAM users were compared to low CAM users to see if particular demographic or disease features would characterize CAM users. The sample was divided into groups by the amount of CAM they used and then examined on these demographic variables. High CAM users were defined as women who used more than 10 types of CAM. This group included 2 European American women and 3 African American women. The moderate CAM users (4-10 CAM therapies) included 4 European American women and 4 African American women, and in the low CAM use group (0-3 CAM therapies), 2 subjects were African American and 4 were European American. The only person who did not use any CAM to manage her breast cancer was a European American woman. Table 6 below shows CAM use by demographic variables.

In this sample, high CAM users ranged in age from 38 to 58 while low CAM users ranged from 39 to 67. The educational level of the high CAM users was very similar to the low CAM users, and the most affluent women in the group were not in the high CAM use group. Many studies of CAM use sample women who are quite affluent compared to this sample. These results are important in that this sample of women, which is more balanced, shows that CAM may be more broadly distributed across demographic characteristics than prior literature indicates.

Table 6

Amounts of CAM Used for Breast Cancer by Demographic Variables

| Variables | Low CAM use (0-3 therapies; <i>N</i> = 6) | Mod CAM use (4-10 therapies; <i>N</i> = 8) | High CAM use (More than 10 therapies; <i>N</i> = 5) |
|--------------------|---|--|--|
| <hr/> | | | |
| Race | | | |
| European American | 4 | 4 | 2 |
| African American | 2 | 4 | 3 |
| Age | <i>M</i> = 55.50, <i>SD</i> = 11.34 Range = 39-67 | <i>M</i> = 50.63 <i>SD</i> = 10.06 Range = 35-67 | <i>M</i> = 46.80 <i>SD</i> = 8.41 Range = 38-58 |
| Years of education | <i>M</i> = 15.00, <i>SD</i> = 1.10 Range = 14-16 | <i>M</i> = 12.00, <i>SD</i> = 3.16 Range = 8-17 | <i>M</i> = 15.40, <i>SD</i> = 2.41 Range = 12-18 |
| Family income* | | | |
| Less than \$25,000 | 3 | 5 | 2 |
| \$25,000-\$75,000 | 2 | 1 | 2 |
| Over \$75,000 | 1 | 1 | 0 |
| Residence | | | |
| Urban | 5 | 5 | 3 |
| Rural | 1 | 3 | 2 |

*Only 17 women reporting.

Residence

The rural or urban nature of the residences of this sample indicated that this may be another factor that characterizes the amount and type of CAM used. There were more than twice as many women in the sample who lived in cities and towns as in very rural areas. It is important to note that the size of the cities and towns ranged from large cities (population over 100,000) to very small towns (less than 5,000) (North Carolina State Data Center, 2006). Ten of the women lived in cities with populations over 100,000 and 4 of the women lived in towns smaller than 5,000. The women living in the moderate size towns (between 5,000 and 99,000) reported the least use of CAM ($n = 5$, $M = 6.4$, $SD = 5.4$). The highest CAM use group by residence was the women who lived in the smallest towns ($n = 4$, $M = 9.75$, $SD = 6.65$). The most frequent CAM strategies used by rural dwellers were prayer, meditation, ginger, herb tea, exercise, and spiritual healing. The most frequently used CAM strategies for the urban respondents were prayer, special diet, antioxidants, and traditional medicine. Since there were racial differences in CAM use as described earlier, the racial breakdown of the participants by residence is of interest. Half of the women in the rural group were African American; this may have affected the therapies reported by this group. Only 6 women self-identified as living in a rural setting, even though 9 (4 European American, 5 African American) of the sample lived in towns of less than 99,000. Rural women shared 4 of the most commonly used forms of CAM (prayer, spiritual healing, meditation, and exercise) with the African American women and none with the women who described their residence as urban.

Past Treatment

Another variable that has been implicated in CAM use is the characteristics of the breast cancer itself such as length of time since diagnosis and past and current treatment. The women in this study who used large amounts of CAM had been diagnosed more than three years ($M = 39.40$ months, $SD = 32.92$), but the women in the moderate CAM use group (4-10 therapies) had been diagnosed just over a year ($M = 16.75$ months, $SD = 18.58$). The women in the high CAM use group had received prior chemotherapy (5 out of 5), radiation therapy (4 out of 5), and hormonal therapy (4 out of 5). More invasive therapy has been identified in the literature to yield more toxicity (Badger, Braden, & Mishel, 2001). There is also some indication in the literature that prior treatment increases the likelihood of CAM use (Alferi et al., 2001; Kessler et al., 2001), perhaps due to the added toxicity of treatment or experiencing side effects with prior treatment that were not managed well. Although this study is limited by a small sample size, these findings indicate that further exploration is warranted.

Current Treatment

If current treatment provides cues in the form of toxicities that are associated with women's choices to add CAM treatments to their regimen, then the treatment the women were receiving may be a relevant variable. Cytotoxic chemotherapy is implicated in more severe toxicities (Ganz et al., 2002; Weiger et al., 2002) than other cancer treatments, so it would be logical to hypothesize that women receiving chemotherapy might have higher CAM use. Table 7 displays this information in detail. In evaluating the current treatments being received by subjects in this sample, 9 of the women were receiving chemotherapy and 8 were receiving hormonal therapy. Of the 5 women in the high CAM use group, only 1 was receiving chemotherapy. The remaining 4 high CAM users were receiving hormonal

treatment, which may indicate that they had already completed their cytotoxic chemotherapy and that the CAM they used helped them to deal with cumulative side effects of their treatment or the side effects of their hormonal treatment. It is also possible that the women's providers were adequately managing the toxicities that the women on chemotherapy were experiencing.

Another concern in the literature has been the interaction between CAM treatments and conventional chemotherapy (Boyle, 1997; Rhodes-Kropf, Lantz, & American Association for Geriatric Psychiatry, 2001). Of the 9 women who were receiving chemotherapy, many used CAM treatments from the biological domain. This domain is especially important because these therapies are ingested for the most part and have a better chance of interacting with chemotherapy. The most frequently used CAM therapies in the biologic domain were health food supplements (5 women), special diet (5 women), vitamin B6 (5 women), vitamin E (5 women), antioxidants (6 women), lemon (6 women), vitamin C (7 women), and special foods (8 women). Vitamins and antioxidants have been implicated in reduced effectiveness of chemotherapy and the potential for bleeding through decreased platelet aggregation (Ernst & Cassieth, 1998; Kumar et al., 2002). Soy is another biologic that has been contraindicated for women with estrogen positive tumors and especially those women using Tamoxifen (Montbriand, 2005) because it mimics estrogen and may interfere with the action of Tamoxifen. The women in this study had heard the messages about soy, and only 3 of the subjects reported using soy; only 1 of the 3 was receiving Tamoxifen.

CAM for Health

In addition to using CAM to help manage the effects of their breast cancer and treatment, the women in this study were asked, during the card sort, to indicate the types of CAM they

were currently using, dividing these cards into CAM that they used for cancer and its side effects and CAM therapies they were using for their general health. Subjects reported using a wide variety of CAM treatments for their general health.

Table 7
Amount of CAM Used by Breast Cancer Characteristics

| Variables | Low CAM use (0-3 therapies; <i>N</i> = 6) | Mod CAM use (4-10 therapies; <i>N</i> = 8) | High CAM use (more than 10 therapies; <i>N</i> = 5) |
|----------------------|---|--|---|
| Type of surgery | | | |
| Mastectomy | 3 | 3 | 3 |
| Lumpectomy | 3 | 2 | 2 |
| Biopsy | 0 | 3 | 0 |
| Current treatment | | | |
| Chemotherapy | 2 | 6 | 1 |
| Hormonal | 3 | 1 | 4 |
| No therapy | 1 | 1 | 0 |
| Time since diagnosis | | | |
| 2-12 months | 2 | 6 | 2 |
| 24-84 months | 3 | 2 | 3 |
| More than 84 months | 1 | 0 | 0 |

In fact, they reported using more forms of CAM for managing their health than for their breast cancer (200 for health; 148 for breast). Of the 81 different types of CAM treatments in

the card sort (see Appendix I for list), this group of women used 48 (59.25%) of the therapies for their health.

Frequencies of CAM Selection

The average number of CAM therapies per woman used was 10.53 (*SD* 6.00), and the range was between 0 and 21 therapies. The therapies were grouped to determine which CAM treatments were used most often. There were 18 therapies that were chosen frequently (between 5 and 11 times) for health. The most frequently used therapies were music, humor, exercise, and vitamin E. One to 4 participants selected 20 therapies. These included massage, zinc, “talking away” illness, meditation, counseling, soy, herbal supplements, support groups, spiritual healing, and art therapy. Thirty-three CAM treatments were not used by anyone (see Appendix I for the list).

Grouping of Therapies

The NCCAM domains were again used to examine the types of CAM used for health (see Table 8). Of the NCCAM domains, the biologically based therapies were selected most frequently, with vitamin E, vitamin C, vitamin B6, and lemon being the most prevalent choices in this group. Many of the women reported taking a multivitamin as part of their daily practice. Few of the women reported vitamin use above the USDA standard daily requirements. Two exceptions were the increased use of vitamin C when they felt a cold coming on and the use of vitamin E oil on scars from mastectomies and biopsies. In these unique situations, the women reported increased doses of vitamins above USDA requirements. As one woman said,

Vitamin C . . . I’ve always taken that a little bit here and there. I used to just take it more for prevention of colds, like if I felt like I was getting a cold; I would just quickly take like 6,000 mg of Vitamin C.

The mind-body interventions were selected the next most often, specifically the therapies of music, humor, and prayer. In the manipulative and body-based therapies, 10 of the sample selected exercise for health. There were no therapies selected from the energy therapies for health.

Table 8

CAM Therapies Used for Health by NCCAM Domain

| | NCCAM Domains | | | | | Total |
|--|-----------------------------|-------------------------|------------------------------|-------------------------------------|------------------|-------------|
| | Alternative medical systems | Mind-body interventions | Biologically based therapies | Manipulative and body-based methods | Energy therapies | |
| CAM therapies in the card sort | 6 | 16 | 48 | 5 | 6 | 81 |
| CAM cards selected by patients (number of times each was used) | 5 (11) | 12 (59) | 26 (109) | 4 (20) | 1 (1) | 49 (200) |

Although the literature links prior CAM use to CAM use during breast cancer, these women used different kinds and different amounts of CAM for the two purposes. While one woman used 20 different types of CAM for her breast cancer she only used 3 forms of CAM for health. Another participant used only 3 CAM treatments for breast cancer but used 21 different types of CAM for health. In the interviews, the women said maintaining good health was important to tolerating treatment and preventing cancer recurrence.

Ethnic Groups

Examination of CAM use for health by race revealed a different profile for European American and African American women (see Figure 3). The European American women were most likely to select prayer, relaxation techniques, and exercise (mostly mind-body therapies) for health, while the African American women selected humor, vitamin E, vitamin B6, and lemon, adding more biologic therapies to CAM for health. Both groups reported using music to stay healthy. The European American women reported in the interviews that they used the strategies for health to reduce stress and to fight recurrences. They tied stress to the occurrence of cancer and described using these forms of CAM as a preventative. One woman said,

I've tried to do it more (exercise) because I think that if I do more of it, that it's going to help me to stay in shape, and to fight the cancer. If my body's in good shape, it's going to be able to do a better job of fighting everything.

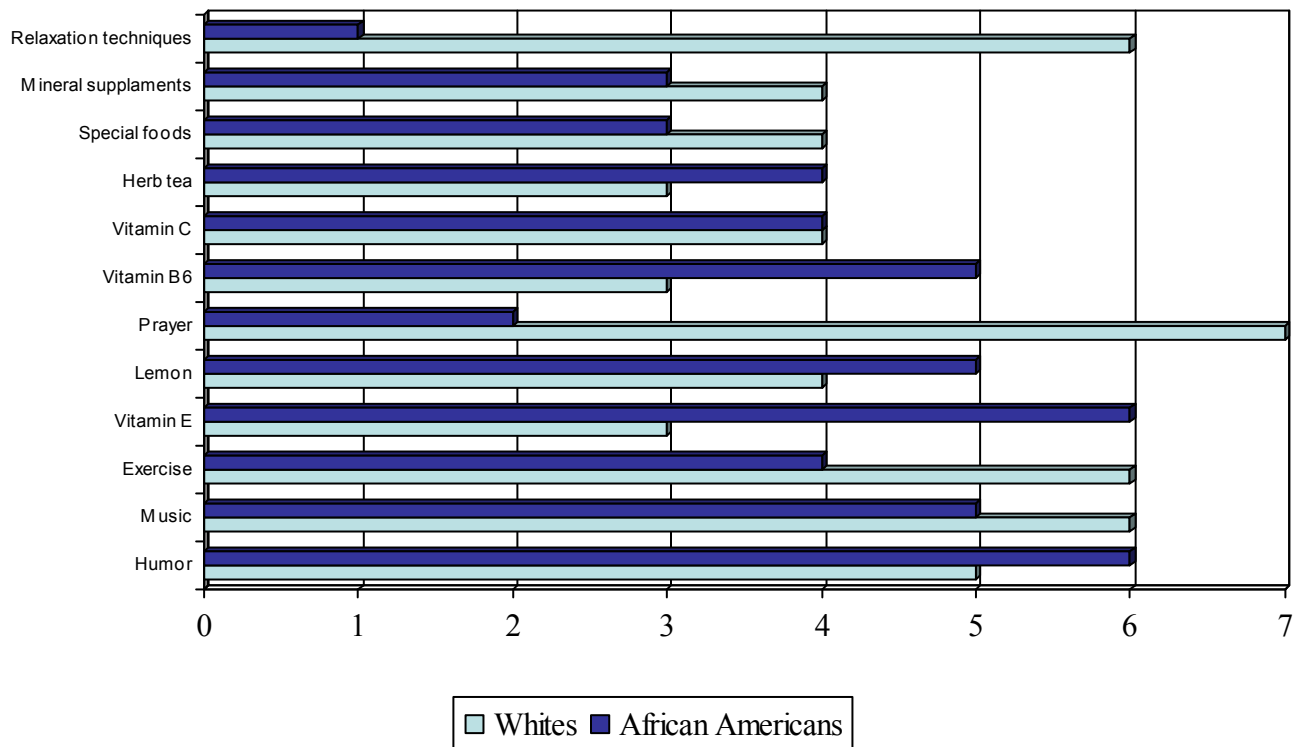
Amount of CAM Used

Looking at the ages of women who used various amounts of CAM in this sample, the high CAM users were older ($M = 60.60$, range 53-67 years), while the younger women ($M = 46.42$, range 35-58 years) were more likely to use fewer forms of CAM for health.

Exploring CAM use for health by place of residence revealed that, for this sample, all the high CAM users for health lived in cities. This may have been due to their close proximity to resources and services. Literature (Eisenberg et al., 1993; Henderson & Donatelle, 2004) indicates that CAM users are more affluent than non-users, and even though that was not found to be the case in this small sample, financial resources may well be linked to the number and type of CAM therapies used since some are very expensive.

Figure 3.

Frequently used types of CAM for health by race



For the women reporting family income ($n = 17$), more than half had family incomes under \$25,000. In this sample of CAM users, the 10 women in the lowest income group had the widest range of CAM use (0-21 therapies for health). The women in the moderate income group (\$25,000-\$75,000) had the highest mean CAM for health use ($M = 11.80$, $SD = 5.54$), and the women who did not report income had the lowest mean CAM use (7.5 , $SD = 6.36$). In this sample, the most affluent women (income over \$75,000 per year) used relaxation and massage, while the least affluent women (under \$25,000) used lemon, vitamin E, music, exercise, and humor for health.

This was an educated sample, with more than half of the sample educated past high school. The years of education ranged from 8 to 18. The mean total specific CAM therapies for health for the women with less than a high school education was 2.5 (*SD* 2.54), while the mean in the group with college degrees was 14.00 (*SD* 2.83). As the women's education level increased, the number of CAM treatments the women used for their health also increased. This is consistent with the literature about CAM users (Brown, Carroll, Boon, & Marmoreo, 2002; Manne et al., 2004).

Past and Current Treatment

Several factors were examined related to the women's breast cancer treatment in terms of their use of CAM for health, including type of surgery, past treatment, and current therapy. The women with a past history of the most invasive surgical intervention, a mastectomy/reconstruction, used only a moderate amount (5-15 types) of CAM for health. Only 3 of the women who used more than 15 CAM therapies for health had received chemotherapy or radiation in the past. Women who had received past treatment with chemotherapy were most likely to use moderate amounts of CAM for health, while the women with past history of radiation used low amounts of CAM for health and women with past hormonal therapy were more likely to use high amounts of CAM for health.

The amount of time since diagnosis may have influenced the women's use of CAM for health. As they moved away from their acute cancer experience they might have been more focused on CAM to maintain their health. The range of time since diagnosis was 2-132 months. However, the 5 heaviest CAM users (15-21 therapies for health) were spread over the entire sample with 3 of the 5 having been diagnosed within a year of the interview.

Examining the current treatment for cancer, the women who had the highest scores for using CAM for health (15-21) were receiving hormonal therapy ($n = 2$), chemotherapy ($n = 1$), or no therapy at all ($n = 2$). The women who reported the highest toxicity scores from the Breast Cancer Toxicity Questionnaire (range 84-95, study $M = 79.21$, $SD = 9.30$) also had the highest average use of CAM for health, averaging 13.75 forms. The women with the lowest toxicity scores (range 63-72) also had the lowest average use of CAM for health, averaging 8.83 CAM forms. Table 9 displays this information in detail.

Table 9

Number of CAM Treatments for Health by Type of Treatment Received

| Amount of CAM used | Past treatment | | | Current treatment | | | |
|---|-----------------------------|----------------------|---------------------|-----------------------------|-----------|----------|-----------------|
| | (number of women receiving) | | | (number of women receiving) | | | |
| | Chemotherapy | Radiation therapy | Hormonal therapy | Chemotherapy | Radiation | Hormonal | No treatment |
| Low CAM use (0-7 therapies) | 5 | 4 | 2 | 4 | 0 | 3 | 0 |
| Mod CAM use (10-14 therapies) | 6 | 3 | 2 | 4 | | 3 | 0 |
| High CAM use (15-21 therapies) | 3 | 3 | 3 | 1 | 0 | 2 | 2 |
| Total | 14 | 10 | 7 | 9 | 0 | 8 | 2 |

Precipitating and Influential Factors in the Choices to Use CAM

Both quantitative and qualitative data were examined for factors that influenced the women to use CAM. The women used CAM either specifically because they had developed breast cancer or to tolerate treatment after their diagnosis. The women reported that the CAM they used for health was to restore health lost to breast cancer.

Cancer as a Wake-Up Call

It just, you get such a jolt in life when you're going along and everything seems smooth and then suddenly your life's turned upside down. You have cancer, and you say, how on earth did I get it? What am I going to do? And it just makes you—it's like a wake-up call.

Many of the women in the study reported beginning the process of using CAM in reaction to receiving a cancer diagnosis, in the hope that using CAM would make them healthier and better able to tolerate treatment and prevent a cancer recurrence. They describe the cancer diagnosis as being out of balance. One woman said, "I kind of lost myself, and I think all that's related to the cancer." Being healthy was equated with not having cancer. After the women were diagnosed they reported a type of life review (Butler, 2002; Riessman, 1989) to determine the cause of their cancer. One woman said, "You go through this period of, you know, why? And then my answer to that is why not?"

Even women with strong family histories of cancer reported this search for the cause of their cancer. One woman said,

No one ever told me why I got cancer. When I went in, it was what did your mother have [lung cancer], what did your sister [breast and ovarian cancer], what did your aunt [breast cancer], everything. No ever said, what do you like, Julie? What are your activities? What is your lifestyle? What are your eating habits? No one ever asked me those questions, and I used to say to the doctor, "You're asking all about everyone

outside of me, but no one knows me, nobody's coming to know, what do you like? . . . So I decided that I was going to do that myself.

Some women determined that their lifestyle could have been to blame for their cancer. They implicated poor lifestyle choices such as stress, poor diet, and not maintaining regular health checks.

Poor lifestyle choices—stress

I could kick myself now because who knows what causes it, you know, I could have just done it to myself, and so I'm trying to be respectful of my body now, and hopefully it's not too late.

The women adopted a variety of CAM therapies to deal with what they saw as their negative lifestyle factors. They began behaviors to reduce stress, such as meditation, yoga, and diversions. One woman said, "I think stress contributes to breast cancer, any kind of cancer, so I try to avoid being stressed." Many of the women described how fear and worry associated with their cancer diagnosis was a potential cause of stress and a detriment to their health that caused them to use CAM. Many of the mind-body therapies that they used, such as prayer, meditation, and music and art therapy, were aimed at reducing these fears and stresses.

Poor lifestyle choices—diet

The women also attributed their cancer to poor diet or eating "junk" food. They became vegetarians, bought organic meats and vegetables, decreased fats, and increased their use of vitamins. Often the women described their dietary modifications as stopping foods and practices that are "bad for you" and increasing practices that are "good for you." One woman said,

Special foods is I'm trying to do basically some cereal, some soy that I'm into, drinking more fruit juice, but like watching it doesn't have a lot of ingredients in it, not

artificial fruit. I'm going to cranberry juice, the real cranberry juice, orange juice, milk. I'm trying to stay away from a lot more sweets. I was a big sweet eater, so by special foods I'm really trying to watch again what I eat, and not just eating junky food, eating chicken . . . I don't want the skin on it. I'm cooking healthier, and so those are a lot of my special foods.

The women adopted CAM therapies to remove the things that they believed were bad for them. Few of the women used anything that contained alcohol. Other cancer populations have identified whiskey and rum-soaked raisins as CAM (Arcury, Preisser, Gesler, & Sherman, 2004; Frate, Croom, Frate, Juergens, & Meydrech, 1996), but not this group. A typical view was exemplified in the following: "Whiskey, I'm not going to drink no whiskey. It's not good for you. It'll mess up your liver in the long run." The women viewed cancer treatment as poison and expressed the need to eliminate it after it had done its work. One woman expressed it this way:

And you know, to detox? I really want to do more of this. I think it's very, very important to get out, I did some detoxing with juices and stuff like that I was putting into my body to take out some of those chemicals that got into it that I don't like in it, like a lot of the radiation and stuff, so I'd like to learn, . . . how I can take out any of that stuff within me.

In reaction to having cancer, the women tried to do things that were good for them, like following a healthy diet, exercising, and taking vitamins and supplements daily. They also tried to avoid things that were bad for them, like alcohol, fatty foods, processed foods, and high-stress situations. One woman said, "I try to be as organic as I can and not eat a lot of junk food that I'm not supposed to, and a lot of fruits and vegetables." The women also attribute their breast cancer to their diet. One woman said,

I think that I blame myself for getting this because I don't think I really took care of my health the way I should have. I'd never worried about what I put in my mouth, I didn't worry about chemicals; I mean I thought somehow I was invincible, that it couldn't happen to me, and I was really stupid, because I didn't care really.

Detoxification was also a part of the “good for you, bad for you” theme. The women described using CAM to detoxify from dietary indiscretions and to eliminate the toxic effects of treatment. One woman described her process and the indications she had that she needed to detoxify. She said,

Detoxification. The way I would detoxify would be green teas and stuff like that that would help flush my system when I wasn't feeling well or something like that. Yeah. I still do. How do I know when I need it? Uh, green tea? I have an upset stomach or, you know, not going to the bathroom as I ordinarily would do or something like that.

Fasting was also part of detoxification. Some of the women used fasting as part of a religious observance while others fasted to eliminate impurities. In describing her religious fasting, a subject said,

Well, I think, well it's good for both [health and breast cancer] because when you fasting and asking God, see, if you need a healing, and you asking God and you turn down your plate, he will come to your rescue.

Another perspective was not at all related to religious faith: “The chiropractor prescribed detoxification, . . . and part of that is an enema, and I would do that, and the fasting? I would do that, too.”

Poor lifestyle choices--lack of health maintained/information seeking

Another reaction to having a cancer diagnosis was to become avid consumers of health information. One woman said, “I've just done a lot of reading through the breast cancer experience and found certain things that Researchers has shown have been helpful in preventing recurrence.” Literature reveals that CAM users seek more information sources than those who do not use CAM (Kakai et al., 2003), and the women in this study followed this trend. They completed a measure of the types of information sources they used, the Sources of Information Questionnaire (Appendix G). Out of the 30 possible choices, the mean number of information scores for the total group was 11.45 ($SD = 6.86$, range 1-25).

European American women consulted fewer sources of information ($M = 9.20$, $SD = 7.13$) than African American women ($M = 14.33$, $SD = 6.10$). The most frequently consulted sources of information were the American Cancer Society (14), friends (14), the chemotherapy doctor (14), and their surgeon (14). The women also consulted pamphlets and fliers (12), chemotherapy nurses (12), family members (11), and the Internet (10). Every information source in the 30-item list was chosen at least once, but CAM providers (2), community centers (2), herbalists and root doctors (2), and patient advocates (1) were chosen the least. The number of CAM therapies that the women used increased with the number of information sources they consulted (see Figure 4 below). The women combined different types of information sources to increase their understanding. One woman said,

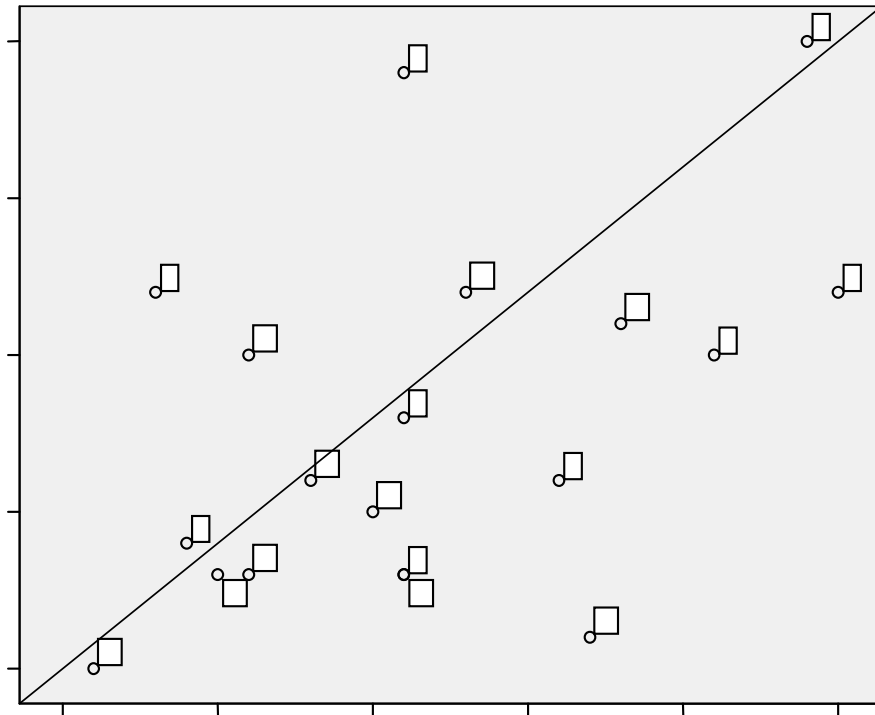
There's also another thing that my friend [first information source] told me about, because my knees have been bothering me, and I looked it up on the Internet [second information source], this Certo. Yeah, I figured I might as well try it, you know, because she . . . when I went on the Internet and saw all these people [third information source], yeah, saw all these people who swore by it, I thought wow. Apparently there's something to it. I just bought some yesterday [she used 3 types of information to come to decision].

Often the women used the Internet to get information—much like using a library. When they had a question or they needed more information about a new CAM form, they used the Internet like a support group for a back-up information source. Two of the women who used breast cancer chat rooms for information called these groups their “cyber sisters.” Some of the women were cautious about Internet information. One said:

The Internet, only, you can't believe half of it. You try to go to a site that you trust, like the American Cancer Society, or the Web M.D. [WebMD.com], anything that you trust. You know, if you just put that in there, you don't know what you're going to come up with. Science is scary stuff.

Figure 4

Relationship of Number of Sources of Information to CAM Used for Breast Cancer



Women also used other formal and informal support groups for information. Formal support groups included those founded by the American Cancer Society, such as Reach to Recovery, and Save Our Sisters within the African American community. When asked in the card sort, 9 of the women reported using support groups as a form of CAM treatment. Informal support groups included social clubs such as a group of retired women, cheerleaders competing in the Senior Olympics, and the fellow patients they saw weekly in the treatment room. These groups provided the women with information to help them decide about CAM use.

An exception was a subject who reported only one source of information. She was diagnosed with breast cancer during pregnancy, and her initial oncologist told her that she would need to terminate her pregnancy to save her own life. She found another oncologist through a series of chance occurrences and subsequently delivered a healthy baby. This subject's only source of information from the 30-item list was her oncologist. She used several forms of CAM for health and reported several factors that influenced her decisions in her interview, but she relied on the oncologist as her ultimate information source.

The expert

Before starting a new CAM therapy and, at times to continue a past CAM treatment, the women consulted experts. Each woman had specific criteria that defined an expert. The most frequently noted people by the women in the sample were health care providers, either physicians or nurses. Friends and family ranked after health care providers. The women did not define who was an expert in the same way, but each woman had her own criteria. During the interviews, the women reported that it was important for a provider to cite published information from the literature to add credibility. In essence, they expected a provider to have digested print information and incorporated that into the discussion of treatment options and CAM. In describing her medical oncologist, one woman said,

He's like a professor when he's trying to explain things to you. Of course, you know, 75% of it goes right over your head because you don't know what all these acronyms are, and all this, but he's writing down all these notes and going over all this stuff.

An important criterion for all the women was seeing information in print. This added credibility to the source. The women reported using several sources of print material from the Sources of Information questionnaire such as pamphlets (11), books from the library (5), and magazines (8).

Many of the women cited experts and qualified their endorsements by the detail that the expert had written a book or was quoted in a magazine. An association with noted cancer treatment hospitals also made a source more credible. One woman said,

One of the big things that people are promoting now, and that I do take is curcumin, which is a supplement. . . . Marisa W., she's the physician who kind of runs that breastcancer.org . . . she has done a lot on that, and then you know that book . . . called *Waking the Warrior* about it. . . . So curcumin is one of the things that . . . but there are other studies. There's somebody at M. D. Andersen, I think, is who's really promoting the curcumin.

Being a licensed physician was also important to the qualifications of an expert. One woman knew root doctors who dealt with cancer, but she preferred to use her conventional provider because of this criterion. She said,

Yeah, it's quite a few that goes to see 'em [root doctors], but I see it like this. Why would you spend your money out there messing with someone that doesn't have the degrees sitting upon the wall? If I'm going to spend some money like that, it will be with somebody that I know is a guarantee.

Women in this study also reported trying CAM therapies that they were uncertain about on the strength of the recommendations from their provider. One woman reported using ginger tea at the recommendation of her chemotherapy nurse even though she said it tasted terrible:

Yeah. It doesn't taste good. I don't like it. But, it works. . . . When I start feeling nauseous and my stomach starts hurting and I just don't want anything to eat. So then if I drink a cup of tea it'll, um, settle my stomach. Then I can eat a little something and feel better.

Several subjects in this study reported using a CAM therapy on the recommendation of a friend. For a friend to be considered an expert they needed to have tried the therapy and had good results. This type of endorsement was conditional, but if a friend or acquaintance, especially one who had had cancer, used a particular type of CAM, the women were likely to at least give the therapy a try. One woman started using the herb turmeric after reading about

it on the Internet and hearing about it from a friend. She describes the process that she went through to decide about using it:

Anyway, so after he [her friend with cancer] told me about these things that he's been taking, I went to the Internet and looked them up, and sure enough they've researched how these things work, like one of them is turmeric, and it's supposed to be a very good anti-inflammatory, and there's a lot of studies going on about that. . . . I think that's really what got me started thinking that there's really something to supplements, you know, and then after doing a lot of reading and reading the cancer boards and seeing what people are doing, there were just certain things that are consistent, and then reading this book, that they tell you to do.

This woman also points to another element of being considered to be an expert, involvement in research. Many of the women list a research base as a criterion for a therapy to have credibility. None of the women in the study had a research background, but often they said that seeing the research helped them decide about CAM use. Several of the women relied heavily on books written about breast cancer and CAM treatments. These books were authored either by cancer patients or by physicians involved with cancer patients.

Health beliefs

General health beliefs and beliefs about the benefits of certain kinds of therapies seemed to be another factor operating in the process of women deciding to use CAM therapies. The belief that certain therapies were “good” or “bad” influenced these women when they decided about using CAM. The source of these beliefs was not clear in the interviews. They were likely to use CAM if they perceived a therapy as “good” and avoided a therapy if they perceived it as “bad.” When given the choice of CAM treatments, often they reported using one form or not using another because of how “good it was for you.” Several of the women reported not using home remedies containing turpentine that had been reported in other literature (Arcury et al., 2004) because they believed turpentine was for cleaning paint

brushes and “bad for you.” Other women reported not using whiskey or rum-soaked raisins because alcohol was “not good for you.”

The women in this study saw some of the CAM therapies as “way out,” “goofy,” or too “new age.” One woman said, “Hypnosis, I think is hokey. . . . I don’t believe in it, and I have no reason for not believing in it other than I don’t believe in it.” Another woman said, “I don’t want to do anything that I consider extreme, like putting certain chemicals or electricity or magnets in my body, because I don’t see that as balance.” The women used a variety of negative phrases to describe CAM treatments that they did not believe in, including “weird,” “freaky,” “loony,” and “new age.”

One woman expressed the belief that CAM treatments employed the placebo effect. She said,

Some of them sound like, uh, they’re just going to enhance your, the placebo effect. And I want real results. I don’t want to just think I’m getting a result and, uh, I don’t want to fool myself and lie to myself and, act all beatnik and flaky.

For the most part the women wanted to avoid these extreme measures. One woman said, “Hydrogen peroxide, I’ve heard of that quack [CAM provider who administers hydrogen peroxide therapy]. I like hydrogen peroxide for a lot of things, but not for a treatment, per se.”

Although the women believed in CAM in general, they often didn’t use a certain form of CAM because of personal preference. This was difficult for the women to explain, but they were very clear that some therapies were just not for them. An example was one woman’s views of biofeedback: “Biofeedback, I don’t think I need it, I just don’t see the usefulness for me, but I do think it’s a useful technique.”

Women did indicate that if their cancer came back or if things got worse, they might consider additional options. One woman said, “The Chinese medicine, if things got really bad, I’ve heard of Chinese medicine. I would consider—a last resort thing.” Another said, “Fasting? Me fast? If I were dying maybe, if they told me I would live, but that’s about it.” Still another reported,

Well, if it come down to really having to, take that, that it were going to help me with my health, benefit me, yes, I’ll go for it. But if it’s just something to keep my blood built up, you know, if it’s to keep my blood pressure down, yes, and keep me built up, yes, but just to take it because, you know, for energy and keep you spunky, I don’t need that. . . . If I had to, yeah, I would do it.

Because of Cancer Treatment

The women in the study also used CAM in reaction to actual and potential side effects of treatment. They started or continued forms of CAM because they experienced or anticipated side effects of treatment. If they had used CAM in the past and it was beneficial then, they would use it again for similar symptoms. One woman who used massage for her lymphedema said:

Massage, it helps a bunch. They [physical therapist] specialize in lymphedema; they’ve had the training, the Vader the German man, the Vader training. I’m not presently going. But I would go back if my arm started hurting, or it started getting red, that happens sometimes, or it swelled up some—definitely!

As indicated in the literature, past CAM use influenced many women’s choices to use CAM when they were diagnosed and treated for breast cancer (Mackenzie et al., 2003). The number of past CAM practices that the women reported using during the card sort ranged from 0 to 21 (mean 5.60 SD 5.61). The mean number of CAM therapies after their diagnosis increased to 8.2 (SD 5.8). Past CAM forms included chiropractic (7), DHEA (6), ginger (5), black cohosh (4), and fasting (4). Subjects reported changing or increasing their CAM practices after their cancer diagnosis.

According to previously published studies, CAM use increases as the level of toxicity rises (Shen et al., 2002), and so the women in this study completed a measure of toxicity, the Breast Cancer Toxicity Questionnaire. For this sample the range of scores was 63-95 (potential range 33-99) with a mean score of 79.6 ($SD = 9.10$). The European American women had higher total toxicity scores ($M = 83.30$, $SD = 7.63$) than the African American women ($M = 75.9$, $SD = 9.29$). The toxicities that the women reported here were both physical and emotional toxicities associated with having treatment. The emotional toxicities included depression, irritability, worry, sadness, and hopelessness. The physical toxicities included fatigue, pain, sleep difficulties, taste alterations, menopausal symptoms, nausea, mouth sores, and watery eyes. The women in this study used CAM to deal with both emotional and physical toxicities.

They told of using herbs to deal with irritability. One woman said,

And the ginseng? I'm taking the ginseng to calm the menopausal symptoms but mostly the emotional stuff, and it has seemed to make a difference. I've been taking it once a day if I remember, and then some days I haven't, I know this is making a difference because there've been days where I've forgotten, and I've gotten really irritable, have a hard time controlling my emotions, and then I'll do it, and later it just will smooth out.

Stress was implicated as a side effect of receiving a cancer diagnosis and of receiving cancer treatment. Psychological distress has been associated with CAM use (Cassileth et al., 1984), and the women in this study reported the belief that a stressful lifestyle can cause cancer (Rakovitch et al., 2005).

They used many types of CAM therapies to deal with the stress they were feeling, including humor. One woman said, "I guess the humor, I've been using that all the while. I think I've used that all the while. I consider it very necessary for your health. Relieves stress. That's the biggest thing." Another woman talked about the healing power of

humor. She said, “I’m sure humor helps heal. And I’ve heard a lot of people talk about that. That if you get sick, watch something funny.” Notice in this account that she cites an outside expert to justify her belief in humor.

The women in this study were like other breast cancer patients (Boon et al., 1999; Montbriand, 1995a) who used CAM to increase their feelings of control. Several of the women described using guided imagery to control where their treatment went. One woman who was pregnant at the time of treatment described her experience with visualization. She said,

When I was getting my chemotherapy, I was picturing it . . . where it was going, what it was going to do, how it would stay away from her [her child], and how it would attack on cancer cells. It made me feel like I had some kind of control over what that poison was going to do, so I mean, I just . . . It made me feel like I had a say in what cells it would kill and maybe not kill. I felt that if I tried hard enough, or concentrated hard enough, or visualized it enough that it would not [hurt the child]. . . . My biggest fear was harming her, of course, and so I just visualized it staying away from the placenta and just kind of attacking any cancer cells.

The women also used CAM to deal with the physical side effects of treatment. They may have tried using conventional biomedicine for side effects but found it unsatisfactory to solve their problems. The women used herbal tea, ginger, and pickle juice for chemotherapy nausea, vitamins and herbs to maintain adequate blood counts, improved nutrition to decrease fatigue, and aromatherapy for increased energy. They also used herbs to deal with neutropenia from treatment. One woman used the herb Papaw for blood counts. There is literature to indicate that this herb may have some activity against breast cancer (Levine et al., 2005). She described the reason she took the herb:

Yeah, the chemo and even the radiation, ‘cause he [the herbalist] said so many times that will pull your commune [*sic*] system down, which it did, but every time I went and got my treatment. I was on that, and my commune system always was up... I didn’t have to miss nary a time.

Another woman reported using lemon juice for the vitamins to prevent treatment delays due to low European American blood cell counts. She said,

‘Cause before the chemo you have to go for a blood test the day before at the hospital, and everything has to be good before they give you the next one [treatment]. They’ve been very good. Yeah. And I was determined I wasn’t going to miss a treatment. The lemon helped, yeah. It was the extra vitamin C.

Another woman used ginger for chemotherapy nausea. She said,

And ginger? . . . Oh, my friends, one took me to like a Chinese-like health food store and got me ginger chewing gum, and they said that it would help settle your stomach, so sometimes if I felt sick, it did, it actually did work, sometimes if I felt like you know, it was sort of like creeping up on me, I would chew on the gum and it would help settle it.

Keeping blood counts up was important to all the women in the study receiving chemotherapy, because low counts meant no treatment. Being able to receive their treatment was a source of pride and a validation of CAM’s effectiveness. One woman said,

They [the provider] told me to take a multivitamin. And, it keep my treatment, keep my blood built up, you know. ‘Cause some of the treatment make the blood go down. Have to—the body wants to build up . . . my blood’s been built up, staying up. But I still get tired, and I figure that’s from the—probably from the treatment and stuff. They check my blood each week. It’ll still be up.

Women in this study reported using salves for radiation-induced skin irritation. Many of the women reported fatigue from treatment, and they used a variety of methods to deal with it—from vitamins to aromatherapy.

Reasons Not to Use CAM

Aversions

Of the 81 therapies in the card sort, 29 were not selected by any subject as being used for either health or cancer. Of the remaining 52, 28 were selected by fewer than half of the 19 women. Prayer was the only form of CAM that was selected by all the women for either cancer or health. Marijuana (16 women) was the CAM that the women selected most often

not to use, followed by turpentine (14 women), hypnosis (14 women), and colored light treatments (14 women). The European American women selected black cohosh, fasting, mushroom extract, hypnosis, colored light treatments, and marijuana least often, while the African American women selected art therapy, whiskey, ginkgo, hypnosis, Rootwork, turpentine, and marijuana least often.

Often the women expressed interest in particular types of CAM treatments but reported not using them due to lack of information about a therapy. They required a certain level of information about a form of CAM before they used it. However, the African American women who declined to use Rootwork described the practice and had made a conscious effort not to use it. They had experience with Rootwork and had very firm health beliefs that prevented them from using it and for choosing other forms of CAM. They said that Rootwork was the work of the devil and that its use was making a deal with the devil.

Some of the women in the study reported aversions to some CAM therapies from their past experiences. A past negative experience with a particular therapy also meant that the subjects were less likely to use it. One woman expressed an aversion to enemas because of her past history. She said,

Enemas, my mother was insanely obsessed with enemas and gave us enemas every two seconds, every time something was wrong when we were kids, I would never have another enema as long as I lived. That's out. Yeah, totally out.

Women were reluctant to use acupuncture because of needle phobias. Other women were averse to aromatherapy because the smells caused chemotherapy-associated nausea. One woman described it this way, "I can't smell nothing [doesn't want to smell anything]. Every time you smell something, it make you sick. It make you . . . throw up some more."

Many women refused to consider hypnosis because they did not want another person to have control of their mind. One woman said, “Hypnosis? Never! I wouldn’t do it. I won’t give my mind over to anybody else.”

Contraindications and co-morbid conditions

There were also contraindications to some forms of CAM. Some women described past chemical dependencies that prevented them from using CAM forms such as whiskey and marijuana. One woman said, “Now I’m a recovering alcoholic and I am a former smoker, and I don’t [want] none of that stuff . . . near me, that’s right.” Several of the women were influenced either to adopt CAM or not to use CAM because of co-morbid conditions such as diabetes, cardiac disease requiring a pacemaker, hyperthyroidism, allergies, and hypertension. One woman said, “Milk Thistle? Again, allergies. When I say that, it makes me think weed, ragweed, and think that I was allergy [sic] to ‘em.”

Cost

Cost of a CAM was also a reason not to use it. Many of the women reported they would love to use the CAM therapy of massage but could not afford it. Over 50% of the women were unemployed, and although they knew about CAM treatments they could only buy so much. These women had very little disposable income, so they often used CAM treatments that did not require money, such as therapies in the mind-body domain of CAM. The women with incomes below \$25,000 used CAM forms such as music, exercise, and prayer. One woman said, “If I could afford this [Co-Enzyme Q10], this is something I’d definitely want to use. I went the other day and it was \$75 for just one bottle of Co-Enzyme Q10.”

Time

As indicated in other literature (Lengacher et al., 2006), women report that one reason not to use CAM is that it takes too much time. The women in this study also reported this as a barrier to certain CAM therapies. Not only do the treatments themselves require time but the investigation of CAM is also time consuming. Several of the women reported that they did not have the time to investigate CAM forms even though they were interested in trying them.

Convenience

Several of the women in the study reported that using certain types of CAM was inconvenient. Because the food and CAM practices were different than the normal family routine, these women found it difficult to adhere to a CAM regime due to family responsibilities. One woman said, “There again, shopping is limited and my teenage daughter would never concede to soy milk in the house.” Another woman said, “See, I don’t have the luxury, if I didn’t have to work and do everything I have to do, I would do this stuff every day, but I’m lucky if I can do it once every two weeks.” Sticking to a healthy diet was seen by some of the women as unpleasant. Another woman said,

I have to be able to be happy when I’m eating. Like if somebody told me today, Julie, you know your chances of having a recurrence increase by 70% if you keep eating the foods you’re eating, it’s like well, keeping the foods I’m eating and be happy eating and maybe the cancer again or stick to this horrible diet that would make me unhappy every day of my life, and make me nasty and crabby, I’d probably try to do a little of both. I wouldn’t be a fanatic about foods, never, even if they told me, you know, gave me all these reasons why I should do it, I’d still say, well, I’m still going to have my chocolate once in a while, I’m still going to drink my Pepsi once a day, and I’m not giving them up.

Cultural relevance

One of the factors that the women used to decide about CAM forms was the cultural comfort and familiarity they felt with a particular CAM treatment. Several of the women did

not want to investigate Chinese medicine because, as one woman said, “Chinese medicine? I’m not a Chinese and I don’t think I need any Chinese medicine.” Other women were leery of folk remedies because they felt they were beneficial to others but not to them. One woman said:

Even though a lot of these folk medicines and stuff are probably a lot less harmful to my body than the candies that I eat or the French fries that I eat, it’s still not part of my culture, it’s not part of who I am, it’s not something I’m used to. If I was born and grew up with this kind of stuff, then I’d probably keep doing it, just part of who I am in my history.

Faith

The role of faith for the African American women was unique in this study. Although the European American women reported religious affiliations and relying on their faith, their experience of faith was not as influential as it was for the African American women. Of the top five most commonly used forms of CAM for the African American women, three related to faith. They were prayer, spiritual healing, and meditation. These CAM forms played an integral role in the way the African American women dealt with the side effects of treatment. As the women described their experiences with dealing with cancer and the way they used faith, they used a combination of meditation, social support, and images to reinforce their faith experience. One woman described it this way. She said:

So my goddaughter, she came up and she brought me some angels [*religious symbols*], and every day I’d go through there and I’d look at and touch the little angels, and I thought well that just chilled [*cheered*] me up, you know. And then I had scriptures all over my ‘frigerator [*visual cues*], all through my house, all scriptures in the Bible talking about healing, about breast cancer, so they had all of those scriptures, so I praise God for that. And then my pastor and other people, missionaries and all of ‘em were just praying for me [*social support*].

The women in this study reported using faith and support from God to deal with emotional and physical sequelae of their cancer. One woman described music that was

particularly meaningful because it was written during the “dark night of the soul,” which she likened to having breast cancer.

Another woman described how she interacted with God. She said:

You know something make me angry, before I had got diagnosed with cancer, and I’d say well, Lord, you saw ‘em gitting on my nerves, didn’t you? And you know, I just had a good time just laughing and talking with him, and after I had that talk, I was fine. The feeling goes away, and I be just as happy and jolly. Yes, because . . . seems like I really held on to him, and you know, after I found out. Like I say, I was talking to him before, but after this, you know, it just made me just cling and hold on to him. It would just give me a good feeling, a good feeling, good feeling.

The women called on faith to help them throughout their breast cancer experience. God was their partner, their social support, and their confidant. One woman described it this way,

From the beginning, you know, the Lord is not going to put any more on you than He feel like you can’t handle. If you get to a point where you can’t handle it all by yourself, He’ll help you through it. He gives you the strength some kind of way to get through it. I remember a time [before her diagnosis] when I would . . . I knew that I was not going through the first treatment, chemo treatment, when I was not doing that on my own. It was like there was some other force there. I don’t know. I never thought about Him not being there.

Faith was also important in dealing with the day-to-day effects of treatment. One woman described her distress related to alopecia from chemotherapy, which is a particularly important side effect for African American women (Henderson, Gore, Davis, & Concon, 2003; Long, 1993). As she was driving down the road she noticed her hair coming out more and more. She said:

I had been reading the book of Job. . . . God took me back to that scripture at the beginning when he loses everything, like his cattle and . . . his family and all of that, and he said, “The Lord giveth and the Lord taketh away, blessed be the name of the Lord.” And so that’s what I thought about with my hair, you know, that the Lord gave it and the Lord has taken away, blessed be the name of the Lord. And then at the end of that, he was just like . . . always remember that at the end of Job there’s restoration, and so that really helped me.

None reported expecting God to prevent cancer recurrence, but their faith complemented and supported their tolerance of treatment. One woman described it this way:

It's so funny because most people would think that you would pray, "Oh, God, heal me, oh, God, heal me," and I recall only a few times that I actually prayed that. Most of my prayers were "God, sustain me," or "God, strength[en] me to get through this," . . . And so, I mostly prayed for that. I prayed that God would just help me to see the lesson, what I was to learn from the experience.

Overview of the Process of Using CAM for Breast Cancer

The process through which women in this study decided to use CAM involved continuous assessment and evaluation. They either began or continued CAM therapies in response to a need to improve their health and avoid cancer recurrence, or to deal with an actual or potential effect of their cancer and its treatment. They consulted experts perhaps in the form of their provider, a friend, or another cancer patient. Or they consulted a reference source such as the Internet or printed materials in the forms of pamphlets or books. In determining whether to use a CAM form, they balanced numerous factors, both pro and con, including the costs, their health beliefs about the therapy, and the therapy's potential to harm them medically.

Trying It Out

The women also gave the CAM that they were using for the first time a trial run. One woman described this phase as "experimenting." She said, "So I'm experimenting, you know, and I don't know how long this kick is going to last, but you know, I'm just experimenting." There was a time period during which they would use a CAM form before they decided to adopt it permanently. This time frame differed from woman to woman, from a one-time trial to several months. One woman said, "I would try it for a while, you know, make my own decision and I would check it out, I would you know, have blood tests done

again or just see how. . . . I would check in with myself, I do a lot of checking in with myself.” Another woman said:

Rum-soaked raisins? They were having reports of Aromasin [her anti-estrogen medication] giving you more aches and pains, and I kind of ache sometimes, just my joints and all, hurt all over, so I tried this because I keep reading about in the People’s Pharmacy, they really supported it. I couldn’t keep it up long enough, I was probably on it for a month, and I couldn’t keep it up long enough to tell. I think I’d probably have had to been on it for three months maybe at least to give it a fair trial.

Defining the CAM Plan

The main reason the women in this study reported for continuing a CAM therapy consistently was that it worked for them. This clear evidence of effect for the woman kept them using a form of CAM regardless of cost, aversions, and co-morbid conditions. When CAM therapies worked, the women reported sticking with them. CAM treatments that were taken for specific symptoms were evaluated in terms of their effects. One woman used vitamin C, Echinacea, and zinc to boost her immunity. She said:

I’ve always used zinc, Echinacea and vitamin C as a sort of like . . . immunity booster, something like that. . . . I usually take them probably starting around December, January and February. Any other times of the year I only take them when I notice like symptoms, like, runny nose, if I’m feeling like achy, sneezing, and stuff like that. . . . I remember hearing something about it on the *Today Show* several years ago, so I thought that I would try it, and probably out of the seven years that I’ve used it, I haven’t had like a cold or anything. Yeah, I did it on a daily basis [during treatment], especially when I was going through the chemotherapy, the routine ones would be like Echinacea and vitamin C. If I started to feel like my nose was running a little bit more, or if I was like on an airplane and people were sneezing, or if I were around like people who were sick and their immune system was already suppressed, then I would add the zinc.

It is unclear from the interviews what motivated the women to continue health promotion behaviors. These seem to be lifestyle changes that have been incorporated and are evolving as the women continue their process of evaluation. They describe the CAM they use for health continuing past the acute time of their intensive treatment. The two women who had completed treatment continued to use CAM for health and for breast cancer symptoms. One

woman used meditation to reduce stress, and the other used massage to deal with persistent lymphedema.

The women also report stopping CAM therapies for various reasons. Some of the women stopped treatments because there was an arbitrary number of CAM therapies they would tolerate. One woman said:

Now I'm not going to continue with all these. I'm taking the turmeric with the bromelain, because the bromelain is supposed to increase the absorption of the turmeric, so I'll probably continue with that. The green tea extract I just started taking it because it was an antioxidant, but that one's getting trashed, because I mean how many pills can I take?

The women stopped CAM because after their CAM trial they determined it did not work for the prescribed symptom or that the symptom resolved. Another reason they stopped a treatment was medical advice. This was especially the case in relation to the use of soy by women whose cancer was estrogen receptor positive. Stopping a treatment did not necessarily mean that the women did not ever use a CAM form again. If a woman had a previous positive experience with a form of CAM she might use it if her symptoms returned or if she had similar symptoms. This was exemplified in a woman's comments about Glucosamine:

Glucosamine, I took it for a couple of years, and I know it helped, but then all of a sudden I decided . . . I just quit taking all of my vitamins. But, it's just within the last couple of months that I decided to go back and start taking them again. I was just aching, my back was hurting me so bad, I think . . . [it is helping] a little bit. I don't think I've been on it long enough, probably one month. I need to be on it a little while longer.

This sample of women demonstrated that CAM is used by a more diverse group of women than those previously described in the literature. By using the definition of complementary therapy as treatments not prescribed by a doctor or things that were helpful in managing the side effects of breast cancer or treatments or to stay healthy, these women

provided a fuller description of what CAM during breast cancer meant to them. These results showed that, even in this small sample, poor women used CAM, less educated women used CAM, and African American women used CAM. There are differences in the types and amounts of CAM used, but all the women used CAM. The process of deciding to use CAM that these women described is multifaceted. They used CAM to deal with the cancer and treatment-related effects, and a larger portion of their CAM use was aimed at staying healthy or becoming more healthy. Their CAM use was influenced by many factors, but the data from this small study emphasized the power and importance of providers in CAM decision-making. This work indicates the importance of providers becoming more current in their understanding of CAM interactions with conventional therapy, evaluating benefits and hazards of CAM use for breast cancer survivors, and of ongoing dialogue with their patients about CAM use.

Chapter 5

Discussion

This chapter will include a discussion of key study findings and how they relate to existing literature; an examination of the implications of the findings for research and practice; and a discussion of study limitations.

The study had several significant findings. One finding was that both African American and poor women with breast cancer used CAM treatments. Another important finding was the differences and the similarities in the types of CAM treatments used by women of different ethnicities. The women in this study used CAM for both self-care and for health in the hope that they could correct past lifestyle indiscretions. They were motivated to adopt CAM by treatment-related side effects and by examination of lifestyle factors that they thought may have been relevant to their cancer. They engaged in a process of “trying it out” that was influenced by multiple environmental and personal factors related to their past history, their health beliefs, and prevailing health information, but they ultimately decided about CAM use after a trial period and personal evaluation.

Limitations of the Study

This was a small mixed methods study. Only 19 women were included in the sample. One of the key aims of the study was to compare CAM use in European American and African American women with breast cancer, but with the small sample, comparisons are clearly preliminary and suggestive rather than conclusive. However, combining the interview

data with the data from the questionnaires provided multiple dimensions to the examination of CAM use by these women and allowed a beginning view of the reasons for and the process of choosing to use CAM therapies during the breast cancer experience.

This was a regional study. The women in this study all lived within a 50-mile radius of the study site, but they represent a variety of communities, from rural to urban. Comparisons of CAM use by type of community generate some interesting questions for future study of CAM use in context.

The cross-sectional design and convenience sample of women who had received cancer treatment also provide some limitations. Although women were asked for retrospective information about their CAM use from the time of diagnosis, a prospective study with longitudinal data might have provided a fuller picture of CAM use specific to changes in toxicities of breast cancer treatment. All of the women in this study used CAM. When they were recruited, only women who reported using some kind of CAM were included. This limits conclusions about CAM use in general by breast cancer patients. Had all eligible women with breast cancer been included regardless of CAM use, decisions to avoid CAM use as well as to use CAM could have been examined. Although this sample provided information about the subjects' reasons to use some CAM therapies and not others, including women who did not use any CAM could have enlarged the continuum of reasons for and against CAM use. A larger study guided by the findings of this study could further elaborate on CAM use for breast cancer patients.

Discussion of Findings

CAM Use During Treatment for Breast Cancer in African American and European Americans Women in the Urban and Rural South

In this study, the investigator used a card sort method to clarify the definition of CAM as it is used by women with breast cancer. CAM was defined for the women in this study as modalities they used to help them stay healthy during treatment or to tolerate treatment. The questionnaires and the interviews identified the therapies in the card sort as CAM. They had previously been identified by experts and in the literature as CAM.

Methods for Studying CAM Use With Understudied Populations

In the discussion of their systematic review of CAM use among cancer patients, Verhoef, Balneaves, Boon, and Vroegindewey (2005) note that the methods of studying CAM must include examination of the process by which patients decide to use CAM. To do this, these authors suggest that women should be allowed to tell their stories rather than be forced into choosing from preconceived categories that may not capture their personal meaning. The data presented here are meaningful to this issue because they are grounded in the women's experiences rather than resulting from forced choices on checklists and questionnaires. Had there not been this open-ended approach to the research questions, information about new forms of CAM would not have been gained. By using the open-ended format of the card sort and the interview, each woman was able to convey her unique definition of CAM and to discuss the process by which she decided to use CAM therapies. This is of particular importance for the African American women in this study as little information is available concerning their CAM practices.

What the women defined as complementary medicine was often different from the prevailing definition of CAM in the literature (Eisenberg et al., 1993; Lengacher et al., 2002; Montbriand, 1994). For example, all of the women in this sample defined the CAM therapy of traditional medicine as using the medication (chemotherapy or Tamoxifen) provided by their oncologist. Another exemplar was the inclusion of grocery products with claims to health promotion as CAM. One woman in this study used the breakfast drink Bright and Early as an energy boost instead of the aloe vera juice that she had previously used. She classified the drink as a health food supplement, based on advertised claims. This operationalization of a health food supplement is quite different from the types of health food supplements described by many authors in the literature (Berrino et al., 2001; Lesperance et al., 2002). The work by Lesperance et al. (2002) describes health food supplements as megadoses of both vitamins and minerals far surpassing the standard daily requirements. Lamson and Brignall (1999) discuss the benefits of using health food supplements in the form of antioxidants to augment cancer treatment but report studies with doses many times higher than would be contained in a daily glass of orange juice. There were other examples in the study findings. Without the open-ended format of the card sort and interview in this study, women's particular definitions of CAM therapy that differed from the "official" definitions in the literature would have been missed.

Characteristics of African American Women's CAM Use: Similarities and Differences

A major aim of this study was to build on and expand knowledge about CAM use by African American breast cancer patients. The current CAM literature contains reports that African American women do not use CAM, but inclusion of African American women as

study subjects has been limited. The literature reports that more European American women than African American women use CAM (Boon et al., 2000). The results of our exploratory study and a few others call that conclusion into question (Gray et al., 2003; Moschen et al., 2001; Navo et al., 2004; Rees et al., 2000). Since African American women had been poorly represented in previous CAM studies, it was important to examine the conclusions of previous literature.

This study sample, although small, was equally balanced between European Americans and African American women. African American women in this study used more forms of CAM both for their breast cancer and for their health than the European American women in the study. Of potential importance as well is the finding in this study that the African American women used different types and amounts of CAM than the European American women. This finding is similar to a few other reports of CAM use. The few studies that have included diverse samples have resulted in the finding that, given the same list of CAM treatments, African American and European Americans women choose some of the same CAM modalities as the European American women, but the number of women using them and the specific types they used were different (Alferi et al., 2001; Cushman et al., 1999; Factor-Litvak et al., 2001). A study by Alferi et al. (2001) that sampled 231 Black, Hispanic, and non-Hispanic European Americans found that 57% of the African American breast cancer patients used spiritual healing compared to only 18% of the non-Hispanic European Americans. In addition, they found that the African American women in their study were more likely to use herbal therapies (35%) than the non-Hispanic European Americans (12%).

Faith as a CAM

You just meditate on the Lord, . . . when I used to lay down at night, and I usually would just meditate on him day and night, and I would say, Lord, I know that you are the healer, I know that you're my doctor, I know that you is my lawyer, I know that you is my everything, and Lord, I know that you will bring me out of this if you intend for me to come out, you will bring me out, and so he did.

One noteworthy area of focus for the African American women was CAM practices associated with faith. They reported using spiritual healing, meditation, prayer, and music to craft a support system that centered on God and faith during the cancer experience. Other authors have identified these factors in African American women's coping with breast cancer (Henderson, Gore, Davis, & Concon, 2003; Lackey, Gates, & Brown, 2001; Wilmoth & Sanders, 2001).

The African American women in this study used faith, spirituality, and belief in God as complementary to their coping with having breast cancer and the side effects of treatment. Their stories about breast cancer experiences were interlaced with accounts of the ways their faith helped them to deal with their breast cancer diagnosis, to decide about treatment options, to tolerate treatment side effects, and to interact with providers. The importance of spirituality and faith for African Americans dealing with chronic illness has been well documented (Polzer & Miles, 2005; Tanyi & Werner, 2003; Westlake & Dracup, 2001; Woodard & Sowell, 2001). Faith has also been studied in a limited way with breast cancer patients (Lackey et al., 2001; Lythcott, Green, & Brown, 2003). In work by Henderson and Fogel (2003), spirituality was used as a form of social support and a way to cope throughout the breast cancer process. The essential importance of faith to African American women during breast cancer has also been documented (Ashing-Giwa et al., 2004). Prayer was the

most frequently cited form of CAM in this and other studies by Henderson (Henderson et al., 2003).

Spirituality and faith as described by the women in this study incorporated a system of several elements that could be considered alternative medicine, specifically an alternative healing system. The NCCAM defines an alternative healing system as, “a system based on the belief that one's body has the power to heal itself. Healing often involves marshalling multiple techniques that involve the mind, body, and spirit. Treatment is often individualized and dependent on the presenting symptoms” (National Center for Complementary and Alternative Medicine, 2004, p 2). Another definition of an alternative healing system is as follows: “Alternative medicine includes practices that incorporate spiritual, metaphysical, or religious underpinnings; non-European medical traditions, or newly developed approaches to healing” (Wikipedia contributors, 2006, p 1). The women studied by the investigator used their spirituality in the same ways that other types of alternative healing observances are used. They used religious symbols and Scripture in the same way that Eastern practices incorporate meditation and icons. They used fasting in the same fashion as do the practitioners of Ayurvedic medicine (Decker, 1999). They sought the support of their community for prayer and for healing rituals that gave them a sense of well-being and of peace. They related examples of anointing after their diagnosis. One woman described a anointing with oil by her pastor during a home visit, and several others reported anointing by the congregation of their church in corporate worship following disclosure of their breast cancer diagnosis. They told of group prayers prior to chemotherapy to give them strength to undergo treatment. They used prayer chains much like the remote prayers documented in the Mantra Project (Horrigan, 1999) with cardiovascular patients. These women also reported

that they held daily conversations with God much as they might seek help from members of a support group or a health care provider. Several of the women related that they had not been particularly religious prior to their diagnosis but that the cancer diagnosis deepened their relationship with God. Some of the women reported that their biologic and church families were remote during their treatment, so they developed a closer personal relationship with God. This may have reflected their feelings of isolation with their breast cancer diagnosis.

In 1999, at the meeting of the Oncology Nursing Society, Dr. Janice Phillips (1999), in her keynote address, discussed the fear, fatalism, and silence associated with breast cancer in the African American community. The African American women in this study did not take part in support groups. It may be that what they describe as their deepened relationship through an ongoing interchange with God is a response to fear and isolation brought on by community silence.

Several authors include prayer, meditation, and spiritual healing in their lists of CAM treatments (Barnes et al., 2004; Morgan et al., 2005; VandeCreek et al. 1999). The African American women in this study used these forms of CAM, and their interviews indicated that it was a powerful way of coping for them. The experiences that they described were different from those of the European American women, although some of the European American women also chose these forms of CAM.

In a study by Bourjolly & Hirschman, 2001, the authors found that both European American and African American women sought social support during breast cancer but that the European American women used friends and family for support while the African American women relied on God. The women in our study reported this type of reliance on God; their church family also provided social support. The African American women were

not necessarily members of a church, but they had access to church-related individuals who provided emotional support in the form of prayer groups and instrumental support in the form of child care and supplemental food during treatments.

It is interesting to note that, despite feeling closer to God, the women did not report that they expected God to intervene to prevent their cancer from returning. Lopez, Eng, Randall-David, and Robinson noted this in their work with other women in North Carolina (2005). They reported that, for the African American women in their study, being healed or cured did not mean that their cancer would not recur but that God would take care of them regardless. The women believed this because of their own personal experiences and the experiences of others they knew. Several of the women told about friends and acquaintances who had great faith but still succumbed to their cancer.

Use of CAM During Treatment

Another important question for this study was which types of CAM were being used. This sample was varied in personal characteristics: some of the women were pre-menopausal and some were postmenopausal; some women were well educated while others had less education; some were new to breast cancer and some had lived with it for years; and some were currently being treated with chemotherapy or hormonal therapy while others had finished treatment. However, CAM use was ubiquitous to their breast cancer experience. The CAM therapies used most often were in the biological domain, which has tremendous implications for the potential of drug–CAM interactions. Montbriand (2004a, 2004b, 2004c, 2005), in a series of articles for the *Oncology Nursing Forum*, reviewed the current reports of studies concerning the use of CAM and conventional biomedicine. Her review, as does other

literature, points up the continued controversy surrounding CAM use during cancer treatment. There is evidence that some CAM forms in specific doses can interfere with the effectiveness of both cytotoxic and hormonal chemotherapy. However, there is also evidence that other forms of CAM can decrease treatment-related toxicities and boost treatment effectiveness (Babu et al., 2000). Some authors have argued the evidence that biologicals offer a way to minimize the toxic effects of cancer treatment (Conklin, 2000; Thomson et al., 2005; Weijl, Cleton, & Osanto, 1997) while others have advocated discontinuing all biologicals during treatment (Beyerstein, 2001; Meijerman, Beijnen, & Schellens, 2006). As evidence accumulates, the only consensus is that there needs to be more study (Lamson & Brignall, 1999; Weiger et al., 2002).

In this study of CAM therapies, the women used mind-body treatments and treatments that they ingested. The therapies that were ingested have more potential to affect the way conventional therapies are tolerated and absorbed. This is relevant for all women receiving conventional therapy and for other breast cancer survivors with estrogen receptor positive tumors. As CAM therapies are studied more rigorously, more information will be gathered about drug/CAM interaction. The women in this study used vitamins, antioxidants, and minerals. Although there is still no definite evidence that the forms of CAM that these women use interfere with conventional therapy, numerous authors counsel practitioners to warn patients to avoid these forms of CAM (Boyle, 1997; Lamson & Brignall, 1999; Weiger et al., 2002) but have only small human studies or animal trials as a basis for their advice. As prevalent as the use of mind-body therapies was in our sample, it is important to make the distinction between these and the CAM treatments that are ingested because mind-body

therapies provided the women in this study relief of treatment-related toxicities without chemically interacting with conventional therapy.

In this study the women reported that the CAM they used for breast cancer and health improved their energy, and, important to the women receiving chemotherapy, they believed that the CAM they used enabled them to receive the curative therapy that they were prescribed on time. Often their providers recommended the vitamins and antioxidants they used. The women took great pride in avoiding treatment delays. So, in this regard, the CAM experience was positive and empowering. Concerns about receiving treatments on time are valid as prognosis is directly related to receiving the prescribed chemotherapy in a timely fashion (Bonadonna, Valagussa, Moliterni, Zambetti, & Brambilla, 1995). This study did not quantify the amount of biologic therapy that the women used, but these women often used CAM therapies that have been specifically discussed both positively and negatively in the literature.

The women in our sample with the most toxicity had gone through acute treatment for their breast cancer (surgery, chemotherapy, and radiation) and were receiving anti-estrogen therapy with Tamoxifen. They did not stop CAM after their acute treatment was over. The CAM therapies they used were in several of the NCCAM domains, but many of them were ingested biological therapy. The use of Tamoxifen and other estrogen-modulating medications with CAM is not addressed extensively in the literature. Literature is emerging that reports on the negative effects of CAM treatments on the effectiveness of these estrogen-modulating medications (Montbriand, 2004a). These anti-estrogen therapies are continued for many years (National Cancer Institute, 2005), but little work has been done to educate women about ongoing vigilance in dietary intake after acute cancer treatment is concluded.

Some studies in Europe have shown benefits of adding CAM when patients are receiving therapy with Tamoxifen. Munoz et al. (2003) found that black cohosh reduced hot flashes associated with estrogen suppression, and Babu et al. (2000) found that concomitant use of vitamin C and vitamin E reduced triglyceride elevations associated with Tamoxifen treatment.

Women in this study who had been diagnosed longer were the heaviest users of CAM. Other work with long-term breast cancer survivors has also demonstrated that CAM use continues past the period of acute care (Hann et al., 2005). There is also some indication in the literature that prior treatment increases the likelihood of CAM use (Alferi et al., 2001; Kessler et al., 2001), perhaps due to the added toxicity of treatment or experiencing side effects with prior treatment that were not managed well. The concomitant use of conventional therapy with CAM in long-term survivors will become even more important as breast cancer becomes less an acute illness and more a chronic disease with chronic treatments and toxicities. Although this study is limited by a small sample size, these findings indicate that further exploration is warranted.

Recommendations

Future longitudinal study is needed to examine the exact doses of vitamins and antioxidants used by women being treated for breast cancer. Examination of CAM use and the conventional treatments given concurrently would begin to quantify the amounts of CAM and the actual benefits accrued by breast cancer patients. At present, clinical trials are under way within the NCCAM to assess the amounts of CAM used over time and the toxicities experienced by women who use them (National Cancer Institute, 2006). Also, providers need to become more educated about including exact amounts of CAM used during treatment and

current research about CAM–drug interactions. The reliance shown by these women on information from providers makes current knowledge about the effects of the use of biologicals during treatment even more vital.

CAM Use for Treatment of Breast Cancer–Related Issues as Compared to CAM Use for Self-Care and Lifestyle Issues

The literature differentiates between CAM that is used for cancer and CAM that is used for health (Astin et al., 2000; Balneaves et al., 1999). The women in this study had a difficult time differentiating one reason for CAM use from another because they said if they were healthy, they were less likely to have cancer. Cancer was a wake-up call for the women in this study. They adopted CAM as a reaction to breast cancer and the effects of treatment. They described two distinct roles for the CAM that they used during treatment. One group of CAM treatments was used for specific side effects of cancer treatment, including emotional and physical toxicities. The women ate specific foods for side effects of treatment, such as lemon for fatigue, and fruits and vegetables for neutropenia. These CAM treatments were very focused and were discontinued after the toxicity was past.

Another group of CAM therapies was used to correct past lifestyle and dietary indiscretions that the patients identified through examination of their own lifestyles. Many of the women reported using therapies that would be considered elements of healthy living such as vitamins, exercise, and a healthy diet (American Cancer Society, 1996). They described using CAM to become more healthy so they could tolerate treatment and lessen the likelihood that their cancer would recur. This finding is similar to the results of Chou et al.’s study (2000) of Hispanics, African Americans, Asians, and European Americans, in which improving health and preventing further cancer were the main reasons women gave for using

CAM. Health-promoting behaviors such as diet and exercise are characterized as CAM (Chou et al., 2000), so they are normally included in lists of CAM therapies (Sparber et al., 2000; VandeCreek et al., 1999). Some of the women in our sample modified their diet in an attempt to correct poor eating habits. Some ate a diet of fruits and vegetables and considered it a special diet because it lacked “junk food.” These women used special diets and exercise in much the same way as has been described in other literature (Djuric et al., 1998): to improve their body environment and to become more healthy during treatment (Schwartz, 2000). Many of the therapies used by the women in this study were a direct reaction to receiving the diagnosis of breast cancer.

The women in this study used CAM to enhance the way they felt during treatment and as a way to help themselves. Using CAM helped them feel as though they were active participants in their care. The concepts of health and cancer are very blended for these women. One woman said,

I don't have a general well-being right now. It's all breast cancer. That's the thing with this sort of thing. . . . I never, ever could have imagined in my life how all-consuming something like this is, and I don't know how people get to a point where it isn't that way anymore, where you just think about it, like even when I don't think about it, it's like I catch myself off-guard, and it's like this little voice in the back of my head that says, *You have breast cancer* [whispered].

Recommendations

This study can provide insight for nurses caring for patients with breast cancer. In planning care, it is important to keep in mind the level of trauma experienced by the patient and help her normalize to a healthy lifestyle. Many of the CAM therapies used by these women did not require expenditure of time or money. More than half of this sample had a yearly income below \$25,000, but they still used a variety of CAM treatments to deal with their cancer experience. They used movies (distraction) to relieve stress, walking (exercise)

to deal with nausea, the radio (music therapy) to calm anxiety, and quilting (art therapy) to increase their sense of well-being. Nurses involved in care for women with breast cancer can investigate the use of these simple and inexpensive CAM forms as the basis for breast cancer support groups. Two of the women in this study identified the exercise that they got as part of a seniors' cheerleading squad as one of their forms of CAM. Both reported that they had tried traditional support groups but dropped out because the support groups were too depressing.

Precipitating and Influential Factors in the Choices of Breast Cancer Patients to Use CAM

Self-Blame and CAM Use

Many of the women in this study reported that they believe they brought their cancer on themselves. The literature describes self-blame (Bennett, Compas, Beckjord, & Glinder, 2005), cognitive appraisal (Lazarus & Folkman, 1984), and posttraumatic growth (Janoff-Bulman, 2004; Tedeschi & Calhoun, 2004) in relation to stressful life events such as breast cancer. For some of these women, the stress and shock of a breast cancer diagnosis precipitated their adoption of CAM treatments. It motivated them to adopt numerous behaviors that are considered CAM, especially dietary and lifestyle changes. Throughout the interviews, the women reported a type of lifestyle review to search for factors that could have caused their cancer. Authors who describe breast cancer survivors who use CAM have described their distress as a negative aspect of their diagnosis (Burstein et al., 1999). In a study by Glinder and Compas (1999), the authors linked psychological distress with self-blame and reported that persistent feelings of self-blame lead to long-term psychological distress. This was also seen in a study by Bennett et al. (2005), who found that persistent self-

blame was related to symptoms of anxiety and depression. The women in our study used their distress to change their lifestyles and health habits, and used positive growth through CAM therapies to help themselves. This is similar to the posttraumatic growth described by Janoff-Bulman (2004) and Tedeschi et al. (2004). The authors describe positive growth after traumatic life events such as breast cancer diagnosis. Perhaps, for these women, adopting CAM was a way of effecting positive personal change. They reported choosing CAM because they viewed breast cancer as a double threat, in that conventional providers were unable to point to a specific cause for its occurrence and offered few effective systems to monitor potential recurrences (Smith et al., 1999). They also used information from medical experts (American Cancer Society, 1996; National Cancer Institute, 2005) and the popular press (Cool, 2006; Looking after your body, 2006) that advocated the use of numerous CAM treatments to prevent cancer.

The Expert

Experts influenced all of the women in this study in their CAM use. Often they relied on their oncologists and oncology nurses for information and recommendations about CAM. This refutes the idea that CAM use is a secret practice that must be hidden from providers. Considerable literature documents a lack of disclosure about CAM use in breast cancer patients. Adler and Fosket (1999) followed breast cancer patients for 5 years and investigated the amount of disclosure of CAM use. Their sample was a multiethnic group, 72% of whom used at least one form of CAM. Only 54% of this sample had disclosed to their provider that they used CAM. Reports by Eisenberg et al. (2001) and Patel (1987) also noted that patient nondisclosure of CAM use poses a danger in the setting of conventional medical treatment.

Our sample of women freely shared their CAM use with providers and used them to help decide about CAM use and CAM drug interactions. Several of the women reported that their providers were uninformed about CAM treatments, and so they did not spend a lot of time discussing CAM with them. In fact, the women's providers often advocated adding CAM to reduce side effects of treatment. Several of the women had co-morbid conditions that caused them to be anxious about using CAM. These women in particular utilized their providers to determine if the CAM they planned to use would hurt the conventional treatment they were receiving for conditions such as diabetes, arthritis, or high blood pressure.

Many of the CAM treatments not selected by the women in this study have proven efficacy for women with breast cancer including: massage (Bredin, 1999; MacDonald, March/April, 2000; Williams, 2000), reiki (Decker, 1999) and acupuncture (Dundee, Ghaly, & Fitzpatrick, 1989; National Institutes of Health, 1997). They were not used by the women in this sample at times because they lacked information about these therapies and often due to the expense involved in using them. More than half of this sample had a yearly income of less than \$25,000 per year. The women in this group were not necessarily averse to these therapies but lacked the resources of time and money to take advantage of potentially beneficial CAM therapies. These women still used CAM treatments but they used modalities that did not require outlay of money such as music, exercise and prayer.

Health beliefs strongly influenced CAM use for the women in this study. They had very definite ideas about the things that were good for them and those things that would harm their health. In a series of articles from Canada (Boon et al. 1999, 2000; Brown, Carroll, Boon, & Marmoreo, 2002; Verhoef et al., 2005), the authors found that health beliefs were very strong influences on the choices that breast cancer survivors made about using CAM. Not only did

the women in our study have specific ideas about things that were good for them, such as exercise, healthy diet, and daily vitamins, but they also had beliefs about things that were bad for them. Although the literature about home remedies in the South describes remedies such as turpentine (Frate et al., 1996), whiskey (Arcury et al., 2006), and Rootwork (Mathews, 1987), this sample of women was very clear that they did not believe in the benefit of these therapies even though past family members had used them. There is some literature that indicates that family traditions and past CAM use will influence patients' choices of CAM treatments. Our findings raise questions about assuming that groups of patients will necessarily use the therapies advocated by family and past traditions.

The African American women in this study sought more sources of information than the European American women. The literature reflects that numerous barriers to information-seeking exist for African American women with cancer, including historical mistrust of the medical community, stigma associated with cancer, and concerns about privacy (Matthews et al., 2002). This small study demonstrates that some African American women of various educational levels are using print and personal sources to gather information about CAM, which influences them to incorporate CAM into their personal treatment plan. This has implications for nurses and service agencies that provide information for patients. It is important to incorporate culturally relevant information in published materials. One woman in the sample was convinced that she had nausea and vomiting after her treatment because she had not peeled a strawberry that she ate after her treatment. Several of the women in the sample religiously followed the information in American Cancer Society and National Cancer Institute materials they had received from their oncology clinic.

Recommendations

Nurses should review and modify materials to meet the needs of all their patients, not just the dominant ethnic group. Food choices and dietary modifications recommended in the literature should be tailored to methods of preparation used by African American women in the home. One woman reported that she was losing weight because the fried food she preferred was prohibited by the American Cancer Society publication she was following to avoid chemotherapy-induced nausea. Another woman who had worked in a college dining hall used her past understanding of nutrition to modify her diet to prevent problems with nausea. These types of inputs would be invaluable in adjusting recommendations in patient publications.

The Process and Timing of Decision-Making by Breast Cancer Patients to Choose CAM

Around the Time of Treatment

Conceptual model revisited

In light of the findings in this study, the exploratory model, generated from the literature (Figure 1) was re-examined. Some of the relationships were reinforced such as the important roles of health beliefs, culture and physical and emotional characteristics of the individual women. However, the sequence that the women in this sample used these elements to decide about CAM use was different than previously described. These elements were precursors of the cancer diagnosis, so they colored the way the women coped with their cancer diagnosis and the types of CAM they chose. The diagnosis of cancer was a motivator to cause the women to seek information about CAM and later the effects of cancer and its treatments became motivators. The types of information used were similar to other Bilodeau & Degner, 1996) studies with breast cancer patients but these women described using experts

as sources who acted as authorities for many CAM decisions. The role of vigilance in the process of appraisal and re-appraisal was less important for this group of women than expected based on the literature.

These data emphasize the importance of the prior uses of CAM to women's decision-making. Often the women had prior experiences with CAM and that affected the ways they dealt with physical and emotional effects of having cancer. Many women had co-morbid conditions and all had personal health beliefs that influenced responses to their cancer diagnoses. Women brought these beliefs to the process of personal appraisal that was motivated by first receiving a cancer diagnosis and then by having emotional and physical side effects associated with breast cancer and its treatment. The women in this study gave added insights into the "black box of appraisal" and that portion of the model was further elucidated. The element of "trying it out" was important for these women and this sample gave more information about this process. They sorted through information about particular CAM treatments made judgments about using them then entered into their own personal trial of effectiveness. Often the sole reason for using a CAM strategy was that it worked for them.

The process that the women in this small study used to decide on CAM involved continuous assessment of symptoms and trying out various CAM therapies. The therapies that they used for specific toxicities of treatment were adopted after they sought information from a variety of sources, including print materials, the Internet, friends and family, and their providers. At least one of the information sources women used was generally a person considered to be an expert. Even after the women decided that a CAM treatment might be useful to them, they had to make a personal commitment to purchase it. Often the women in

the study reported being interested in a CAM form and acknowledged the CAM therapy's potential for them but had not taken the final step to buy it.

However, after the CAM form was acquired or adopted, the women began the process of trying it out. The time frame for the process was variable. Some of the women would give a treatment just one try, while other women would use a treatment for months in order to give it a chance to work. This process applied to the use of CAM for specific symptoms. Women continued CAM treatments because they worked. If a CAM therapy worked, the women used it as long as the potential existed that the symptom might return. This was the case for neutropenia associated with chemotherapy. These women reported continuing the use of herbs, vitamins, and healthy foods as long as the threat of low blood counts and missed treatments loomed. The two women in the study who had completed chemotherapy still used CAM forms for persistent side effects of treatment. This has been documented in other literature about breast cancer survivors (Canales & Geller, 2003). When the threat of side effects passed, they were likely to stop the CAM treatments.

This was not the case for the CAM treatments that the women used to maintain good health. They started them soon after their cancer diagnosis and continued them after treatment was done. The factors that influenced these women to stop health-related forms of CAM were not clear. Some data indicate that women continue these types of CAM to prevent cancer recurrence (Hann et al., 2005; Montbriand, 2004b).

Recommendations

It is important to further describe the process that women with recurrent breast cancer use to continue CAM treatments and to identify the role they see for CAM in their treatment plan. For instance, the relief of depression and anxiety by mind-body treatments such as

prayer and art therapy provides important information for providers about alleviating the suffering associated with a cancer diagnosis without the risks associated with pharmacotherapeutics.

Summary of the Study

For the women in this study, CAM use supplemented the conventional medical treatment that they used to deal with their breast cancer. This small study raised questions about the reports that attribute CAM use only to European American, affluent women. The European American and African American women in this study used CAM often for specific effects of treatment and to improve their general health. The two ethnic groups differed in the types of CAM they used, but both groups used CAM. They went through a process that involved collecting information from experts and other sources as well as trial and error. Their health beliefs and other factors that affected their overall health influenced decisions to use CAM. Often they involved medical providers in their decision-making. This group was not reluctant to disclose CAM use to providers, as has been previously described (Adler et al., 1999; Astin et al., 2000; Boon et al., 2000; Tasaki et al., 2002), but sought medical input to prevent CAM–drug interactions. With the lower-income women in this sample it is important to note that the CAM used did not require financial outlays. This has implications for coping coaching by oncology nurses involved in treatment-related care. Even women with limited finances can benefit from CAM interventions they can practice at home. In addition, some CAM treatments, such as massage, music, and art therapy, could be provided by volunteers at cancer centers to patients who could not afford them.

This small study points up the importance of spirituality and faith, especially to African American women. Prayer was the CAM therapy chosen most frequently by all of the women in the sample. As the women were most likely to use their spirituality to cope, this aspect of their well-being should also be assessed. Religious practices were individual to each woman, but all appreciated acknowledgment of their faith and the role it played for them in sustaining them during breast cancer treatment.

Recommendations for Future Study

Allowing subjects to define CAM therapy is essential until such time as the definition is consistent and transparent to the lay public. Constraining participants to lists or categories of CAM as defined in the literature will result in an incomplete picture of CAM use that may not include common, everyday strategies women use to cope with breast cancer and its side effects. It is vital to clarify, in this and other populations of CAM users, their definitions of CAM and their perceptions of CAM use and to get detailed information about CAM use history in order to better describe the nature and extent of the larger problem--the potential for interaction and augmentation of conventional therapy by CAM treatments.

Based on the results of this study and a few others, future research in this area needs to include larger, more diverse samples of breast cancer patients. Our data indicated that the study of CAM use during breast cancer must include ethnically diverse samples even though difficulties in recruitment continue to be an issue. Other characteristics of CAM users may influence CAM use, including age and education. In addition, prospective longitudinal studies of CAM use from the time of diagnosis into the survivorship period would add to information about the CAM decision-making process, including but not restricted to the use

of CAM for side effects of differing types of treatments. Women in this study reported using CAM, but their criteria for CAM were diverse and their reasons for using it extended to a variety of health promotion issues and were not limited to managing their cancer.

The amounts of biologic therapy used by the women in this study who were actively engaged in treatment and with the knowledge of their providers merit further study to delineate the extent of this type of CAM use. Biologic therapies are of particular concern since so little information exists about the probability of CAM–drug interactions. As evidence accumulates, the only consensus is that there needs to be more study (Lamson et al., 1999). Studies with patients who record doses of CAM and conventional treatments with the effects they experienced would help to further explain the actual experiences of the women who use CAM.

This study points to the potential power of informed providers in guiding patients to CAM use to effectively augment conventional biomedical treatment. Intervention studies with providers to provide them with education about CAM, characteristics of CAM users, skills in obtaining CAM-use histories, and current evidence for the efficacy of particular CAM therapies could enhance the patient-provider dialogue about CAM use and potentially benefit both provider and patient.

More research is needed to clarify what motivates women to continue CAM long past the time of treatment. Also, it is important to study long-term CAM users with recurrent disease to determine if they continue CAM after their disease has returned. Some literature notes that CAM use continues and increases in women with advanced breast cancer (Helyer et al., 2006; Shen et al., 2002). It is important to understand if CAM use changes when breast cancer returns and what toxicities women are targeting with their CAM therapy.

This study began with the idea of exploring CAM use, the process of deciding about using CAM during breast cancer, and including African American women in the sample studied. The results provide a beginning look at these questions and a clarification of some of the issues from the current literature. This small sample provides new insights into which types of CAM this group of southern breast cancer patients used and the influences they deemed important in choosing CAM forms. This work also echoes other Researchers that reports that women with breast cancer engage in self-blame about lifestyle factors that may have been related to their developing breast cancer. However, the women in this study made this process an empowering one by moving on to adopt positive health behaviors—changes to improve their health as well as to tolerate treatment and its side effects. The finding that women were using CAM with the knowledge and often the recommendations of their health care providers, and using their providers as expert resources for such decisions, affirms the potential importance of educating health care providers about the evidence base for the efficacy of CAM as well as the potential for CAM interactions with conventional treatment. In addition, the importance of dialogue with patients about their decisions concerning CAM use is supported.

Appendix A

Fliers for patient recruitment



**Are you being treated for Breast Cancer?
Do you use treatments and activities to help
you manage the side effects of your cancer
and its treatment like prayer, home**

remedies, herbs, exercise or vitamins?

If so, you may be eligible to participate in a research study about using home remedies and other complementary therapies (CAM) during breast cancer treatment. The study will involve a discussion group and private interviews about women's practices during breast cancer treatment.

You may qualify for this study if you are:

18 years of age or older,

Using home remedies or complementary therapy treatments,

Receiving treatment for your breast cancer,

Are either White or African American.

**Taking part is confidential
Participants will be paid \$20.00 for their time**

**Call toll free:
1-877-625-3380**



Are you being treated for Breast Cancer?

Do you use treatments and activities to help you manage the side effects of your cancer and its treatment like prayer, home remedies, herbs, exercise or vitamins?

If so, you may be eligible to participate in a research study about using home remedies and other complementary therapies (CAM) during breast cancer treatment. The study will involve a discussion group and private interviews about women's practices during breast cancer treatment.

You may qualify for this study if you are:

18 years of age or older,

Using home remedies or complementary therapy treatments,

Receiving treatment for your breast cancer,

Are either White or African American.

Taking part is confidential
Participants will be paid \$20.00 for their time

Call toll free:
1-877-625-3380





**Are you being treated for Breast Cancer?
Do you use treatments and activities to help
you manage the side effects of your cancer
and its treatment like prayer, home remedies, herbs,
exercise or vitamins?**

If so, you may be eligible to participate in a research study about using home remedies and other complementary therapies (CAM) during breast cancer treatment. The study will involve a discussion group and private interviews about women's practices during breast cancer treatment.

You may qualify for this study if you are:

18 years of age or older,

Using home remedies or complementary therapy treatments,

Receiving treatment for your breast cancer,

Are either White or African American.

Taking part is confidential

Participants will be paid \$20.00 for their time

Call toll free:

1-877-625-3380





**Are you being treated for Breast Cancer?
Do you use treatments and activities to help
you manage the side effects of your cancer
and its treatment like prayer, home remedies,
herbs, exercise or vitamins?**

If so, you may be eligible to participate in a research study about using home remedies and other complementary therapies (CAM) during breast cancer treatment. The study will involve a discussion group and private interviews about women's practices during breast cancer treatment.

You may qualify for this study if you are:

18 years of age or older,

Using home remedies or complementary therapy treatments,

Receiving treatment for your breast cancer,

Are either White or African American.

**Taking part is confidential
Participants will be paid \$20.00 for their time**

**Call toll free:
1-877-625-3380**



Appendix B



Complementary Therapy Use during Breast Cancer Treatment

Consent

You are being asked to take part in a research study being conducted by Camille Lambe, RN, MSN, AOCN, NP that will help nurses and doctors learn more about how women decide to use complementary therapy during treatment for breast cancer. Complementary therapy is a type of treatment not prescribed by a doctor that may be helpful to manage side effects of breast cancer or its treatments or to stay healthy. These therapies may include herbs, vitamins, meditation, prayer, exercise and other things. What they learn from this study may help other breast cancer patients when they receive treatment for cancer although this may not benefit you. Being in this study is completely your choice.

You were selected because you have breast cancer and are receiving additional treatment besides surgery for your cancer. You will be one of approximately 20 patients who will be asked to be in this study. To be in the study you will be asked to take part in an interview about your use of complementary therapy since you have had breast cancer. The interview will take about 1 ½ hours and you may be asked, if you are willing, to also have a follow-up interview lasting less than an hour. Both interviews will be taped recorded and transcribed, a written word-by-word account. Tapes of the meeting will be stored in a locked cabinet in the School of Nursing and destroyed after the study is complete. You will also be asked to complete three short questionnaires about your cancer and yourself at the end of the interview. That should take less than 20 minutes to complete.

Talking about your breast cancer experience and complementary therapy treatments may help you feel better, or it may be a little upsetting. It is also possible that talking about these things will not affect you in any way. If talking about them does upset you, you may talk about your feelings after you finish answering the questions, or you may stop answering questions at any time. You will receive \$20.00 as a token of appreciation for your participation in the individual interview and another \$20.00 if you take part in a second interview.

Nothing that you say will be shared with people other than the researcher's faculty advisors. Results of interviews with all the women in the study may be grouped together and reported in professional meetings or in professional publications but without information that could identify you or any particular individual. Although every effort will be taken to keep all the research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, you can be assured that all steps allowable by law to protect the privacy of information will be taken.

You are free to participate or not to be in the study and you may drop out of the study at any time if you want to. If you do not participate or if you drop out, it will not affect your care in any way.

You have been told about the reason for the study and about your part in it, and you have been able to ask questions. If you are willing to be in this study, you will get a copy of this form. The signed forms will be kept in a locked cabinet in the School of Nursing for at least 5 years.

You understand that the study has been approved by the Nursing IRB. You may contact this committee at 919-966-3113 any time during this study if you have any questions about your rights as a subject in this study. You may also contact the researcher Camille Lambe, a doctoral student at 919-818-8747 or her dissertation advisor, Dr Barbara Germino at 919-966-9209.

I agree to take part in the individual interview.

| | |
|----------------------|------|
| Signature of patient | Date |
|----------------------|------|

I agree to a second follow-up interview.

| | |
|----------------------|------|
| Signature of patient | Date |
|----------------------|------|

| |
|---------------------------------------|
| Signature of person obtaining consent |
| Date |

Convenient phone number and time to call to arrange an interview.

Appendix C

CAM Card List

| | |
|---------------------------|-----------------------|
| Antioxidants | Metabolic therapy |
| Acupuncture/Acupressure | Milk Thistle |
| Aloe vera juice | Mineral supplements |
| Aromatherapy | Mistletoe |
| Art Therapy | Mullen |
| Biofeedback | Mushroom Extract |
| Black Cohosh | Music |
| Cannabis, Marijuana | Natural medicine |
| Chelation | Naturopathy |
| Chinese medicine | Noni |
| Chiropractic | Ozone Therapy |
| Coenzyme Q10 | Pickle juice |
| Colored light treatments | Polarity |
| Counseling | Prayer |
| Detoxification | Red clay |
| DHEA | Red Clover |
| Echinacea | Reflexology |
| Electro-stimulation | Reiki |
| Enemas | Relaxation techniques |
| Exercise | Remifemin |
| Fasting | Rootwork |
| Folk medicine | Rum soaked raisins |
| Ginger | Salves |
| Gingko | Selenium |
| Ginseng | Soy |
| Glucosamine/Chondroitin | Special diet |
| Guided Imagery | Special foods |
| Health food supplements. | Spiritual healing |
| Herb tea | Support group |
| Herbal supplements. | Talking away illness |
| Home remedies | Therapeutic Touch |
| Homeopathy | Traditional medicine |
| Honey | Turpentine |
| Humor | Vinegar |
| Hydrogen peroxide therapy | Vitamin B6 |
| Hypnosis | Vitamin C |
| Lemon | Vitamin E |
| Magnetic Therapy | Vitex |
| Massage | Whiskey |
| Meditation | Yoga |
| | Zinc |

Appendix D

| CAM Tally Sheet | | | | | |
|------------------------------|-----------------------------------|----------------------------|-----------------------------|--------------------|------------------|
| Patient ID | Are using for breast cancer | Are using for health | Have used in the past | Are considering | Would not use |
| Antioxidants | | | | | |
| Acupuncture/Acupressure | | | | | |
| Aloe vera juice | | | | | |
| Aromatherapy | | | | | |
| Art Therapy | | | | | |
| Biofeedback | | | | | |
| Black Cohosh | | | | | |
| Cannabis, Marijuana | | | | | |
| Chelation | | | | | |
| Chinese medicine | | | | | |
| Chiropractic | | | | | |
| Coenzyme Q10 | | | | | |
| Colored light treatments | | | | | |
| Counseling | | | | | |
| Detoxification | | | | | |
| DHEA | | | | | |
| Echinacea | | | | | |
| Electro-stimulation | | | | | |
| Enemas | | | | | |
| Exercise | | | | | |
| Fasting | | | | | |
| Folk medicine | | | | | |
| Ginger | | | | | |
| Ginkgo | | | | | |
| Ginseng | | | | | |
| Glucosamine/Chondroitin | | | | | |
| Guided Imagery | | | | | |
| Health food supplements. | | | | | |
| Herb tea | | | | | |
| Herbal supplements. | | | | | |
| Home remedies | | | | | |
| Homeopathy | | | | | |
| Honey | | | | | |
| Humor | | | | | |
| Hydrogen peroxide therapy | | | | | |
| Hypnosis | | | | | |
| Lemon | | | | | |

| | | | | | |
|-----------------------|--|--|--|--|--|
| Magnetic Therapy | | | | | |
| Massage | | | | | |
| Meditation | | | | | |
| Metabolic therapy | | | | | |
| Milk Thistle | | | | | |
| Mineral supplements | | | | | |
| Mistletoe | | | | | |
| Mullen | | | | | |
| Mushroom Extract | | | | | |
| Music | | | | | |
| Natural medicine | | | | | |
| Naturopathy | | | | | |
| Noni | | | | | |
| Ozone Therapy | | | | | |
| Pickle juice | | | | | |
| Polarity | | | | | |
| Prayer | | | | | |
| Red clay | | | | | |
| Red Clover | | | | | |
| Reflexology | | | | | |
| Reiki | | | | | |
| Relaxation techniques | | | | | |
| Remifemin | | | | | |
| Rootwork | | | | | |
| Rum soaked raisins | | | | | |
| Salves | | | | | |
| Selenium | | | | | |
| Soy | | | | | |
| Special diet | | | | | |
| Special foods | | | | | |
| Spiritual healing | | | | | |
| Support group | | | | | |
| Talking away illness | | | | | |
| Therapeutic Touch | | | | | |
| Traditional medicine | | | | | |
| Turpentine | | | | | |
| Vinegar | | | | | |
| Vitamin B6 | | | | | |
| Vitamin C | | | | | |
| Vitamin E | | | | | |
| Vitex | | | | | |
| Whiskey | | | | | |
| Yoga | | | | | |
| Zinc | | | | | |

Appendix E

Interview Questions

- Introduction of the PI
- Answer questions about the study. Have participant sign consent. Provide them with copy of consent.
- Would you describe your breast cancer experience and talk about your treatment and any side effects you have had?
- This study is about Complementary Therapy that women use during breast cancer. Complementary therapy treatments are not prescribed by a doctor but are any of the things you have found helpful to you in managing the side effects of breast cancer or treatments or to stay healthy. They may include herbs, vitamins, meditation, prayer, exercise or other things.
- On these cards are things that other women have used to help them during breast cancer treatment. What I would like you to do is to take some time to divide the cards into piles.
- Divide the cards into the things you are using now and the things you are not using. If you don't know what something is, we can discard those cards.
I also have blank cards to write any other things that you have done to help yourself since you found out about your breast cancer. Deleted last sentence

When the woman is finished:

I. (Addressing the appropriate pile): For the things you are using, let's divide those into the ones you use for breast cancer and treatment side effects and those you use for your general health?.

a. About the things you use for the breast cancer:

Tell me about using these. (Probes: Tell me how you decided to use this to help yourself? How do you use them? When do you use them? How do they help you? How can you tell that it's helping?).

How did you find out about these things? (Probes: Did someone suggest it? Did something happen to make you think it might help you? Did you read something, find something on the internet or other? Did you talk with anyone about using this?)

Have you talked to your doctor about the things you are using for your breast cancer? Why or why not?

b. About the things you use for your general health:

Were you using this before your breast cancer? How does it help your health? (Probes: When did you start using this? What made you start using it at that time?)

II. Let's look at the things you put in this pile—the things you are NOT using: Divide these into things you have used in the past, things you are considering using and things you would definitely not use?

- a. Let's go through these things, the ones you have used in the past. [Ask for each:] Why did you stop them? Could you tell me more about that decision? (Probes: Can you tell me about stopping them? What made you decide to stop? Would there be a time that you might consider restarting them? What might make you reconsider? Have you had a bad experience with them?)
- b. Now let's go through the things you are considering. [Ask for each:] (Probes: Why have you not started these? What concerns do you have about them? Are you still thinking that you might use them? What would make you decide?)
- c. Now tell me about the things you would not use. [Ask for each:] Is there a special reason why? (Probes: How did you find out about these things? Have you talked to anyone about them? Has that been a factor in deciding not to use them?)

Is there anything else that's important for me to understand about your decision to use Complementary Therapy?

Thanks—this has been really helpful.

The last thing is filling out these three short questionnaires about you, the information sources you use about CAM and the effect cancer and its treatment have had on you.

After collecting these, hand out the honorarium and thank the participant again for her time. Mention that you may be contacting her for a brief follow up and why.

Appendix F

Breast Cancer Treatment Toxicity Questionnaire

This questionnaire is for women receiving treatment for breast cancer. We are interested in how you have been feeling, physically and emotionally during the last 2 weeks. The questions focus on some of the problems and feelings reported by women who have received treatment for breast cancer. Check the one box in each line that best applies to you.

| | All of the time | Some of the time | None of the time |
|---|--------------------|---------------------|---------------------|
| How often during the past 2 weeks, have you felt that: | | | |
| You were positive or optimistic regarding the future? | | | |
| Your fingers were numb or felt like they were “asleep”? | | | |
| You were having trouble remembering things? | | | |
| You were low in energy? | | | |
| You were tearful or down in the dumps? | | | |
| You were troubled or upset because of feeling unattractive? | | | |
| You were uncomfortable or embarrassed because of changes in your skin or nails? | | | |
| You were irritable? | | | |
| You were worried or tense? | | | |
| You were uncomfortable or embarrassed because of thinning or loss of your hair? | | | |
| You were sad or tearful because of losing your breast? | | | |
| You were feeling good about yourself? | | | |
| You were having pain? | | | |
| The future looked hopeful and promising? | | | |
| You were troubled by weight loss? | | | |
| You were drowsy or sleepy during the day? | | | |
| You had an upset stomach? | | | |
| You had trouble getting a good night’s sleep? | | | |

| | | | |
|---|----------------------------|-----------------------------|-----------------------------|
| You had a runny nose? | | | |
| You had a loss of appetite? | | | |
| | All of the time | Some of the time | None of the time |
| How often during the past 2 weeks have you felt that: | | | |
| You had the feeling that you smelled of chemicals? | | | |
| You had a change in the way your food tastes. | | | |
| You had problems with fatigue or tiredness that interfered with your housework? | | | |
| You had more than the usual amount of gas? | | | |
| You had menopause symptoms? | | | |
| You had constipation? | | | |
| You had burning, watery, or sore eyes? | | | |
| | A great deal | Some | None |
| How much time during the last 2 weeks would you say that your family has been worried about you and about your health? | | | |
| How much time during the past 2 weeks have you had problems with fatigue or tiredness which limited your social activities? | | | |
| How much help and support have you received from people outside your family during the past 2 weeks? | | | |
| How much trouble have you had in the past 2 weeks because of feeling nauseated or sick to your stomach? | | | |
| How much trouble or inconvenience have you had during the past 4 weeks because of low blood counts? | | | |
| How much trouble or distress have you had because of pain, soreness, or sores in your mouth during the past 2 weeks? | | | |

Appendix G

SOURCES OF INFORMATION

When you are looking for information about cancer, its treatment, and complementary therapies which of the following sources influence you the most? Check all that apply.

| | |
|--|---|
| <p>_____ American Cancer Society</p> <p>_____ Audiotapes, Videotapes or CDs</p> <p>_____ Books from the Public Library</p> <p>_____ CAM provider</p> <p>_____ Cancer Information Groups (like, Reach for Recovery)</p> <p>_____ Church or Spiritual leader</p> <p>_____ Community Center</p> <p>_____ Family members</p> <p>_____ Friends</p> <p>_____ Health Food Store assistant/clerk</p> <p>_____ Herbalist or root worker</p> <p>_____ Home Health Nurse</p> <p>_____ Hospital Cancer Center</p> <p>_____ The Internet</p> <p>_____ Magazines</p> <p>_____ Medical Library, or Bookstore</p> <p>_____ National Cancer Institute Cancer Information Line</p> <p>_____ Newspapers</p> <p>_____ Pamphlets and Fliers</p> <p>_____ Patient Advocate</p> | <p>_____ Pharmacist</p> <p>_____ Primary Care Provider</p> <p>_____ Television/Radio</p> <p>_____ Therapist or counselor</p> <p>_____ Your chemotherapy doctor</p> <p>_____ Your chemotherapy nurses</p> <p>_____ Your nurse practitioner/physician assistant</p> <p>_____ Your surgeon</p> <p>_____ Your radiation therapy doctor</p> <p>_____ Other</p> |
|--|---|

Appendix H

Use of Complementary Therapy Survey for Breast Cancer

Demographic and Cancer Treatment Form

Modified from (Lengacher et al., 2002)

1. **Age** _____

2. **Education** (check all that apply):

Less than High School _____ High School Diploma _____ Some College _____ Four-
Year College Degree _____

College past Four-Year degree _____ Advanced College degree _____

3. **Work:**

Full time _____ Part time _____ Unemployed _____ Retired _____

Disabled _____

Other (please describe) _____

4. **Ethnicity:**

African American _____ American Indian _____ Asian _____ Caucasian

_____ Hispanic _____

Pacific Islander _____

Other _____

5. **Area where you live:**

City Residence _____ Rural Residence _____

6. **Approximate family income:**

Under \$25,000 _____ \$25,000 - \$75,000 _____ Over \$75,000 _____

7. **Religion:** Fill in the name of faith and church or circle NONE.

_____ NONE

8. How long have you known that you have breast cancer?

_____ Years, _____ Months. Have you had other cancers?

_____. If so what type? _____

9. Family history of cancer?

Breast cancer? _____ Yes _____ No If yes for breast cancer, list the family

member's relation to you. _____

Other cancer in your family

10. Treatments you have received (check all that apply):

Surgery _____ Biopsy _____ Lumpectomy _____ Mastectomy _____ Reconstruction

_____ Chemotherapy _____

Radiation _____ Hormonal therapy _____

Other, please describe

What treatment are you receiving now (please describe)?

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Appendix I

CAM used for Health and for Cancer by Race and NCCAM Domain

| NCCAM Domain | | CAM for Cancer | | | CAM for Health | | |
|--------------|---------------------------|----------------|------------------|-------|----------------|------------------|-------|
| | | White | African American | Total | White | African American | Total |
| 1 | Chinese medicine | 0 | 0 | 0 | 0 | 0 | 0 |
| 1 | Folk medicine | 0 | 0 | 0 | 1 | 0 | 1 |
| 1 | Naturopathy | 0 | 0 | 0 | 1 | 0 | 1 |
| 1 | Home remedies | 1 | 2 | 3 | 1 | 1 | 2 |
| 1 | Natural medicine | 2 | 2 | 4 | 1 | 1 | 2 |
| 1 | Traditional medicine | 6 | 2 | 8 | 2 | 3 | 5 |
| 2 | Biofeedback | 1 | 0 | 1 | 0 | 0 | 0 |
| 2 | Colored light treatments | 0 | 0 | 0 | 0 | 0 | 0 |
| 2 | Hypnosis | 0 | 0 | 0 | 0 | 0 | 0 |
| 2 | Rootwork | 0 | 0 | 0 | 0 | 0 | 0 |
| 2 | Guided Imagery | 1 | 0 | 1 | 1 | 0 | 1 |
| 2 | Support group | 4 | 2 | 6 | 1 | 1 | 2 |
| 2 | Art Therapy | 3 | 0 | 3 | 2 | 1 | 3 |
| 2 | Spiritual healing | 1 | 4 | 5 | 2 | 1 | 3 |
| 2 | Meditation | 2 | 4 | 6 | 3 | 1 | 4 |
| 2 | Relaxation techniques | 2 | 3 | 5 | 6 | 1 | 7 |
| 2 | Counseling | 1 | 0 | 1 | 2 | 2 | 4 |
| 2 | Talking away illness | 0 | 0 | 0 | 2 | 2 | 4 |
| 2 | Prayer | 2 | 7 | 9 | 7 | 2 | 9 |
| 2 | Music | 2 | 3 | 5 | 6 | 5 | 11 |
| 2 | Humor | 4 | 1 | 5 | 5 | 6 | 11 |
| 3 | Aloe vera juice | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Black Cohosh | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Cannabis, Marijuana | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Chelation | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Coenzyme Q10 | 1 | 2 | 3 | 0 | 0 | 0 |
| 3 | DHEA | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Ginkgo | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Homeopathy | 0 | 1 | 1 | 0 | 0 | 0 |
| 3 | Hydrogen peroxide therapy | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Metabolic therapy | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Milk Thistle | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Mullen | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Noni | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Ozone Therapy | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Pickle juice | 0 | 1 | 1 | 0 | 0 | 0 |
| 3 | Red clay | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Red Clover | 0 | 0 | 0 | 0 | 0 | 0 |

| | | | | | | | |
|---|--------------------------|----|----|-----|-----|----|-----|
| 3 | Remifemin | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Rum soaked raisins | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Selenium | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Turpentine | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Vitex | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | Detoxification | 0 | 1 | 1 | 1 | 0 | 1 |
| 3 | Herbal supplements. | 2 | 3 | 5 | 3 | 0 | 3 |
| 3 | Enemas | 1 | 1 | 2 | 0 | 1 | 1 |
| 3 | Fasting | 0 | 1 | 1 | 0 | 1 | 1 |
| 3 | Mistletoe | 0 | 0 | 0 | 0 | 1 | 1 |
| 3 | Mushroom Extract | 0 | 0 | 0 | 0 | 1 | 1 |
| 3 | Whiskey | 0 | 0 | 0 | 0 | 1 | 1 |
| 3 | Ginger | 1 | 2 | 3 | 1 | 1 | 2 |
| 3 | Glucosamine/Condroitin | 1 | 0 | 1 | 1 | 1 | 2 |
| 3 | Vinegar | 0 | 0 | 0 | 1 | 1 | 2 |
| 3 | Soy | 0 | 0 | 0 | 2 | 1 | 3 |
| 3 | Echinacea | 0 | 1 | 1 | 0 | 2 | 2 |
| 3 | Ginseng | 1 | 0 | 1 | 0 | 2 | 2 |
| 3 | Salves | 2 | 1 | 3 | 0 | 2 | 2 |
| 3 | Special diet | 4 | 4 | 8 | 2 | 2 | 4 |
| 3 | Health food supplements. | 2 | 3 | 5 | 3 | 2 | 5 |
| 3 | Antioxidants | 4 | 3 | 7 | 4 | 2 | 6 |
| 3 | Zinc | 1 | 0 | 1 | 1 | 3 | 4 |
| 3 | Aromatherapy | 1 | 0 | 1 | 2 | 3 | 5 |
| 3 | Honey | 1 | 0 | 1 | 3 | 3 | 6 |
| 3 | Mineral supplements | 2 | 1 | 3 | 4 | 3 | 7 |
| 3 | Special foods | 3 | 3 | 6 | 4 | 3 | 7 |
| 3 | Herb tea | 2 | 2 | 4 | 3 | 4 | 7 |
| 3 | Vitamin C | 3 | 3 | 6 | 4 | 4 | 8 |
| 3 | Vitamin B6 | 2 | 1 | 3 | 3 | 5 | 8 |
| 3 | Lemon | 1 | 2 | 3 | 4 | 5 | 9 |
| 3 | Vitamin E | 1 | 2 | 3 | 3 | 6 | 9 |
| 4 | Chiropractic | 0 | 0 | 0 | 0 | 0 | 0 |
| 4 | Massage | 1 | 3 | 4 | 4 | 0 | 4 |
| 4 | Reflexology | 0 | 0 | 0 | 0 | 1 | 1 |
| 4 | Yoga | 0 | 0 | 0 | 2 | 3 | 5 |
| 4 | Exercise | 2 | 4 | 6 | 6 | 4 | 10 |
| 5 | Acupuncture/Acupressure | 0 | 0 | 0 | 0 | 0 | 0 |
| 5 | Electro-stimulation | 0 | 0 | 0 | 0 | 0 | 0 |
| 5 | Magnetic Therapy | 1 | 0 | 1 | 0 | 0 | 0 |
| 5 | Polarity | 0 | 0 | 0 | 0 | 0 | 0 |
| 5 | Reiki | 0 | 0 | 0 | 0 | 0 | 0 |
| 5 | Therapeutic Touch | 0 | 1 | 1 | 1 | 0 | 1 |
| | | 72 | 76 | 148 | 105 | 95 | 200 |

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