

# Disclosing Complementary and Alternative Medicine Use in the Medical Encounter

## A Qualitative Study in Women with Breast Cancer

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**BACKGROUND.** Despite recent findings that patients who use complementary and alternative medicine (CAM) typically choose not to mention this to their physicians, little is known about the reasons for this lack of communication. Understanding the reasons for nondisclosure of CAM use is critical to improving physician-patient communication and patient care.

**METHODS.** We are conducting a 5-year prospective cohort study consisting of 4 interview cycles. The multiethnic, population-based sample consists of 86 San Francisco residents with recently diagnosed breast cancer (response rate = 87%). Findings are determined using qualitative analysis of transcribed interviews.

**RESULTS.** At initial contact, 72% of the participants were using at least 1 CAM therapy for breast cancer. Six months later, 65% of participants were using CAM. Of the women being treated by an alternative practitioner, 54% disclosed their CAM use to their physicians. Conversely, 94% discussed details of their biomedical treatments with their alternative practitioner. Reasons for not disclosing CAM use included anticipating the physician's disinterest, negative response, or unwillingness or inability to contribute useful information; the perception that the CAM therapies used were irrelevant to the biomedical treatment course; and the patients' views regarding the appropriate coordination of disparate healing strategies.

**CONCLUSIONS.** Discussions of patients' CAM use are more poorly integrated into the medical encounter than discussions of biomedical treatment are with alternative practitioners. Patients' disclosure is often cautiously modulated, even by those who would welcome an open discussion with their physicians. Specific suggestions for discussing CAM use with patients are presented.

**KEY WORDS.** Alternative medicine; physician-patient relations; breast neoplasms. (*J Fam Pract* 1999; 48:453-458)

Complementary and alternative medicine (CAM) can be defined as all health care resources to which people have recourse other than those intrinsic to biomedicine and its specific theoretical and practice models.<sup>1</sup>

The extensive use of complementary and alternative medicine in the United States has been documented by a number of studies. Estimates of the percentage of adults using CAM cancer treatments in a variety of populations range from 9% to 50%.<sup>2-6,31,32</sup> Studies of patients in a variety of populations outside the United States have shown that between 9% and 75% of adult patients with cancer use CAM.<sup>6,10,20-27</sup>

The overwhelming majority of CAM users in the United States also use biomedicine — either concurrently or serially — but most patients do not tell their physicians about their CAM use.<sup>3,5,7,8</sup> Despite preliminary findings that some physicians perceive communication prob-

lems about CAM to reside primarily with patients, very little is known about issues of disclosure from the patient's perspective.<sup>10</sup> Although some studies report greater physician attention to CAM, recent findings indicate that interest in alternative therapies resides almost entirely with family physicians and psychiatrists, and is rare among cancer specialists.<sup>9,10</sup> One element of physicians' hesitation may be the concern over professional liability. Eisenberg<sup>20</sup> reports, however, that "[a]lthough physicians have been prosecuted for malpractice when they have personally delivered alternative treatments, no cases have involved conventionally trained physicians who have advised patients about alternative medical therapies." Indeed, *not* asking about patients' therapeutic choices may involve risk. The importance of physicians' awareness of patients' health-related beliefs and practices is elevated in the context of CAM usage: Certain CAM therapies have demonstrable beneficial effects, some can be harmful under certain conditions, and others may interact with pharmacologic therapies in clinically significant ways.<sup>11</sup>

### METHODS

The findings we report were determined using 2 discrete cycles of interviews from an ongoing 5-year qualitative

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investigation of treatment decision making by women with breast cancer. The study protocol and consent form were approved by the Committee on Human Research, University of California—San Francisco. To interview a representative group of women as soon as possible after their breast cancer diagnosis, participants were recruited using a population-based rapid case-finding technique. A team of case finders from the Northern California Cancer Center was sent to the medical records offices of each hospital in San Francisco County every 2 to 3 weeks for 13 months. The team assembled a list of new cases by reading pathology reports supplemented by hospital records. The patients' physicians were telephoned to determine medical contraindications to contacting them. In the absence of contraindications (the assessment in all but 15 cases), the women were sent an introductory letter, which was followed by a recruitment telephone call 1 week later.

Eligibility requirements for study participants included: aged 35 to 49 years or 60 to 74 years, inclusive; resident of San Francisco, California, at the time of breast cancer diagnosis; able to be interviewed in English, Spanish, or Chinese (Cantonese or Mandarin); histologic diagnosis of breast cancer (in situ or invasive); diagnosis given at a hospital within San Francisco County during the 13-month period of case ascertainment (May 1995 to May 1996). Exclusion criteria were cases of recurrent breast cancer and patients whose physicians refused to grant permission for them to be contacted. A total of 86 women were enrolled (87% of those known eligible).

Data are collected through a series of 4 in-depth, face-to-face interviews. Participants are initially interviewed within a few months of diagnosis (average = 2 to 4 months) and again after 6 months, 18 months, and 30 months. The interviews take place in participants' homes or at private locations of their choosing. We use a semistructured interview guide that is specifically adapted for each of the 4 interview cycles. Open-ended questions are designed to encourage women to articulate their personal understanding of their beliefs and practices regarding health and illness. The domains of questions asked during the initial and first follow-up interviews reported here include: (1) conceptualizations of health and illness; (2) the process of discovery and confirmation of the breast cancer; (3) the woman's views of the etiology, nature, and extent of her illness; (4) biomedical and CAM cancer treatments used; (5) experiences with and attitudes toward physicians and alternative practitioners; and (6) interactions regarding CAM and biomedical treatment use with physicians and alternative practitioners, respectively. All interviews are audiotaped and transcribed verbatim. Cantonese, Mandarin, and Spanish interviews are translated by the interviewers and then transcribed. Concurrent qualitative text-based analysis is conducted with the use of QSR NUD\*IST software.<sup>33</sup>

The data related to patients' disclosures of treatment use and interactions with physicians and alternative practitioners were analyzed separately. Each transcript was

reviewed and coded by 2 researchers who did not conduct the interview. After the identification of topics and themes that repeatedly appeared in the data, codes were developed and subsequently assigned to the transcribed interviews. The data set was then analyzed and interpreted in terms of linkages between the derived concepts and recontextualized data.

## RESULTS

The characteristics of the enrolled participants are shown in the Table. Comprehensive tumor registry data that typically become available 1 to 2 years after initial case ascertainment shows that sociodemographic and cancer stage characteristics of the participants are similar to those of the target population. Our study findings indicate a substantially higher prevalence of CAM usage than is reported in the biomedical literature. Sixty-nine percent of the 86 participants had used at least 1 CAM treatment or modality before the diagnosis of breast cancer (95% confidence interval [CI], .58-.78). Since the women were interviewed an average of 2 to 4 months after initial diagnosis, their recall regarding treatment usage before diagnosis was presumably excellent. In the first few months post-diagnosis, 72% of participants reported using CAM treatments specifically targeted to their breast cancer (95% CI, .61-.81). At the second interview — approximately 6 months later — 65% of the participants were using CAM (95% CI, .54-.75). Six women died during the interval between the first and second interview cycles. In terms of the 2 age cohorts, the younger cohort (35 to 49 years) consistently displayed greater prevalence of usage than the older cohort (60 to 74 years). Before the breast cancer diagnosis, 78% of the women in the younger cohort had used CAM, compared with 58% of those in the older cohort. At the time of the first interview, the prevalence of CAM use for breast cancer treatment in the 2 cohorts was 84% and 58%, respectively; and at the time of the second interview, 74% and 54%.

Of the patients who were simultaneously treated by an alternative practitioner (n = 47), 54% disclosed their CAM use to their physicians. Overall disclosure for women using CAM generally was 33%, similar to reported findings in the general population.<sup>3</sup> Conversely, 94% of the participants seeing alternative practitioners discussed details of their biomedical treatments with those providers. Patients' disclosure of CAM usage to physicians was cautiously modulated and carefully adapted, even by those who would welcome an open discussion. Participants who chose not to reveal their CAM practices gave 1 or more reasons for their decision (listed in decreasing order of participant emphasis): the impression of physician disinterest; the anticipation of a negative response; the conviction that the physician is unwilling or unable to contribute useful information; the perception that the CAM therapies used are irrelevant to the biomedical treatment course; and the patients' views regarding the appropriate coordi-

TABLE

## Demographic Characteristics of the 86 Women Interviewed

Characteristic	No. (%)
Age, years	
35 to 49	45 (52)
60 to 74	41 (48)
Race or ethnicity	
African American/black	5 (6)
Chinese American	13 (15)
European American/white	59 (69)
Filipina American	3 (3)
Hispanic American/Latina	4 (5)
Japanese American	1 (1)
Biracial (black/white)	1 (1)
Education	
Less than high school	7 (8)
High school	21 (24)
Some college	17 (20)
Bachelor's degree	29 (33)
Graduate school	12 (14)
Annual family income	
Less than \$20,000	18 (21)
\$20,000 to \$39,999	21 (24)
\$40,000 to \$74,999	26 (30)
\$75,000 or more	14 (16)
Refused to respond	7 (8)
Breast cancer stage at diagnosis	
In situ	11 (13)
Localized	55 (64)
Regional, extension only	1 (1)
Regional, nodes only	17 (20)
Regional, extension plus nodes	2 (2)

Note: Because of rounding, percentages do not always total 100.

nation of disparate healing strategies. Although a few participants mentioned insufficient time as a barrier to disclosure, it was considered a relatively minor impediment. An abbreviated appointment was seen as contributing to the problem of poor communication, but was not viewed as a primary or determining factor.

### IMPRESSION OF PHYSICIAN DISINTEREST

The most frequently cited reason for lack of disclosure was the feeling that the physician was not interested in the patient's use of CAM: "He'd think it was frivolous. . . . I think he wouldn't take it very seriously." Even in instances where patients attempted to initiate discussion, their efforts were frequently not reciprocated: "[The doctor] knows. . . but she's never asked me for details," and "Yeah, I told him — I don't know if he remembers or not." Unresponsiveness was taken as a sign that the physician did not want to hear more about the patient's practices: "I don't feel that they're interested. . . . I did tell the doctor...and he didn't say, 'Good,' or 'Not good,' or 'Okay,' or anything. It's kinda like, 'We're looking at the platelets here, and the white count — let's not get too far afield!'" The impression of physicians' disinterest — even on the

part of women who had initially volunteered information — often prevented further discussions.

### ANTICIPATION OF NEGATIVE PHYSICIAN RESPONSE

Patients are aware of the persistent ambivalence and occasional hostility of some biomedical practitioners toward CAM.<sup>11,12</sup> One patient reported, "When I said to my oncologist, 'I've used shark cartilage,' he almost laughed me out of the office." When participants fear a negative response from their physicians, they carefully assess the potential receptivity before disclosing information about their practices: "My Chinese American doctor is very against *qi gong*. He told me that *qi gong* is really just full of it — that it is really a scam. I think that's somewhat biased, so I did not talk to him about my practicing of the *qi gong* — that I went back to China to learn more — 'cause I don't want him to make me feel bad." The same participant, however, did disclose her CAM use in another context: "My radiation oncologist — he's a white person, but he knew something about *qi gong*. He seemed to be a lot more open." A physician's indiscriminate disapproval can have a broader impact than merely discouraging the use of a specific CAM treatment: "When I raised the subject of alternative medicine, my oncologist would really pooh-pooh it. It isn't that I need him to believe in it — I just don't want someone to dismiss it all. . . and thereby, in some ways, be disrespectful to me."

### BELIEF THAT THE PHYSICIAN IS UNABLE OR UNWILLING TO CONTRIBUTE USEFUL INFORMATION

Another common reason for withholding details about CAM use was patients' conviction that disclosure would not yield any benefit. Whether the physician was felt to be unable to help because of inadequate training, or unwilling to help because of a bias against alternative health systems, the unlikelihood of a useful outcome was a sufficient deterrent to pursuing further discussion. As one participant recounted, "When I started taking these herbs, I gave my primary care doctor a description of what was in them and what they were supposed to do — and she never said, 'I think it's good' or 'I think it's bad.' She looked at them and just goes, 'I don't see anything in here that's harmful.' My Chinese herbalist requested that I get copies of my [laboratory] tests, which I did. My medical doctor gave me copies, but, again, without any comment or questions — indicating to me a sort of unwillingness to work with this alternative doctor."

### PERCEPTION THAT DISCLOSURE OF CAM USE IS NOT RELEVANT

Patients may feel that their use of CAM is not germane to the process of medical decision making. Some participants believed that the CAM therapy they used was not directed at the same target as concurrent biomedical treatments, and therefore could not cause a harm-

ful interaction. Patients have reported, "I'm just using it to strengthen my antibodies" and "I really just took [the herbs] to control the spread of the tumor *before* my surgery. It really wasn't for *treating* my cancer." One participant who felt it was unnecessary to inform her oncologist of her CAM usage was, however, concerned enough about potential cross-reactions to keep her herbalist informed about her biomedical treatment: "[I inform my herbalist] just in case the herbs might have some side effect on the Western medical treatment that I'm receiving. You know, you don't want to be mixing Chinese herbs and Western medicine, because the combination of the 2 could be pretty lethal. You can't just combine them."

### VIEWES REGARDING THE APPROPRIATE COORDINATION OF DISPARATE HEALING STRATEGIES

Participants also made disclosure decisions according to their understanding of the proper roles for the various practitioners in their therapeutic encounters. For women who thought of their CAM use as a personal healing strategy — "Just something positive that I'm doing for myself" — there was a sense of protectiveness and desire for privacy regarding their treatment choices. Other participants distinguished between the realms of knowledge and the authority of physicians and alternative practitioners: "I didn't bring it up with the doctor. . . I don't feel like that's why I go to her. That's not really her job." Perhaps most interesting, however, are the cases in which patients perceive the value of integrating and coordinating their care, but choose to focus their efforts entirely on the alternative practitioner, as in "I send my acupuncturist my pathology reports," and "When you do surgery, of course you listen to your Western doctor — but I also went to my Chinese herbalist. I actually took my pathology report to him, and he looked at it and felt that it's a good idea to have surgery."

### FACILITATING DISCUSSIONS

Finally, to better understand patients' disclosure decisions, it is helpful to consider the factors that promote discussion. When study participants did reveal details about CAM treatment, it was because they perceived their physician to be respectful, open-minded, and willing to listen. Patients found it easier to discuss their alternative treatments when they believed that their physician expected them to be using some form of CAM. Participants were also particularly impressed by the few instances in which physicians opened a dialogue with patients' alternative practitioners (usually by recommending or trading journal articles).

## DISCUSSION

We believe that our findings more accurately reflect prevalence rates of adult cancer patient CAM use than previous

investigations. To our knowledge, this is the only qualitative, population-based, prospective cohort study designed to investigate changing patterns of CAM use over time. A number of methodologic factors account for the present investigation's higher prevalence rates: (1) the study uses a population-based sample (including Chinese and Spanish monolingual participants), thus avoiding the selection bias of clinic-based or English-only samples; (2) the prospective cohort design effectively eliminates problems of recall bias (see also the work by Risberg and colleagues<sup>13</sup> for the merits of a prospective versus cross-sectional design in increasing the accuracy of estimates of CAM prevalence); (3) the study investigates the use of all CAM therapies, not a predetermined subset; (4) the study is inclusive of spiritual and religious practices undertaken specifically to address breast cancer; and (5) the study is inclusive of CAM modalities that are not practitioner-directed, thus enabling the study of self- and intrafamilial-care that is often overlooked.

The fact that so many participants used CAM treatments *before* they knew they had breast cancer is significant because it challenges the persistent stereotype of the desperate patient who is willing to try anything after receiving a diagnosis of cancer. The high prevalence of prior usage also indicates the extent to which a host of CAM modalities and treatments are integrated into general health practices. Interestingly, the prevalence of post-diagnosis CAM use does not represent a significant increase from prior use for the study participants. At least in the first few months after initial diagnosis, therefore, most participants appear to maintain their prediagnosis health behaviors with regard to CAM. This finding is significant, because it suggests the possibility that our conclusions regarding disclosure behavior in women who recently found they had breast cancer may be applicable to the broader population. The study findings also challenge earlier assumptions that older women are more likely to engage in general CAM treatment use.<sup>16</sup> Our results confirm findings that people who use CAM tend to be younger and have relatively more resources with which to explore and obtain nonbiomedical treatments.<sup>2,4,15,17</sup>

Our reported rates of patient disclosure of CAM use to physicians are similar to previous study findings<sup>3,7</sup> — but these rates, taken alone, can be misleading. In the vast majority of cases, patients who are using self-treatment are much less likely to initiate discussions of CAM use than those who are seeing an alternative medicine practitioner. Also, even among those patients who actively seek to initiate discussion, many do not achieve their goal of establishing an interaction or receiving feedback. Therefore, even more significant than the number of patients who disclose CAM use to their physicians is the nature and quality of any subsequent discussion. In the biomedical encounter, this interaction was frequently truncated, while discussions with alternative practitioners were quite comprehensive, often including a review of biomedical

## Physicians Can Learn from Consumers How to Discuss CAM

data, such as laboratory tests and pathology reports.

Participants mentioned different reasons for discussing their use of biomedical treatments with their alternative practitioners: concerns about biomedical and CAM treatment cross-reactions; the desire to target specific biomedical treatment side effects; and the view that alternative practitioners are more open-minded and more adept at integrating diverse strategies than physicians: "[My acupuncturist] always asks me — she writes down in her chart when my next [medical] visit is. When I go to see her the next time...that's one of the first questions she asks me. So, she's really up on what other people tell me or what I've done. And in any other area, she's really good at wanting to know about it, what I've been told." The nature of the interaction after describing biomedical treatment use to most alternative practitioners is, thus, qualitatively different than most participants' experiences in medical encounters.

### LIMITATIONS

Adding to the disparity between our results and previous findings is the fact that we are most likely underestimating the prevalence of CAM use. First, 77% of the study participants had been given a diagnosis of *in situ* or localized breast cancer, and there are indications that advanced stage may correlate with increased use of CAM. Second, women aged 50 to 59 years were not enrolled in the study — for purposes of facilitating cohort comparison, while maintaining an appropriate sample size for in-depth, qualitative research. Women in the omitted age group would be relatively more likely to use CAM than older women<sup>13-15</sup> because of greater access and more resources, as well as the desire to mitigate menopausal symptoms. Thus, the potential limitation regarding the generalizability of our results is that the prevalence of CAM use is likely to be even higher than the study findings indicate.

### CONCLUSIONS

It is important to remember that interest in CAM use may be prompted by a wide range of factors, from the desire to avoid the invasiveness of a biomedical procedure to the fact that a particular healing modality is a part of a patient's cultural heritage.<sup>11,12,18,19,32</sup> The significance of a patient's use of CAM, therefore, is not limited to the impact of the discrete treatment itself; it usually indicates concurrent belief in at least 1 nonbiomedical explanatory health model (eg, the influence of the mind on the body, the importance of holistic healing, or the role of spirituality in medicine). Indiscriminate criticism of alternative treatment use has broad implications for the medical encounter, as well as patient outlook and hope. Respectful discussion of CAM, however, "sheds light on patients' world-views, values, explanatory models, lifestyles, health beliefs, and goals for care — all of which are clinically relevant and contribute to the ongoing development of effective and mutually rewarding

physician-patient relationships."<sup>11</sup>

Study participants emphasized several points both explicitly and by implication that can be elaborated into specific suggestions for discussing CAM use with patients. These recommendations can assist with initiating and encouraging open, honest discussion of patients' interest in or use of CAM.\* Since most patients are simultaneously or serially engaged in nonbiomedical health practices, it is critical not to make assumptions about who uses CAM on the basis of persistent stereotypes regarding the influence of age, socioeconomic status, or ethnicity: All patients have the potential to be interested in or to use a variety of alternative treatments. It is important to become familiar with recent sociodemographic and ethnographic data regarding CAM, particularly as they pertain to local patterns of use.<sup>3,11,12,20,22,34</sup>

Discussions of CAM should be approached in the same way as any sensitive topic about which patients may fear disapproval. When the subject of alternative treatments is initiated in a respectful manner, however, most patients will be able to discuss it matter-of-factly. The introduction of the topic can be made by stating, "People use a variety of different methods to maintain or improve their health. What kinds of things are you doing to take care of [your health/this problem]?"<sup>11,19,20,22</sup> Using the content of the patient's answers, the physician can then also probe for use of or interest in commonly or locally used treatments and modalities. Follow-up questions should be asked on the full range of treatment options in which the patient is engaged or interested.

It is important to ask broad, open-ended questions. Patients are not necessarily looking for a cure when they explore CAM options, and the treatments used may not be targeted to a specific disease or symptom. Also, inquiries about CAM should be a routine part of initial patient history taking as well as subsequent visits.<sup>11,18,20-22</sup> Discussion should not be confined to a single interaction, but rather should involve periodic inquiries to assess changes in patient interest in and usage of CAM over time.

Finally, study participants made clear that they greatly value their physicians' respect and understanding regarding treatment choices, even in the absence of agreement. Participants typically were not looking for physicians' belief in or endorsement of particular alternative therapies, but they did appreciate physicians who were respectful, open-minded, willing to listen, and honest about the limitations of their own knowledge of CAM. Patients should, therefore, be encouraged to contribute to the therapeutic relationship through mutual information sharing.

In recent years, a national trend has been revealed as health maintenance organizations and other insurers make alternative treatments available to plan members as benefits. With increasing information about and access to CAM therapies, it seems likely that the prevalence of its use will continue to rise. Clearly, discussions of CAM use provide

\*For strategies for advising patients regarding specific CAM treatment choices, see Hufford<sup>18</sup> and Eisenberg.<sup>30</sup>

physicians with important information about patients' health-related beliefs and practices. Both patient care and the physician-patient relationship will benefit from better integration of comprehensive discussions of CAM use into the medical encounter.

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