



Complementary & Alternative Therapies

Creating Comprehensive Cancer Care

A Journey

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The Problem

Almost every person with cancer who has come to see me over the last 20 years—man or woman, young or old, rich or poor, with early- or late-stage disease—has asked the same question. Of course, the words vary slightly from person to person, but the content is essentially the same: “What else can I do?”

It is a wonderful question; urgent, profound, and challenging. The emphasis falls in two places. What *else* means what else besides the surgery, radiation, and chemotherapy, that may have been recommended by my oncologists, can I do? What other therapies can I use together with (complementary to) or instead of (alternative to) these conventional approaches? This part of the question is the basis for much of the public interest in complementary and alternative medicine (CAM), and the spur to research into these approaches.

The second part of the question is just as important. “What can *I* do?” One of the deepest problems in cancer care, and indeed in the care of all chronic illnesses, is the patient’s feelings of passivity and helplessness. However powerful and useful conventional care may be, its procedures are done *to* people with cancer, not *with* or *by* them. There is no opportunity for them to act on their own behalf, to participate actively in their own care.

In recent years, this two-part question has been asked with increasing frequency. A study by Richardson et al,¹ published in the *Journal of Clinical Oncology*, showed that 69% of all patients treated at the MD Anderson Cancer Center were using one or more complementary therapies as part of their care and that an even larger number wanted more information about these therapies. A 1998 survey of a

Sacramento, California, cancer center published in *Cancer Practice*,² indicated that 85% of *all patients* wanted complementary care to be included in their oncology treatment and that 75% wanted to be able to ask their doctors for referrals to CAM practitioners.

For the most part, however, patients have been discouraged from asking their oncologists or other cancer-care professionals these questions, or have been disheartened and disturbed by the answers they received. Most oncologists still know little or nothing about CAM or, indeed, where to look for reliable information or referrals. More ominously, many have been dismissive of their patients’ interests and, at best, condescending toward the CAM approaches that most of these patients are already using, and that many more would like to explore. Meanwhile, many CAM practitioners have avoided contact with orthodox oncologists by whom they have felt misunderstood, rejected, or persecuted. Some have operated outside of, or at the edge of, the law.

The dismissive attitude of the mainstream coupled with the fear and defensiveness of CAM practitioners has made it difficult for patients to receive guidance about complementary and alternative therapies and all but impossible for them to make use of a care that thoughtfully integrates the “best of both worlds.” Therapies that may be extremely helpful in prolonging life or enhancing quality of life have been marginalized and excluded. The physicians’ hostility and lack of attention have been dispiriting and insulting to patients, often proving harmful to the patient-physician relationship.

The Beginnings of a Solution

Despite the demand for authoritative information about CAM, it has been extremely difficult for both oncology professionals and persons with cancer and their families to obtain authoritative information about the therapeutic programs that could safely integrate the best of modern oncology with the most effective of CAM approaches.

Until recently, there were only a handful of people who had an unbiased understanding of CAM approaches and who were counseling patients about them. These services were limited to the few people who were fortunate enough to find and, in some instances, pay for them. For the vast majority of patients with cancer, there was (and con-

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tinues to be) nobody to help them figure out *what else* they can do. Meanwhile, those physicians, nurses, and psychotherapists who have been interested in answering their patients' questions about CAM have been struggling to find answers themselves. In the mid-1990s, 70% of the phone calls that were coming to the Office of Alternative Medicine at the National Institutes of Health were about cancer—close to 900 each month.

In 1996, we at the Center for Mind-Body Medicine (CMBM) decided to find a more effective way to explore the questions that patients with cancer and oncology professionals were struggling to answer. We decided to create a conference that would bring the most promising CAM practices and practitioners together with mainstream oncologists, researchers, and other clinicians. We called it *Comprehensive Cancer Care: Integrating Complementary and Alternative Therapies*.

We wanted those who were using and studying these innovative therapies to present their work to critical but fair-minded mainstream scientists, to have their work evaluated in an open forum, and to make the proceedings available to all, without cost, on the Internet. We sought to further the dialogue between mainstream and CAM clinicians, and to bring patients, practitioners, and policy makers together to develop evidence-based programs of integrative care. We were determined, in short, to help both patients and practitioners take a look at *what else* they could do and to encourage programs that were trying to provide it.

The *Comprehensive Cancer Care: Integrating Complementary and Alternative Therapies* conference (cosponsored by the National Center for Complementary and Alternative Medicine and the National Cancer Institute), now in its third year, has grown in scope, quality, and attendance. The first year more than 900 persons attended, last year more than 1400. About one third of attendees were physicians, one third were other health professionals, and one third were patients, family members, and patient and public advocates. Controversial topics of immediate importance have been addressed (for example, the pros and cons of using antioxidants with chemotherapy and radiation), and cutting-edge research on herbal therapies has been presented. In addition, the work of widely discussed but little understood and controversial researchers, such as Nicholas Gonzalez, MD, and Stanislaw Burzynski, MD, has been given full and fair evaluations.

These gatherings have been extraordinary, marked with respect and kindness as well as careful scientific presentations and critical evaluations. And each year, as we help to advance the practice of comprehensive cancer care, we learn how far we have yet to go. We are reaching out to help clinicians, who need assistance in pulling their research together, and working with the National Cancer Institute and the National Center for Complementary and Alternative Medicine to promote more and better studies of promising therapies. We are giving the new integrative programs in cancer centers an opportunity to share their work. We are providing better information for patients and their families—a kind of core curriculum of CAM. Still, clinicians and persons with cancer and their families need more help in exploring their options than any series of conferences can offer.

Comprehensive Cancer Care

After the first two CAM conferences, I decided to write a book that would make the best of the best of the conference material and its perspective widely available. The result was *Comprehensive Cancer Care: Integrating Alternative, Complementary, and Conventional Therapies*,³ coauthored by Sharon Curtin. In the last chapter, Ms. Curtin and I advise our readers on the four steps to comprehensive cancer care that each person with cancer should take, and the role that oncology professionals can play in their journey.

Remember: You Can Do Something

"The first step," we say, "in creating a program of comprehensive cancer care is realizing you have the power to do it." This shift from passivity and resignation to awareness and activity is the answer to the "what can I do" part of the cancer question. Taking this step, feeling more in control of one's care and one's life is, itself, energizing and health enhancing. It is also fundamental to the whole process of integrative care. The realization that one can do something allows him or her to make choices about which healing partners (oncologists, therapists, and others) to choose, which ones to avoid, and which therapies to include in one's own program.

Finding Healing Partners

Realizing that one has the power to create one's own cancer-care program also means a choice of which healing partners will be part of one's team. This second step is crucial, not only because different oncologists and surgeons have vastly different rates of complications, but because patients' relationships to their clinicians have a profound effect on their psychological state. It is, as we all know, altogether different to feel listened to and respected than it is to feel dismissed.

It is equally important to reach out for help to others in one's life. At the CMBM and at the conference, we have observed that persons who have family members and friends actively engaged in helping them to create integrative programs feel far more relaxed and confident than those who are alone or isolated.

The evidence for the efficacy of group support in enhancing quality of life and improving immune functioning is strong enough that it should be available to every patient with cancer. Studies by Spiegel⁴ (which is now being replicated) and Fawzy et al⁵ indicate that group support also may significantly prolong life.

Making Self-Awareness and Self-Care Cornerstones

Step 3 involves making self-awareness and self-care cornerstones of cancer care. Most of the CAM therapies that seem to have a significant effect on quality of life, and perhaps extension of life, are included in self-awareness and

self-care. These include such “mind-body” therapies as relaxation, meditation, guided imagery, yoga, and nutritional therapies. These are exactly the kinds of approaches that can be taught easily by clinicians in hospitals and office settings. Self-care is a low-tech approach that professionals can share with the many patients who are eager to use it. These techniques not only help to relieve symptoms of stress and improve mood, but also enhance a patient’s sense of control over his or her own life—almost immediately. At the CMBM, we have found that these mind-body techniques are best taught in a small support group format.

Nutrition is a natural supplement to the aforementioned mind-body approach. Though there is considerable conflict about nutritional alternatives to conventional treatment, there is little doubt that integrating a program of good nutrition into one’s cancer care can decrease stress, enhance immunity, and improve overall functioning. At our conferences and in the *Comprehensive Cancer Care* book, we present a simple nutritional program of diet and dietary supplementation that can be safely recommended by clinicians and used by patients with cancer.

Balancing Treatment Decisions

Step 4 is certainly the most difficult, and precarious, of steps. My coauthor and I are encouraging clinicians and patients to take an open-minded *and* critical look at all therapies—complementary, alternative, and conventional—and to use the same types of criteria to assess them. We ask a number of questions of each possible intervention: What are the odds that a particular therapy will produce a cure or long-term survival? What is the down side, in terms of side effects, convenience, and expense? How does one approach compare with another, and how many and which ones can be safely and easily integrated? In our estimation, the literature on some approaches, such as acupuncture and Chinese herbal therapies, suggests the possibility of successful integration in a large majority of patients’ care. Other approaches, including some that have been highly praised, have far less evidence to support their use. In helping patients with these decisions, it is important to be aware both of the research on these therapies and of the data provided by oncologists who have critiqued them and to understand that our knowledge of these approaches is rapidly evolving.

Creating Integrative-Care Counselors

As we at the CBMB reviewed our clinical experience and the evaluations of conference attendees, it became

clear that information alone, no matter how well presented, is not enough. Persons with cancer need support to sustain them in coping with diagnosis and treatment as well as ongoing guidance in the choices that they must continually make.

We have, therefore, recently decided to create a program to train *integrative-care counselors*—physicians, psychologists, social workers, nurses, and dieticians—for persons with cancer and their families. This training program will combine elements of the Professional Training Program in Mind-Body Spirit Medicine of the CMBM (focusing on mind-body approaches to individual counseling and group support) with easily comprehensible information on the biology of cancer, discussions of criteria for evaluating research, and authoritative and continually updated information on the efficacy and limitations of CAM therapies and the ways they might be integrated with conventional cancer care. As a part of this program, we will provide extensive listings of resources that counselors may share with patients, updates on state-of-the-art therapies, and guidance in making appropriate referrals.

The clinicians we train will be able to offer psychological support to patients and their families as they cope with the diagnosis of cancer and begin to design their own integrative-care programs. They will be trained to provide patients with practical assistance in assessing and choosing CAM therapies and with creating individualized programs of comprehensive cancer care.

It is our hope at the CBMB that, in time, every cancer center and oncology practice will have one or more of these integrative-care counselors available to help patients to more clearly answer the question that I first began to hear more than 20 years ago: “What else can I do?”

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