



## Oncology Patients' Experience with Complementary and Alternative Forms of Therapy: A Preliminary Report

***In this study phase, we report use of complementary and alternative medicine (CAM) forms of therapy by a group of health plan members diagnosed with cancer.***

### Introduction

Complementary and alternative medicine (CAM) for improvement or maintenance of health is becoming increasingly popular among the general public. However, studies among cancer patients indicate that as few as 35% and as many as 75% of patients never discuss their CAM treatment with clinicians.<sup>1,2,3,4</sup> This lack of communication is of serious concern, given the possibility of unforeseen side effects and the potential of some forms of CAM therapy (eg, herbal medicine) to inhibit or improve the activity of conventional treatment.<sup>5</sup>

We report on the first phase of our current study, designed to investigate cancer patients' use of CAM, their experiences with treatment, and the nature of interactions with allopathic health care providers regarding CAM therapy.

### Methods

We conducted semistructured, in-depth interviews with 29 Health Plan members in the Kaiser Permanente Northwest (KPNW) Division who had been diagnosed with cancer of the breast, colon, or prostate during the previous two years. This convenience sample<sup>6</sup> was selected from members who responded

to the Kaiser Permanente Oncology Member Survey through the Cancer Prevention Research Unit at the Center for Health Research (CHR) (Eakin E, Glass A, Vogt T, unpublished study).<sup>\*</sup> We contacted respondents who had indicated on that survey that they used CAM and were willing to participate in our study. During interviews, we learned that two participants had not used CAM. These interviews were excluded from our analysis of CAM use, although they provided important insights into the reasons some people choose not to use CAM. Characteristics of the 27 participants who used various forms of CAM therapy are listed in Table 1.

Our interview method was selected to encourage participants to delve into topics to describe, in their own words, their knowledge, beliefs, and experiences about CAM.<sup>6,7</sup> We used an interview guide to ensure consistency in the topics discussed at each interview, although the sequence of questions varied somewhat from interview to interview in response to information offered by participants. Interviews were conducted at the CHR, at KPNW medical offices, or in participants' homes, at their preference. All interviews were audiotaped and were an hour long on average. After each interview, we recorded detailed field notes that summarized participants' responses to interview questions. The field notes are the basis for this preliminary report.

At the start of each interview, participants were given the researchers' definition of CAM as well as examples of this type of therapy. We indicated that we were interested in learning more about use of "any therapies not part of conventional medical treatment," including modalities used by the individual directly (eg, vitamins, diet) or offered by practitioners (eg, chiropractic, massage); products that were either ingested (eg, herbs, tonics) or applied (eg, ointments, magnets); and folk remedies as well as formal (eg, traditional medicine) practices. We also included in our definition prayer or other spiritual practices as well as "mind-body" techniques such as meditation, visualization, and relaxation.

### Results

#### Reasons and Information Sources for Using CAM Therapy

Nearly all the 27 participants who used CAM treatment did so to supplement (ie, not to replace) allopathic treatment for cancer. Only one person used

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**Table 1. Characteristics of 27 KPNW oncology patients who use complementary and alternative medicine (CAM)**

	No. of patients		
	Female (n = 16)	Male (n = 11)	Total (n = 27)
Mean age (years)	54	64	59
Type of cancer:			
breast	15	0	15
prostate	0	11	11
colon	1	0	1



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**Table 2. Reasons for use of complementary and alternative medicine (CAM) among 27 KPNW oncology patients**

Type of CAM	Reason for use of CAM				
	Cure	Enhance treatment	Counter side effects	Prevent recurrence	Promote health
Vitamins, supplements				x	x
Herbs	x	x	x	x	x
Prayer/Spirituality	x	x			
Acupuncture			x		
Chiropractic			x		
Massage			x		
Meditation/ Visualization		x	x		
Diet				x	x
Exercise					x
Energy healing		x			

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*“Recommendations from people “in the know” or who otherwise cared about the participant’s welfare appeared to be highly motivating.”*

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alternative methods instead of conventional treatment to treat cancer; the other participants indicated that they used CAM treatment to counter the side effects of conventional treatment, to enhance the effect of conventional treatment, or to regain or maintain strength and well-being after conventional treatment (Table 2). Some participants spoke of “hedging their bets,” saying that they felt better knowing they were doing everything they could do to become and stay healthy.

Participants’ knowledge about forms of CAM therapy came in large part from reading about the topic in books and on the Internet. Some participants reported no trouble in finding information and making decisions about which therapy to use; others reported some difficulty in deciding what sources of information to believe. Friends, family, and members of cancer support groups were also influential by making recommendations and sometimes by providing products. Recommendations from people “in the know” or who otherwise cared about the participant’s welfare appeared to be highly motivating.

All participants paid for CAM therapy out of pocket, and most felt that the treatment was affordable. A

few participants, however, had discontinued or foregone some CAM treatment because of cost. As expected, participants indicated that they would prefer having the cost of CAM treatment at least partially paid for by their health plan.

#### Types of CAM Therapy Used

Although most participants had never used CAM before receiving the cancer diagnosis, several continued to use CAM—particularly vitamins, dietary supplements, and herbs—to promote health. Most treatment was a self-care measure—ie, taken without intervention of a practitioner. Acupuncture/traditional Asian medicine, massage, naturopathic, and chiropractic treatment types were exceptions to this trend.

Vitamins and other dietary supplements were the forms of CAM treatment used most often by participants, generally to promote good health and to enhance immune response. Several participants mentioned that by improving their health, they hoped to prevent or be better able to fight off cancer recurrence. Certain vitamins (eg, vitamin C, vitamin E) and supplements (eg, flax seed oil, chromium, selenium) were thought by some participants to help



prevent cancer and thus were especially useful for averting recurrence. Products such as specially fortified juices and herbal teas were also used for this purpose. For the most part, participants who used vitamins and supplements noticed neither demonstrable effects nor side effects but nonetheless reported feeling “better,” having more energy, or getting sick less frequently and attributed this to their use of vitamins and supplements.

Changes in diet, too, were meant to reduce risk of cancer recurrence and to improve general health. Many participants who changed their diets soon after receiving their diagnosis reported that they maintained those changes. Principal modifications were increased consumption of fruits and vegetables, reduced intake of fat in general and red meat in particular, and reduced consumption of processed foods. Participants saw multiple benefits to this diet (eg, cholesterol reduction, weight control) beyond cancer prevention. Changes in diet were sometimes paired with a program of increased physical activity. In addition to improving health, exercise was intended to reduce stress, to increase stamina and energy, and to control weight.

For several participants, prayer and other forms of spirituality played a major role in healing. These patients reported that personal prayer and the prayers of others (eg, prayer circles) helped to ease their worry and stress about being ill and provided social as well as emotional support. Several participants also used meditation, exercise, and music therapy to reduce stress in their lives, believing that reducing stress was important for regaining health and for preventing recurrence of cancer.

Two participants had participated in formal healing ceremonies conducted through their churches. One of these participants reported that his cancer went into remission after the ceremony. The other did not expect a cure to result from the ceremony but felt reassured afterward that her allopathic treatment would be successful.

Treatment forms such as massage, acupuncture, herbal treatments, visualization, and meditation were the primary forms of CAM used during cancer treatment to overcome the nausea and fatigue that resulted from chemotherapy and radiation. Participants who used these forms of CAM treatment while simultaneously receiving conventional cancer treatment found them helpful but discontinued their use after the cancer treatment ended due to the cost of treatment or lack of time.

Female participants with breast cancer who were treated with tamoxifen reported longer-term use of CAM. Unable to use standard hormonal replacement therapy, these women turned to CAM to relieve their drug-induced menopausal symptoms. They reported that the frequency or intensity of symptoms—particularly hot flashes—was reduced by the CAM treatment, including use of vitamin E, black cohosh, and soy products.

### Discussing CAM Therapy with Health Care Practitioners

Only four participants said they had not discussed use of CAM with their medical practitioners. Two of these people explained that the topic “had not come up” in the course of visits; two others said they did not bring up the discussion because they expected conflict or ridicule. The other participants said that they had mentioned their use of CAM to one or more medical practitioners; of these participants, the only one who met resistance was a person who told his doctors that he wished to treat his cancer with CAM before using conventional treatment. The other participants characterized their discussions with medical practitioners as neutral or noncommittal: providers were not critical of CAM but did not endorse its use or suggest particular therapy.

Although participants were pleased that they had not met with resistance from their medical practitioners, several patients expressed disappointment that their practitioners had not shown more interest in or support for use of CAM. These patients would have liked their practitioners to be more knowledgeable about CAM so that they could provide information and advice. Participants also suggested that the KPNW Health Plan act as a clearinghouse for information on forms of CAM therapy, both to reduce the amount of research participants must do on their own and to provide a credible source of information.

### Discussion

“With a life-threatening illness, you can’t afford to be closed-minded about any approach to healing.”

This statement, made by a participant in our study, summarized an attitude common among the 27 participants in that study, the Cancer Patients Use of Complementary and Alternative Medicines (CACAM) study. Those persons, all KPNW members diagnosed with cancer within the previous two years, had incorporated alternative forms of therapy as a complement to allopathic treatment to improve their quality of life and to optimize their chance for long-term



health. Indeed, our small study sample reflects a growing trend toward use of CAM by the general public<sup>8,9</sup> and by KPNW members (Whitlock EP, Russell A, unpublished manuscript)."

Other reports indicate that between 7% and 64% of patients diagnosed with cancer use some form of alternative medicine in addition to conventional cancer treatment.<sup>1,2,3,10,11,12</sup> Sixty percent of inquiries to the Office of Alternative Medicine (OAM) at the National Institutes of Health are about cancer.<sup>13</sup>

Participants in our CACAM study characterized CAM as natural, holistic (ie, treating the whole person), slower to act but free of side effects, and focused on health promotion. Allopathic medicine, in contrast, was viewed as faster-acting but harsher, more narrowly directed (ie, treating a specific body part or system), and focused on curing rather than preventing disease. These attitudes and opinions may be influenced by participants' recent experience with cancer treatment, which is typically invasive and severe. Nonetheless, the opinions of participants in this study are similar to those expressed by participants without cancer in other studies.<sup>14,15,16</sup>

## Conclusion

The qualitative nature of our current study is not meant to provide numerically generalizable results. The in-depth exploration of the attitudes and behaviors of a sample of cancer patients does, however, offer important information about cancer patients' experience with CAM as well as their motivations for using this type of therapy. This initial phase of the study also suggests that patients value clinicians' acceptance of CAM and would prefer that their clinicians and health plan more actively support and inform patients' use of these forms of therapy. The audiotapes recorded in the present phase of the study will be transcribed so that we can more comprehensively examine the issues raised in the study. In the second phase of the present study (which will begin in Spring 1999), we will interview clinicians about their communication with patients concerning CAM therapy.

That phase of the research will undoubtedly tell us more about this increasingly important component of patient-provider communication. ❖

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