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Healing Logics

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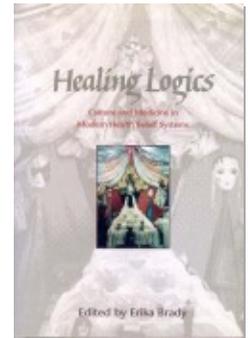
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INTEGRATING PERSONAL HEALTH BELIEF
SYSTEMS: PATIENT-PRACTITIONER
COMMUNICATION

SHELLEY R. ADLER

As students of folk medicine are well aware, the uneasy coexistence of diverse health belief systems in the United States is nothing new. Popular interest in these various healing systems seems to have increased with the development of patient empowerment and medical consumerism, as well as recent changes in the organization of health care delivery, particularly managed care (Adler, McGraw, and McKinlay 1998). Despite this widespread public interest, researchers noted in 1992 that “most physicians are unaware of [alternative medicine’s] popularity, much less that many of their own patients are also being cared for by practitioners of alternative medicine” (Murray and Rubel 1992). Only one year later, many physicians became aware of the “invisible mainstream in the U.S. healthcare system” (Eisenberg 1997) with the publication of Eisenberg and others’ seminal article on the prevalence and cost of complementary and alternative medicine (1993). The rate of usage and amount spent on complementary and alternative medicine, although surprisingly high to many biomedical scientists, were not the only significant findings—the investigators revealed that “72 percent of the respondents who used unconventional therapies did not inform their medical doctor that they had done so” (1993, 246). Four subsequent studies (including Eisenberg et al. 1998 as a follow-up) confirmed the high rates of patient nondisclosure (Keegan 1996; Begbie, Kerestes, and Bell 1996; Elder, Gillcrist, and Minz 1997; Eisenberg et al. 1998), but until now very little has been known about patients’ own reasons for sharing or withholding information about their own alternative treatment use.

CONTEMPORARY COMPLEMENTARY AND ALTERNATIVE MEDICINE USE

Health belief systems have been explored by scholars from diverse academic backgrounds, including folklore, medical anthropology, sociology, history of medicine, public health, nursing, and biomedicine. This diversity of theoretical and methodological orientations is evidenced by the myriad disciplinary terms that are presently used—for example, folk medicine, ethnomedicine, traditional medicine, unorthodox medicine, and unproven remedies, to name a few. My own training and research in folkloristics and medical anthropology results in my being most comfortable with terms and definitions that are appropriate to healing systems and practices in any location and at any point in time. The definition developed by a multidisciplinary panel convened by the National Institutes of Health Office of Alternative Medicine (recently reconfigured as the National Center for Complementary and Alternative Medicine) comes closest to doing justice to this large, diverse, and dynamic field of research: “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, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period” (Panel on Definition and Description 1997).¹ I have selected this definition of CAM to inform my ongoing study of women’s treatment choices for breast cancer. For the purposes of this research, therefore, all nonbiomedical healing strategies used in the contemporary United States will be referred to as CAM. I conceptualize folk medicine as a subset of CAM, distinguished by its dependence on oral transmission, informal structure, and lack of commercialism (Hufford 1997).

The extensive use of CAM 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 have ranged from 9 percent (Lerner and Kennedy 1992) to 50 percent (Cassileth et al. 1984).² My own research, based on face-to-face interviews with women with breast cancer, indicates that 72 percent use at least one CAM treatment in the first few months after diagnosis (Adler 1999).

The notion that the majority of patients a doctor sees are engaging in CAM usage on a regular basis has caused concern on the part of many physicians. Although it is always beneficial for doctors to be alert to their patients’ health-related beliefs and practices, many argue that the importance of this awareness is elevated in the context of CAM usage: “The medical literature expresses a number of primary concerns about alternative therapies: that they are incorrect and unfounded; that they will cause direct harm; that they will

delay or replace use of conventional medicine, thus causing indirect harm; and that they are perpetrated by quacks and frauds motivated by profiteering impulses” (O’Connor 1995; see Guzley 1992 for a representative example of this type of thinking). A more neutral portrayal of the reasons for physicians to stay aware of patients’ use of different treatments is that “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 (Lazar and O’Connor 1997).

The overwhelming majority of users of CAM also use biomedicine, either concurrently or serially. This is a remarkable situation, in which vast numbers of patients consistently participate in complementary and alternative healing practices outside of their physician’s purview—and usually without his or her knowledge.

PREVIOUS APPROACHES TO CAM USE

For purposes of expedience (Sharma 1993), most researchers have selected CAM cancer treatments to study based on two criteria: the treatments have been limited to a specific number of therapies derived from the literature, from pilot studies, or intuitively (Eidinger and Schapira 1984; Eisenberg et al. 1993; Faw et al. 1977; Harris, Louis, and Associates 1987; Yates et al. 1993); and the selected treatments tend to be those with the greatest structural similarity to biomedicine (practitioner-dependent and clinic-oriented). Investigators’ catalogs of CAM treatments most often reveal an exclusively etic perspective, with no evidence of informants’ actual knowledge or usage. Many of the same problems that plagued earlier folk medical studies have been present in CAM research, with the result that patients’ behavior is made to appear foolish, risky, and illogical. Historically, folk medical research in the United States has been conducted among marginal or peripheral communities, to the exclusion of more mainstream groups. The long-standing scientific misconception of the distribution of nonbiomedical practices is in large part a result of earlier notions of where populations of users of folk medicine could be found for study. From at least as early as the beginning of the present century, the belief has been widespread—in both the health professions and much of nonmedical academia—that folk and popular healing systems were in the process of gradually dying out with the advent of modern, Western medicine. An evolutionary model of the development of health systems has been to a large extent responsible for the perception of the waning popularity of nonbiomedical health practices. “Progress” implicitly defined as “increasing similarity to the culture of the scholar” (Hufford 1983, 307) was viewed as a natural and

inevitable process. Discarded, obsolete ideas drifted down and were preserved in the sediment of the lower layers of culture—*gesunkenes Kulturgut* (Hufford 1988, 228; Hultkrantz 1960, 158–59).

The legacy of nineteenth-century social theories, which incorporated positivist assumptions of the unilinear evolutionary process of human thought, remains remarkably influential today. In this context, the persistent fascination with recent reports of the high prevalence of CAM usage (Eisenberg et al. 1998) and the “conventional” and “mainstream” characteristics of CAM users (Cassileth et al. 1984; Eisenberg et al. 1993; McGuire 1988) becomes clear: research findings challenge the still-prevalent view of the marginalized user of nonbiomedical therapies.

Evolutionist and survivalist assumptions have sustained a series of stereotypes of participants in nonbiomedical health systems as being socially marginal. The stereotypes of marginality typically include one or more of the following features: geographic remoteness or isolation (the image of rural Appalachia is frequently invoked); recent immigration or minimal acculturation to core American culture; ethnic minority membership or strong ethnic self-identification or group affiliation; poverty or low socioeconomic status; low formal educational attainment; mental or emotional imbalance; or desperation induced by grave illness or poor outcomes of conventional therapeutic efforts (O’Connor 1995, 17). I add three characteristics to this list of common stereotypes: being a woman, being elderly, and being gullible (see Pepper 1984 for classic examples of belief in these stereotypes). I think that this view of marginality has contributed to the fact that many physicians feel that their patients’ use of CAM is intentionally enveloped in secrecy (Gray et al. 1997). In the medical literature, patients have been portrayed as willfully withholding information about their health beliefs because they are “afraid to ‘confess’ to the general practitioner their contacts with non-medical practitioners” (Guzley 1992, 523).

Scientific research has also contributed to the stereotype of the CAM user by focusing on nonrepresentative groups of people (Brown 1975; Ingelfinger 1976; Durant 1991). Convenience sampling has resulted in study populations that are poorly differentiated in terms of ethnicity and age. Prevalence studies have included people who use CAM for a variety of different conditions—from short-term discomforts to chronic or life-threatening illness—thus confounding the informants’ reasons for and satisfaction with the choice of CAM treatments. Additionally, clinic-based samples, which continue to comprise the most common study populations, can introduce recruitment bias in terms of the types of patients that physicians allow researchers to approach (“compliant” patients). Finally, there is also a “context

bias” that can arise when informants are interviewed in a clinic or hospital, locations at which “an adherent is least likely to feel at ease discussing beliefs and practices deemed ‘deviant’ by the larger society” (McGuire 1988).

Another problem in CAM research has been the difficulty of ascertaining accurate prevalence estimates. The broad range of reported prevalence rates (from 7 to 50 percent in the U.S.) appears to be directly related to each project’s chosen methodology. The continuum of research findings from low to high rates of usage is paralleled by a methodological continuum ranging from quantitative telephone survey research to qualitative, face-to-face interviews. Also, not surprisingly, studies that rely on narrow definitions of CAM culled from the biomedical literature report lower prevalence of usage than investigations that utilize broader, emically derived definitions. Problems due to unclear definitions, nonrepresentative study populations, and underestimated prevalence rates have hindered progress toward a better understanding of the nature of people’s use of CAM.

THE WOMEN’S BREAST CANCER TREATMENT CHOICES STUDY

The findings discussed in this chapter are based on two cycles of interviews from an ongoing five-year qualitative study of treatment decision-making on the part of women with breast cancer. In order to interview a representative group of women as soon as possible after their breast cancer diagnosis, participants were recruited using a unique population-based rapid case finding method. 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 biweekly for thirteen months. The team assembled a list of all new cases by reading pathology reports, supplemented by hospital records. After patients’ physicians were contacted, the women were sent introductory letters, followed by a recruitment telephone call.

Eligibility requirements for study participants included the following: ages 35–49 and 60–74, inclusive; residents of San Francisco, California, at the time of diagnosis; ability to be interviewed in English, Spanish, or Chinese (Cantonese or Mandarin); histological diagnosis of breast cancer (in situ or invasive); diagnosed at a hospital within San Francisco County; and diagnosed during the thirteen-month period of case ascertainment (May 1995–May 1996). Exclusion criteria included recurrent breast cancer and patients whose physicians refused to grant permission for them to be contacted. A total of eighty-six women were enrolled (87 percent of those known eligible).

Data is being collected through a series of four in-depth, face-to-face interviews. Informants are initially interviewed within a few months of diagnosis

(two to four months average) and again after six months, eighteen months, and thirty months. The interviews take place in participants' homes or at private locations of their choosing. The study utilizes a semistructured interview guide that is specifically adapted for each of the four interview cycles. The open-ended questions are designed to encourage informants to articulate their personal understandings of their beliefs and practices regarding health and illness. The domains of questions asked during the initial and first follow-up interviews include: (a) conceptualizations of health and illness; (b) the process of discovery and confirmation of the breast cancer; (c) the individual's views on the cause, nature, and extent of her illness; (d) biomedical and/or CAM cancer treatments utilized to date; (e) experiences with and attitudes toward physicians and alternative practitioners; and (f) interactions regarding CAM and biomedical treatment use with physicians and alternative practitioners, respectively. In order to elicit answers with unbiased questions, informants were asked to describe all aspects of their health beliefs in their own words: potentially etic terms or concepts, such as cancer or alternative medicine, were not used by the interviewer unless introduced by the informant.

All interviews were audiotaped and transcribed verbatim. Cantonese, Mandarin, and Spanish interviews were translated by the interviewers and then transcribed. Concurrent qualitative text-based analysis is conducted with the use of QSR NUD*IST software. The data related to patients' disclosures of treatment use and interactions with physicians and alternative practitioners were analyzed separately. Transcripts were reviewed and coded by two persons 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.

LOGICS OF DISCLOSURE

Of the patients simultaneously being treated by an alternative practitioner, 54 percent discussed their CAM use with their physicians.³ Conversely, 94 percent of the participants seeing alternative practitioners discussed details of their biomedical treatments with these providers. These quantitative rates of disclosure, however, 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 with their doctors than those who are seeing a practitioner. Also, even among those patients who actively seek to initiate discussion, many do not achieve their goal of prompting 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 brief and superficial, while discussions with alternative practitioners were quite comprehensive, often including a review of biomedical data, such as laboratory tests and pathology reports.

Patients' disclosure of CAM usage was cautiously modulated and carefully adapted, even by those who would welcome an open discussion with their physicians. Informants who chose not to reveal their CAM practices gave one or more of the following 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 coordination of disparate healing strategies. Although a few participants implicated 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.

The reason for lack of disclosure most frequently cited by informants was the feeling that the physician was simply not interested in a patient's use of CAM: "He'd think it was frivolous . . . I think he wouldn't take it very seriously." Even when patients did attempt to initiate discussion, their efforts were frequently not reciprocated: "The oncologist 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 clear message 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 oncologist . . . 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! [*laughs*]." The impression of physicians' disinterest—even on the part of women who had initially volunteered information—often prevented further discussions.

Patients are aware of the persistent ambivalence and occasional hostility of some biomedical practitioners towards CAM (Lazar and O'Connor 1997; Adler and Fosket 1999): "When I said to my oncologist, 'I've used shark cartilage,' he almost laughed me out of the office." Because patients sometimes 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 didn't 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 be viewed as having a broader scope 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.” Informants’ perceptions of physician disinterest and ambivalence echo findings from a preliminary study of physicians’ attitudes toward patient use of CAM. Among the physicians interviewed, “there was little interest in initiating communication about unconventional therapies, with most seeing such discussions as a poor use of their time” (Gray et al. 1997, 14).

Another common reason for withholding details about personal 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 due to 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 [lab] 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.”

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 harmful interaction: “I’m just using it to strengthen my antibodies” or “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 unnecessary to inform her oncologist of her CAM usage, however, was concerned enough about potential cross-reactions to keep her herbalist informed about her biomedical treatment: “Just in case when the Chinese herbalist gives me herbs they 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 two could be pretty lethal. You can’t just combine them.”

Participants also based disclosure decisions on 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 regarding their treatment choices. Other participants distinguished between the realms of knowledge and authority of physicians and alternative practitioners: “I didn’t bring it up with the surgeon . . . I don’t feel like that’s why I go to her. That’s not really her job.” Perhaps most interesting, though, 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: “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 a surgery.”

Not unexpectedly, the preliminary data available on doctors’ attitudes toward CAM usage presents an entirely different picture of the context of disclosure. In discussing barriers to communication, the majority “identified the problem as being with the patients” (Gray et al. 1997, 17): “[patients’] unrealistic expectations of their physicians, inability to tolerate reality, hostility or denial in the face of bad news, disorganization in seeking information, and secretiveness about use of unconventional therapies” (18). Some doctors identified systemic communication problems associated with an overloaded health care system, such as limits on time. In general, “learning about, or having access to information, seemed to be much more important to physicians than actually discussing [CAM] issues with or passing the information on to patients” (18).

Finally, in order to understand better patients’ disclosure decisions, it is helpful to consider the factors that promote discussion. When study participants did choose to reveal details about CAM treatment use 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 also were particularly impressed by the few instances in which physicians opened a dialog with patients’ alternative practitioners (most frequently by recommending or trading journal articles).

Participants mentioned different reasons for discussing their use of biomedical treatments with their alternative practitioners: concerns about biomedical/CAM treatment cross-reactions; the desire to target specific biomedical treatment side effects; and the view that alternative practitioners are relatively more “open-minded” and more adept at integrating diverse strategies than physicians are: “[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 a patient describes her biomedical treatment use to her alternative practitioner is thus often qualitatively different than in the medical encounter.

PERSONAL INTEGRATED HEALTH BELIEF SYSTEMS AND VIRTUAL COLLABORATORS

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 (Lazar and O'Connor 1997; Hufford 1992; O'Connor 1995). 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 one nonbiomedical explanatory health model (like the influence of the mind on the body, the importance of holistic healing, or the role of spirituality in medicine). A physician's 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' worldviews, 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 doctor-patient relationships" (Lazar and O'Connor 1997). The interviews emphasized patients' spontaneous, that is, unsolicited, disclosures of CAM use. It is likely that some women would have overcome their hesitation to discuss CAM if their physician had asked them a direct question. It is telling, however, that, even in a part of the country with a reputation for open-mindedness regarding health care diversity, physicians rarely initiated discussion of CAM use.

The emic perspective that the informants provide reveals that an intricate framework of logic underlies their health behavior. A patient's integration of biomedical and various CAM therapies is, of course, not desperately haphazard, as sometimes portrayed in the medical literature: patients' integrative healing systems involve deliberate and complex strategizing. A helpful construct for the study of complementary and alternative medicine is personal integrated health belief systems, in which individuals combine disparate elements—from what may appear to be mutually exclusive health traditions—into a syncretic whole. In order to understand better the intricacies of these

unique syncretic healing systems, the individual's own health beliefs must be studied as the locus for integration. As is often the case, the different biomedical and alternative health traditions may only appear to be irreconcilable—their apparent inconsistencies are either not viewed as such or are deemed insignificant from the individual's perspective.

The interviews with women with breast cancer revealed that accurate models of patient decision making regarding breast cancer treatments, even exclusively biomedical therapies, must take into account the role of alternative practitioners. The conventional view of the dyadic patient-physician relationship only reveals one side of a potential triangle of patient and practitioners. In actuality, the majority of physicians are engaged in a virtual collaboration with patients' alternative practitioners. Although the "partnership" is frequently invisible, its effects are not.

FOLKLORISTICS AND CAM RESEARCH

To conclude, I would like to emphasize that folkloristics is ideally situated to investigate the wide variety of CAM systems, including modalities, practices, theories, and beliefs. As Claire Cassidy explains, qualitative research methodologies display a high degree of "model fit"; that is, they comprise "research design and techniques [that] fit the explanatory model/s of the study population/s" (Cassidy 1995, 35). By sharing what amounts to a common perspective with many CAM systems, folkloristic inquiry avoids many of the problems that can arise with mismatched methodological techniques.

Another strength of folkloristics is its "populist" orientation (Hufford 1992)—an approach that links well with the patient consumerism that is so influential in the phenomenon of complementary and alternative medicine. Folklorists emphasize—or, more accurately, insist on—taking into account the emic perspective. As David Hufford observed, "ordinary people tend to be underestimated and . . . their knowledge tends to be discredited by authorities" (1992). By promoting participants' views and understandings, folklorists and other qualitative researchers can interpret CAM phenomena in terms of the meanings that people bring to them. Through the use of unstructured or semi-structured interviews, informants are given the opportunity and encouraged to describe their beliefs and practices using their own logic and terminology.

The holistic nature of qualitative inquiry blends well with the holistic model of many CAM healing systems (Cassidy 1995). Just as many CAM systems do not involve the traditional biomedical hierarchy of doctor and patient, for example, in qualitative inquiry the researcher-participant dyad is constructed to promote a more egalitarian relationship. Perhaps the most

important contribution a folkloristic approach can make to CAM studies is the valuing of participants' "subjective" views as expert and the integration of informants' conceptualizations and models into research design and analysis.

NOTES

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1. "Complementary and alternative medicine" is defined as "all health care resources to which people have recourse other than those intrinsic to biomedicine and the specific theoretical and practice models of biomedicine" (Panel on Definition and Description 1997).
2. Studies of patients in a variety of populations outside the U.S. have shown that between 9 percent and 75 percent of adult patients with cancer use CAM (Lerner and Kennedy 1992; Gray et al. 1997; Eisenberg 1997; La Valley and Verhoef 1995; Hufford 1997; Clinical Oncology Group 1987; Downer et al. 1994; Eidingen and Schapira 1984; Himmel, Schulte, and Kochen 1993; Millar 1997).
3. Overall disclosure for women using CAM generally was 33 percent, similar to reported findings in the general population.

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