Use of Complementary and Alternative Medicine in Hawaii Cancer Patients

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Abstract

This research investigated complementary and alternative medicine (CAM) use by Hawai'i cancer patients. Thirty-six percent of patients used CAM, most commonly religious/spiritual therapy and herbal treatments. CAM use was linked with younger age, female gender, Catholic religion, and more education. More research is needed to inform decision-making.

Introduction

Complementary and alternative medicine (CAM) has received increased attention in the past few years, both in the lay and professional literature. Although alternative medical practices and systems have a long history in the US,¹ the establishment of an Office of Alternative Medicine (OAM) within the National Institutes of Health in 1992 gave impetus to defining the field and setting a research agenda. The most recent definition of CAM, developed by a panel of experts convened by the OAM includes the following points: "Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs... CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being...".² Specific types of CAM have been classified by the OAM to include alternative systems of medical practice (e.g., acupuncture), bioelectromagnetic applications (e.g., electromagnetic fields), diet, nutrition, and lifestyle changes, herbal medicine, manual healing (e.g., massage therapy), mind/body control (e.g., meditation), and pharmacological and biological treatments (e.g., anti-oxidating agents).

Given that cancer is a potentially fatal disease which is often not curable with currently-available allopathic medical treatments, it is not surprising that cancer patients are likely to seek out CAM therapies. Published reports of the prevalence of CAM use in cancer patients vary; a recent review of 26 surveys found reported use rates varied from 7% to 64%, with a mean across studies of 30%.³ Such variations are likely to reflect differences in definitions of CAM used by various investigators, as well as differences in characteristics of the respondents.

Correspondence to: Carolyn C. Gotay PhD Cancer Research Center of Hawaii University of Hawaii 1236 Lauhala St Honolulu, HI 96813 CAM use in cancer patients poses a number of serious concerns. For example, some CAM therapies have significant toxic side effects.⁴ Further, no quality control standards are in place for herbal supplements, creating inconsistency in dosages and the potential for contamination.³ CAM can be costly as well: in excess of \$14 billion overall is estimated to be spent annually in the US on CAM treatments.⁵ Patients may delay or refuse potentially curative cancer treatments in favor of CAM. On the other hand, some of types of CAM may be benign, or have some therapeutic effect. CAM may also contribute to better quality of life. Understanding these potential effects is essential before physicians can make recommendations about CAM use.

Hawai'i presents an exceptional environment to investigate the use of CAM therapies in cancer patients. Given the cultural diversity of the state, many different kinds of CAM therapies are readily available, including traditional Hawaiian healing and Chinese medicine, such as herbs and acupuncture. While intense ethnobotanical research is ongoing to identify biologically active components in native plants used in traditional medicine,^{6,7} no information is available about how many patients use these and other approaches and why they do so.

This report provides a summary of the results of two studies in newly diagnosed Hawai'i cancer patients: a survey of CAM use developed to determine the types of CAM therapies used, document the prevalence of use, and describe characteristics that distinguish CAM users; and an interview study designed to gain in-depth information about why breast cancer patients used CAM and how they evaluated their experience.

Study 1

Methods

Participants. Patients were identified through consecutive registrations on the Hawai'i Tumor Registry (HTR), a member of the National Cancer Institute-supported Surveillance, Epidemiology, and End Results Registry. Eligibility criteria were: histologic confirmation of any kind of cancer diagnosed between four and six months previously; ability to understand English; permission of primary physician; Oahu residency; Caucasian, Filipino, Hawaiian, or Japanese ethnic origin; 18 years of age or older. Participation was not limited by stage or site of disease.

Procedures. Permission was obtained from the attending physician before patients were contacted. Patients received a letter followed by a telephone call, and data were collected by interviews, most often at the patient's home. Interviews were conducted by one of four female research associates, all of whom had completed graduate work in social sciences as well as extensive training in

interviewing cancer patients. The patients completed a semi-structured interview which included the questions discussed in this paper. (Additional questionnaires were also administered which will be discussed in separate reports.)

Type of CAM use. Patients were asked, "Have you tried any alternative, traditional treatments or remedies? What were they?" The interviewers recorded verbatim responses in the patients' own words. The responses were then compiled and coded using the previously-mentioned classification scheme for CAM therapies developed by the OAM. The OAM's criteria provided a framework for classifying the responses of the patients in this study.

Results

Participation. A total of 367 cancer patients participated in the study, representing 58% of the total of 646 eligible patients who were invited to take part. The most frequent reasons for nonparticipation were patients not feeling well enough to take part or being "not interested." A comparison of participants and non-participants showed that there was some variation in response rate by ethnicity: 65% of Caucasians and Hawaiians, 56% of Filipinos, and 51% of Japanese patients agreed to take part. There was a gender difference in participation as well: 49% of men and 68% of women participated in the QOL interview. The participants were slightly younger than the patients who refused to take part (means of 62 vs. 68 years). Breast cancer patients were particularly likely to participate: 82% of the breast cancer patients agreed to take part in the study.

Three hundred forty three patients who provided complete information about CAM use comprised the sample for this paper. Cancer sites for these patients included breast (34%), prostate (29%), bladder (6%), and uterus (8%), as well as smaller numbers of a variety of other cancers. All patients had undergone some kind of cancer therapy; 81% had surgery, 39% radiation therapy, 24%, hormonal therapy, and 18% chemotherapy.

Types of CAM used. Table 1 provides a summary of the different kinds of CAM approaches, the number of patients in this study reporting use of each type, and examples of the kinds of remedies mentioned by patients. One hundred twenty two patients reported using a total of 195 different types of therapies, an average of 1.6 per patient. The most frequent type of CAM was religious or spiritual therapy; followed by herbal medicine and lifestyle changes. Within each category, patients reported many different types of treatments.

Prevalence and correlates of CAM use. Table 2 summarizes characteristics of study participants who did and did not report use of CAM therapies. It can be seen that, overall, 36% of the participants said that they had tried CAM. A number of patient characteristics were related to therapy use: age, gender, religion, and education. We did not observe significant differences according to ethnicity, marital status, cancer site or stage of disease.

In order to determine which of these variables was the best predictor of CAM use, a stepwise logistic regression was performed using the sociodemographic and clinical variables in Table 2. Two variables were significantly associated with CAM use in this analysis: having a college degree (odds ratio = 2.4, 95% confidence

Table 1.—Types of Complementary and Alternative Medical Therapies Used By the Patients.				
Type of CAM	Number of Patients	Examples of Specific Treatments		
Alternative Medicine	5	Acupuncture; Chinese, Hawaiian, or Japanese Medicine; Detoxifying Bodily Systems; Naturopathy		
Lifestyle Changes	46	Dietary or Exercise Changes; General Improvements; Macrobiotic or Special Herbal Guidelines; OTC Vitamins and Minerals		
Herbal Medicine	40	Aloe Juice; Herbal or Mushroom Teas; Herbal Supplements; Herbs and Vitamins Together; Marijuana; Seaweed; Wheat Grass		
Mind / Body Control	24	Guided Imagery; Meditation; Mental / Spiritual Self- improvement; Positive Thinking; Reading Self-help Books; Relaxation; Support Groups; Visiting a Psychic; Visualization		
Manual Healing	9	Massage; Shiatsu; Touch Therapy / Healing Touch		
Pharmacological and Biological	10	Anti-oxidants; Enzymes; Flavonoids; Shark Cartilage		
Prayer	61	Prayer By Others or By Oneself; Faith Healing or Healing Mass		

Note: Some patients used more than one CAM. The total number of patients was 122.

intervals = 1.3, 4.3) and being Catholic (odds ratio = 1.9, 95% confidence intervals = 1.1, 3.3).

Study 2

Methods

Participants. Participants were asked to participate in an interview about their CAM experience on the basis of an affirmative response about CAM use on a mailed questionnaire that was part of an ongoing study of patterns of care in breast cancer. This study was open to all patients with newly-diagnosed breast cancer at several major Honolulu medical centers. Physician permission was obtained before patients were enrolled in the study. The study included

Table 2.—Variables Associated with CAM Use				
Variable	Used CAM	Did Not Use CAM	Sig.	
Age				
Under 50	26 (45.6 %)	31 (54.4 %)		
50 — 69	59 (35.8 %)	106 (64.2 %)		
70 or Older	35 (30.4 %)	80 (69.6 %)	p = 0.147	
Mean (Std. Dev.)	60.2 (13.1)	63.5 (12.1)	p = 0.022	
Ethnicity				
Hawaiian	16 (38.1 %)	26 (61.9 %)		
Caucasian	38 (33.9 %)	74 (66.1 %)		
Japanese	45 (34.9 %)	84 (65.1 %)		
Filipino	21 (38.9 %)	33 (61.1 %)	p = 0.911	
Education		·····		
Never Finished High School	15 (32.6 %)	31 (67.4 %)		
High School Graduate	20 (23.3 %)	66 (76.7 %)		
Some College	39 (36.4 %)	68 (63.6 %)		
College Graduate	43 (46.7 %)	49 (53.3 %)	p = 0.012	
Gender		<u></u>		
Male	46 (30.3 %)	106 (69.7 %)		
Female	74 (40.0 %)	111 (60.0 %)	p = 0.063	
Religion				
Catholic	40 (45.4 %)	48 (54.6 %)		
Other Christian	40 (30.1 %)	93 (69.9 %)		
Buddhist	14 (28.6 %)	35 (71.4 %)		
No Preference	16 (30.8 %)	36 (69.2 %)	p = 0.044	
Marital Status				
Not Married	31 (31.6 %)	67 (68.4 %)		
Married	83 (36.7 %)	143 (63.3 %)	p = 0.378	
Cancer Stage				
Stage 0, 1, or 2	98 (33.8 %)	192 (66.2 %)		
Stage 3 or 4	21 (45.7 %)	25 (54.3 %)	p = 0.118	
Cancer Site				
Breast	49 (42.2 %)	67 (57.8 %)		
Prostate	28 (28.3 %)	71 (71.7 %)		
Other	43 (35.2 %)	79 (64.8 %)	p = 0.103	

a number of questionnaires as well as review of medical records which will not be discussed here.

Methods. A female medical student interviewer conducted semistructured interviews at a location of the patient's choice. Most patients were interviewed at home. The interview included both open-ended questions and self-administered questionnaires.

Results

Participation. Twenty-eight patients were asked to take part in an interview about CAM, and 24 agreed. The ethnic distribution was: Caucasian (n=9), Japanese (n=6), Filipino (n=4), Chinese (n=3),

Hawaiian (n=1), and Native American (n=1).

Allopathic treatment. All patients had received surgical treatment, 13 had received chemotherapy, and 15 had received radiation. Most women were very satisfied with their medical care; on a scale of 1 to 10, where 10 signified "completely satisfied," respondents gave a mean score of 9.4 (n=20; four women did not wish to use the scale to respond to this question).

Types of CAM used and perception of results. Findings indicated that the patients used a great variety of therapies. The most common CAMs were herbs (n=13), vitamins (n=11), and massage (n=5). A great variety of CAMs were used by smaller numbers of patients, including aloe, meditation, noni, qi gong, meditation, healing touch, shark cartilage, and acupuncture. Most patients used more than one CAM simultaneously.

Most women were very satisfied with their CAM experience; on a scale of 1 to 10, where 10 signified "completely satisfied," respondents gave a mean score of 8.7 (n=17). Many women could identify specific outcomes that were associated with their treatment. For example, one woman took herbs prescribed by a Chinese herbalist for lymphedema and remarked, "He gave me great relief. Wow, my hands are almost the same size – he brought the swelling down." Several women cited the positive effects of aloe on wounds, and general increases in energy levels attributable to herbs, vitamins, and teas. A number of women were not sure if CAM had helped or not; as one person said about meditation and breathing exercises, "Psychologically, it was excellent. Physically, I don't know." Another woman was cognizant of possible placebo effects: "I think it's attitude too. You have to believe in it."

Discussion of CAM use with physician. No doctor advocated CAMs other than dietary changes as part of cancer treatment, although one physician recommended an herbal mixture along with an antibiotic. The women were asked if they had discussed their CAM use with their physician. About half (n=14) had done so. Of those who had not mentioned this to their physician, the most common reason was "It didn't come up." No woman who had discussed her CAM use reported a negative reaction. Most physicians seemed to take a neutral stance ("he didn't discourage or encourage me"), although a number were supportive, making remarks such as "Go for it!," "If you feel you want to take it, then go ahead." Several physicians asked to see the treatment (e.g., the bottle of pills or, in one case, a plant).

Case examples of patient experiences. To illustrate the variety of CAMs used by some women, and their experiences with them, several case studies of heavy CAM users are described below.

<u>Case A.</u> A 50 year old Japanese women who was diagnosed with a second primary breast cancer used a number of CAM approaches. She had received an advanced degree and worked full-time in a professional position. Mrs. A. obtained several herbs through a mail order company including pau'd arco (bark of the tahibo plant) and "neolife" vitamins (which included vitamins C, E, a selenium supplement, and others). She also ingested wheatgrass tea (to "clean my system"), lymph tea ("it's anti-cancer"), and "antioxidants." In addition, she consulted with an iridologist, a Christian prayer healer and someone who conducted colon cleansing. Further, she engaged in meditation. An auntie had been the person who suggested most of these remedies to her, and she had used them for the decade following her first diagnosis. She felt that using CAM gave her peace of mind and would save her from dying. In her view, in fact, CAMs should serve as primary cancer treatments since they are more likely to lead to healing than medical care. Mrs. A. added, "Take time out for fun. One of the major medications is to be happy."

<u>Case B.</u> Ms. B. was a single 50 year-old Caucasian woman who was a high school graduate. She had received surgery and radiation for her Stage I breast cancer. Ms. B. took Chinese herbs as well as Vitamins A, B, and C, evening primrose oil, garlic, calcium, antioxidants, and oolong tea. In addition, she practiced qi gong, participated in a reiki group, and underwent light therapy. She also took nutrition classes at a local medical center to improve her eating habits. She worked full-time in a service industry, and one of her clients had alerted her to these options. She said she chose CAMs "because I believe in alternatives. I don't believe that doctors aid you in healing. I didn't have any expectations. I went in with an open mind. It couldn't hurt and it felt right." Ms. B. felt that the CAM, qi gong in particular, "works because it's positive and natural. We have the capability of curing ourselves. Your mind can cure you or kill you."

Case C. Ms. C. was a single woman in her forties of Chinese-Korean ancestry who was diagnosed with Stage 2B breast cancer. She was a college graduate who worked full-time in a professional position. She had received surgery, chemotherapy, and radiation therapy for her disease and was currently taking Tamoxifen. With respect to CAMs, Ms. C. took sunrider (Chinese-oriented herbs), antioxidants, therapeutic tea, vitamins, garlic, Echinacea, aloe, and florabalane, as well as shiatsu massage. She believed that the herbs played a role in purging the body of toxins and also helped her to get through the chemotherapy: "I know it's done something, since being on the products helped me to respond to the drugs." She also noticed that the shiatsu helped her to regain motion in her shoulder after surgery. She saw CAM as complementing medical care: "It works hand in hand. They're two different things. The medical treatment blocks disease. (CAMs) are as effective as medical treatment in building up the body."

Discussion

This study provides the first report of CAM use in Hawai'i cancer patients. Study 1 is based on responses from a registry-based population and includes a heterogeneous group of patients who were assessed at the same time after diagnosis. Study 2 provides in-depth information on a specific population sub-group: women with breast cancer. Several caveats to data interpretation should be mentioned, however. Given the differential response rates, the results may be more valid for Caucasians, Hawaiians, women, breast cancer patients, and younger individuals. In addition, the survey and interviews relied on self-reports. Even though the interviewers were not part of the medical care team and had been trained to elicit candid responses to personal questions, it is possible that some patients may not have wanted to discuss full CAM use with the interviewer. The patients reported using a tremendous variety of CAM approaches, and many used more than one approach simultaneously. For the most part, the kinds of therapies cited were consistent with the OAM classification. However, several significant differences are seen. The OAM listing includes "bioelectromagnetic applications," which includes blue light treatment and artificial lighting, electroacupuncture, electromagnetic fields, electrostimulation and neuromagnetic stimulation devices, and magnetoresonance spectroscopy. Only one patient in the interview study mentioned having tried one of these approaches. Perhaps they are not as popular in Hawai'i as elsewhere. On the other hand, the CAM listing includes "prayer therapy" within the general "mind/body control" category. In this sample, the use of prayer was so prevalent that we listed it as a separate category.

With respect to prayer, and in fact to all the therapies mentioned, sometimes patient responses indicated behaviors that did not greatly differ from everyday practices, while others represented a special cancer-related activity. For example, many patients reported saying prayers, or having prayers said by their church, to help themselves get well, while one patient said that the priest conducted a healing mass "to try to remove my sickness," and another had gone to a Christian prayer healer. Dietary changes included changes as simple as eating healthier foods and as complex as daily preparation and ingestion of a special soup using six fresh vegetables recommended by an alternative medicine institute. Many herbal medicines were mentioned, the most common being essiac tea and shark cartilage. While manual therapies were relatively uncommon, a number of patients reported experiences with "healing touch" in the hospital. One patient related how a staff member in the same day surgery unit included healing touch in preparations for her lumpectomy. "She 'laid over hands' and told me to 'see the light' and let it heal me. Wheeling me to surgery, (she) sang Happy Trails." The patient said she laughed, went along with it, and also felt more at peace.

Thirty-six percent of patients in this study reported using some kind of CAM. As mentioned earlier, previous estimates of how many cancer patients use CAM have varied considerably. These reports differ for a number of reasons: the year when the data were collected (since CAM's popularity has increased over the past decade), patient population (site of disease and type of institution), the length of time since cancer diagnosis, methodological differences in how patient response was elicited (e.g., an open-ended question, such as that in the current study, compared to a checklist), and the varying definitions of CAM that were employed. The findings of this study are quite consistent with the average percentage — 30% — reported in the world's literature. However, additional research is needed to replicate and refine this estimate.

These results of the survey indicated that CAM users tend to be younger, women, Catholic, and better educated. These correlations, with the exception of the link to Catholicism, are consistent with all other studies of CAM in cancer patients and other populations.³ Educational level has been investigated in virtually all studies of CAM use and consistently emerges as the strongest predictor. While this may seem surprising initially, it likely reflects greater knowledge and access to resources among people with higher education. Education may also confer increased self-confidence in knowing how to seek out additional support beyond what is provided in the hospital and doctor's office. Religion, and Catholicism in particular, have not been identified with increased CAM use in other reports. However, as noted previously, the current population appeared to be much more likely to mention religious approaches for their cancer. It should be noted that a high percentage (73%) of Filipino patients were Catholics. While religion emerged as a more powerful predictor than ethnicity in our analysis, the small number of individuals in some groups limited statistical power to detect differences. It is likely that the many Filipino cancer patients seek support from their religion. We did not see other ethnic variation in CAM use, although our sample sizes were small. However, it is possible that the ethnocultural mix that occurs in many aspects of life in Hawai'i extends to this area as well, and that cancer patients in this state draw on the full range of options available from a variety of cultures. We did not find that CAM use varied according to stage of disease. However, it is possible that larger and more varied samples may report stage-associated differences in types and frequency of CAM use. For example, patients with completely resected cancer may be more likely to seek therapy to manage the symptoms associated with adjuvant chemotherapy or radiation as well as preventative interventions. Patients with advanced or incurable cancers may seek CAM modalities directed at treating their existing cancer. These issues may be addressed in future studies.

This study has shown many cancer patients in Hawai'i are using alternative treatments in conjunction with their medical treatments for cancer. Of 38 patients who were undergoing chemotherapy at the time they completed the survey, 11 (29%) reported taking herbal supplements of some sort at the same time. It is not known how many of these patients discussed their CAM practice with their physicians, although the interview study indicated that almost half of the women did not discuss their CAM use with their physicians. However, herbal remedies may have a number of side effects and may possibly interact with chemotherapeutic agents and other medications. Thus, physicians, and oncologists in particular, need to be aware of the common alternative practices available and used here in Hawai'i so that they may initiate discussion about these issues with their patients and guide them away from potentially harmful treatments.

The interviews with the breast cancer patients replicated a finding that has been reported elsewhere: satisfaction with medical care was rated highly, indicating that for many patients, using CAM is not a reflection of dissatisfaction with medical care. Although there were a few cases where the patient was "anti-biomedical therapy," most women in this study rated their medical care highly. Obtaining CAM appeared to meet different needs, including symptom control, psychological support, including stress management, spiritual concerns, and the ability to exert control over their health. A number of women remarked, "I had nothing to lose."

Additional research is required to examine the efficacy of CAM interventions. Since so few of the approaches used by the patients in this study have received rigorous evaluation, their value is unknown. Patients remain at the mercy of unsupported claims and powerful advertising, and they may waste time, energy, and money and end up demoralized or with worse outcomes than if they had not used CAM. Yet it is possible that CAM offers benefits in terms of symptom control, enhanced quality of life or survival. The very process of seeking out CAM may enhance patients' morale, and improve their efforts at self-care. The investigators at the Cancer Research Center have several other studies planned and in progress that will lay a foundation to understanding more about why cancer patients seek CAM and its effects on patient outcomes. The team is also working to identify CAM approaches that will be acceptable to patients and physicians for testing in controlled trials. Such rigorous research will provide necessary information to enable cancer patients and their physicians to make informed choices about CAM.

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Correction

Please note that the above manuscript entitled, "Use of Complementary and Alternative Medicine in Hawaii Cancer Patients" by Carolyn C. Gotay PhD, Wendy Hara BA, Brian F. Issell MD, and Gertraud Maskarinec MD, PhD, was originally published (*Haw Med. J.* 1999;58:49-51, 54-55) without entire list of authors. We reprinted the corrected manuscript in its entirety. We apologize to the authors and to the readers for the error.