EDITED BY MERRIJOY KELNER, BEVERLY WELLMAN
BERNICE PESCOSOLIDO AND MIKE SAKS

COMPLEMENTARY AND ALTERNATIVE MEDICINE

Challenge and Change



Complementary and Alternative Medicine

'This book places complementary and alternative medicine (CAM) in a broad social context to increase understanding of the forces that shape the development and growth of CAM in Western developed countries.... a unique addition to the body of literature in this field.'

Focus on Alternative and Complementary Therapies

'This is a sensitive, intelligent, reflective, considered and insightful book that deserves to become a classic.'

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'This volume certainly deserves attention from diverse readerships, and it should go a long way toward strengthening the case for those who would like to see a greater integration of social science research into CAM research funding portfolios.'

The Journal of Complementary and Alternative Medicine

Complementary and Alternative Medicine: Challenge and Change

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The Social Dynamics of Medical Pluralism, Foreword

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We are all faced with illness at some time in our lives and most of us end up caring for a loved one who is ill. When illness comes, be it a minor or major problem, we all purport to want basically the same thing - a rapid, gentle treatment that cures us or at least can allay our fears and alleviate our suffering. Yet, despite this apparently common goal the social responses to disease and illness are remarkably varied and differences are often strongly held. Who we approach for help, what we decide is the best treatment for us, how we evaluate success, and when we look for alternatives - depend on many factors. These include how we conceive of health and illness, what we believe has gone wrong and why, and who we associate with and get advice from. In short, it depends on our models and perceptions of the world, the preferences and values we share, and the perceived benefit we get from associating with trusted others. Even in the age of modern science, decisions about the nature of humankind, health and illness, its meaning and how to prevent and treat it is primarily a social process. It is logical then that in order to understand the forces that shape any prominent change of behaviour toward health care – like the rising popularity of alternative medicine - we must carefully examine those social forces. This is the first book to do this in depth and is therefore essential reading for anyone who wants to understand this phenomenon, be they scientist or statesman.

During my tenure as the Director of the Office of Alternative Medicine at the National Institutes of Health, I recognized that 'unofficial' medicine has always been an important part of what the public uses in healthcare. Homeopaths and herbalists, folk practitioners and spiritualists provide a multiplicity of ways to address suffering. The public goes through periods of enchantment with unorthodox medicine. Homeopaths, herbalists, hypnotists, and various 'eclectics' were popular and public over a hundred years ago. At that time, orthodox physicians had little to no training and there was little regulation of practice. The popularity and use of the unorthodox would vary, depending on

the perceived value of orthodox medicine, the needs of the public, and changing values in society. With the development of scientific medicine and its dramatic advances in the understanding and treatment of acute and infectious disease, these practices largely subsided (Gevitz, 1988).

The prominence of complementary and alternative medicine (CAM) is now rising rapidly. Two identical surveys of unconventional medical use in the United States done in 1990 and 1996, showed that CAM use by the public increased 45% over that six year period. Visits to CAM practitioners went from 400 million to over 600 million visits per year and the amount spent on these practices rose from \$14 billion to \$27 billion - most of it not reimbursed (Eisenberg et al., 1998). The overwhelming effort now is toward an 'integration' of these practices into the mainstream. Seventy five medical schools in the United States have begun to teach about CAM practices (Wetzel et al., 1998), hospitals have developed complementary and integrated medicine programs, health management organizations and health insurers are offering 'expanded' benefits packages that include CAM practitioners and services (Pelletier et al., 1997). Biomedical research organizations are investing more into the investigation of these practices. For example, the budget of what was called the Office of Alternative Medicine at the U.S. National Institutes of Health rose from \$3 million to \$50 million in four years and changed from a coordination office to an independent center now called the National Center for Complimentary and Alternative Medicine (Marwick, 1998). It appears that complementary and alternative medicine has again 'come of age'.

This trend reflects not only changing behaviours but changing needs and values in modern society. It is the details of these changing values and behaviours that the scholars in this book examine. The book explores the psycho-social determinants of CAM use (Astin; Furnham and Vincent), the 'normalization' of users over time (Blais), how different concepts of the body influence health care practices (O'Connor), the relationship between the growing fitness movement and CAM (Goldstein), and the key role of the nature and quality of the therapeutic relationship in shaping health care preferences (Kelner). Chapters also address how CAM practices diffuse throughout society (Valente), and the role of health networks in influencing therapeutic choices (Wellman). Of note is that CAM practices, like most conventional practices, are adopted and 'normalized' long before scientific evidence has established safety and efficacy. Key differences in how this occurs, however, are that in conventional practice, procedures are usually introduced by professional bodies or industry rather than the public (McKinlay, 1981). This says something about the nature of public preferences and predicts that new unconventional practices will rise as current CAM groups become more professionalized and are adopted by the mainstream.

This is not the first time that the importance of unorthodox medical practices has risen in prominence. Orthodox medicine usually fights CAM practices by attacking them, limiting access to them, calling them quackery, and penalizing those who practice them. When they persist, mainstream medicine examines them, finding similarities with the orthodox and adopting them into normal medical practice (Worton, 1999). Medicine benefits from their selective integration by abandoning harmful therapies such as mercuralization, finding new drugs such as digitalis, and accepting more rigorous scientific methods with which to test them (Gevitz, 1988; Kaptchuk, 1998).

We now have sophisticated scientific methods for the application of basic science to clinical practice and for the management of acute and infectious disease. However, current methods for examining chronic disease or practices that have no explanatory model in western terms are not adequately informed by science (Linde and Jonas, 1999). CAM offers us the opportunity to debate and test new approaches for examining these areas as their importance increases in medicine (Pincus, 1997). Four authors in this book consider the role of science in informing us about CAM by examining use of the randomized control trial (Ernst), naturalistic inquiry (Glik), non-dichotomous models of conceptualizing and researching illness behaviour (Pescosolido), and the place of health services research in building a future of 'integrated' medicine (Best and Glik).

Other social factors are also influencing the growth in CAM use. These include: a rise in prevalence of chronic disease, increasing access to health information, increased democratization of medical care decision-making, a declining faith that scientific breakthroughs will have positive effects on personal health, and an increased interest in spiritualism (Fox, 1997; Starr, 1982). In addition, the public and professionals are increasingly concerned over the side-effects and escalating costs of conventional health care (Lazarou et al., 1998; Smith et al., 1998). As the publics' use of CAM accelerates, ignorance about these practices by physicians and scientists risks broadening the communication gap between the public and profession that serves them (Chez and Jonas, 1997; Eisenberg et al., 1998). This book addresses aspects of these broad influences by examining the remergence of pluralism in medicine (Sharma), the political consequences of CAM professionalization (Saks), and new strategies for a social and scientific research agenda for CAM (Best and Glik).

If we do not examine more closely the social and scientific forces that shape medicine we are destined to repeat many of the divisive tactics that have characterized the relationship between mainstream and non-mainstream practices of the past (Jonas, 1998). To adopt CAM without developing quality standards for its practices, products, and research is to return to a time in medicine when therapeutic confusion prevailed. Modern conventional medicine excels in the

areas of quality healthcare and the use of science, and CAM must change to adopt similar standards. Conventional medicine is also the world's leader in the management of infectious traumatic and surgical diseases, in the study of pathology, and in biotechnology and drug development. All medical practices have the ethical obligations to retain these strengths for the benefit of patients (Chez and Jonas, 1997).

At the same time, there are important characteristics of CAM that risk being lost in its 'integration' with conventional care. The most important of these is an emphasis on self-healing as the lead approach for both improving wellness and the treatment of disease. All the major CAM systems approach illness first by trying to support and induce the self-healing processes of the person. If recovery can occur from this, the likelihood of adverse effects and the need for high-impact, high-cost interventions is reduced (Jonas, 1999). It is this orientation toward self-healing and health promotion (salutogenesis rather than pathogenesis) that makes CAM approaches to chronic disease especially attractive (Antonovsky, 1987).

The main "obstacles to discovery" writes Daniel Boorstin (1983), in his book The Discoverers, are "the illusions of knowledge". Humans fool themselves by making exaggerated claims of truth, clinging to unfounded explanations and denying observations they cannot explain. In addition, the complexity of disease and the powerful ability of the human body to recover often make it difficult to apply science to clinical medicine. K.B. Thomas (1994) demonstrated that nearly 80% of those who seek out medical care get better no matter what hand waving or pill popping we provide. I call this 'The 80% Rule', meaning that data collected on novel therapies delivered in an enthusiastic clinical environment will frequently yield positive outcomes in 70-80% of patients. Often our most accepted conventional treatments are shown to be non-specific in nature (Roberts et al., 1993) or even harmful (Pratt, 1990) when finally studied rigorously. Their apparent effectiveness in practice is due to the powerful ability of the body to heal (with or without expectation), statistical regression to the mean (a measurement problem) and self-delusion (sometimes called bias; Jonas, 1994).

It is little wonder, then, that for the majority of physicians and patients there are many therapies both orthodox and unorthodox, that seem to work. Science has emerged as one of the few truly powerful approaches for mitigating this self-delusionary capacity. It will not continue to be a useful guide to medicine, however, unless we are willing to use it rigorously to examine both the social and the statistical forces that shape what we perceive and accept as reality. This book goes a long way in doing that for unorthodox medicine and also for orthodox medicine. Complementary and alternative medicine is here to stay. It is no longer an option to ignore it or treat it as something outside

the normal processes of science and medicine. Our challenge is to move forward carefully, using both reason and wisdom, as we attempt to separate the pearls from the mud.

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Introduction Complementary and Alternative Medicine: Challenge and Change

MERRIJOY KELNER AND BEVERLY WELLMAN

This book began years ago, long before complementary and alternative medicine (CAM) became so popular. In the 1970s, we began, separately and independently, academically and personally, to be involved in different forms of alternative care. One of us (Wellman) studied the Alexander Technique (postural re-education) while the other (Kelner) undertook a national study of chiropractors in Canada. These initiatives led us both to the offices of CAM practitioners. As we spent time sitting in these offices awaiting our turn for treatment, we both observed that the composition of the clientele was undergoing changes. At the outset, the patients consisted of a narrow slice of society. People attracted to the Alexander Technique were almost entirely artists. They were either dancers, musicians or actors; people who used their bodies strenuously. Those who were drawn to chiropractic, on the other hand, were largely people who did hard physical labour and had injured their backs in some way.

Over time, the range of people who sought both kinds of care began to expand and diversify. The artists were joined by truck drivers, academics and people who were resisting the recommendation for surgery they had received from their physicians. Similarly, chiropractic patients included more and more patients who wanted a treatment that was less invasive than surgery. Contrary to the stereotype of CAM patients as poor and uneducated, these more recent patients were obviously well dressed, well educated, affluent, and sophisticated in their approach. We asked ourselves: What is going on? Why are these people coming here when they must pay out of their own pockets instead of going to a doctor who is reimbursed by the government? And how are they learning about these options?

These types of questions led to our meeting and a decision to pursue social scientific research together that would help us find the answers. When we began the research, it was considered exotic by our colleagues and friends.

They were skeptical, dismissive and interested, all at the same time. They asked lots of questions but remained unconvinced about the utility of CAM and the academic merits of researching it. Later, people began coming up to us at social gatherings and confiding that they had decided to try some form of CAM. What did we know about it? And could we recommend somebody? The pace of inquiries kept accelerating as did the attention paid to CAM by television, newspapers, magazines and later on, by the Internet. We recognized that a personal and academic interest had become a public phenomenon. This book reflects the convergence of our personal, intellectual, and scholarly worlds and also draws on an international frame of reference, primarily covering the United States, Canada and Britain. This comparative perspective is also represented in the international editorial team which has been instrumental in putting together this volume. This includes Merrijoy Kelner and Beverly Wellman from Canada, Bernice Pescosolido from the United States and Mike Saks from Britain.

Complementary and alternative medicine is not new. Unorthodox therapies such as homoepathy, acupuncture and herbalism have been around before the advent of scientific medicine. Most societies have historically been medically pluralistic (Wallis and Morley, 1976). What we are seeing today, however, is a new kind of medical pluralism. People from various backgrounds and socioeconomic groups are choosing to consult CAM practitioners for a range of conditions while at the same time continuing to use medical services. The popularity of CAM therapies has become increasingly widespread since the 1960's, as more and more people in Western societies have developed an interest in using them. In the United Kingdom (Ernst, 1996a; Thomas et al., 1991), in the United States (Astin et al., 1998; Eisenberg et al., 1993, 1998), in Canada (Kelner and Wellman, 1997a; Blais et al., 1997; Millar, 1997; Verhoef and Sutherland, 1995), and elsewhere in the industrialized world (Fisher and Ward, 1994; MacLennan et al., 1996), the use of CAM is clearly on the rise.

This book uses social science research to examine the emergence of this dynamic change in the pattern of health care services. While the mass media have showered an avalanche of attention on non-orthodox therapies and healers, scholarly knowledge has lagged far behind. Some reliable information is being amassed. Epidemiologists such as Eisenberg and his colleagues (1998) and Paramore (1997) have been conducting research on the use of CAM in the U.S. which shows it now to be widespread and extensive. Similar surveys have been done in the U.K., Europe, Australia and Canada. These surveys show that in spite of the insurance for medical services available in many of these countries, people are still choosing to pay (out of pocket) for CAM services. Clinical scientists have also begun to turn their attention to examining why and how CAM influences the state of health. Under the aegis of the Office of

Alternative Medicine now the National Center for Research on CAM (U.S. National Institutes of Health) a series of studies have been initiated to test questions such as the usefulness of acupuncture for treating drug addiction, the efficacy of alternative approaches to pain control and the effectiveness of CAM treatments for cancer. Physicians in some leading North American hospitals are conducting experiments to test the impact of CAM therapies such as therapeutic touch and energy healing on the rate of recovery after surgery. Rigorous tests of efficacy are being conducted in the United Kingdom where researchers are investigating issues such as the utility of acupuncture in the treatment of asthma and the effect of homeopathy on chronic headaches.

The social sciences provide yet another way of understanding the phenomenon of CAM, using the large canvasses of sociology, anthropology and politics as well as the more detailed brush strokes of psychology. In the pages of this book, a multidisciplinary, cross-national group of social scientists apply their research experience and theoretical expertise to building a valid knowledge base. They employ social science concepts and research findings to clarify the social context in which CAM has created such popular interest. This includes explanations of who uses these therapies, why they choose to consult CAM practitioners and how they find their way to their offices. The book also encompasses the key issues of research and policy in response to user demands.

Less developed in the book is analysis of the characteristics, aspirations and motivations of CAM practitioners and physicians who elect to use CAM therapies in their practice. This is because less work has been done in this area to date. In the future social scientists will undoubtedly focus more attention on practitioners and their potential for winning professional recognition and a more central role in the overall health system.

In an environment where so much of the knowledge has been anecdotal and subject to the biases and claims of various camps, this book offers important information, new perspectives and creative models for thinking about a significant social development. The readers of this book can be confident that they will find here a compilation of knowledge and ideas that reflect the work of reputable scholars. Here we lay out some of the most complex questions currently troubling scholars. The first issue we grapple with is the basic question of how to define CAM.

DEFINING CAM

The definition of CAM is open to many interpretations, making it difficult to ensure a common understanding. This lack of consistency is not surprising in a field that has such diverse cultural and historical roots, and is evolving so rapidly. There is confusion about which therapies to include or exclude from

the definition and how to classify the multitude of therapies in some coherent way. There is confusion even about what such therapies should be called – alternative, complementary, holistic, unorthodox, unconventional, non-scientific, and marginal are only some of the many descriptors in the literature. Indeed, the borders between orthodox medicine and CAM are themselves unclear as particular CAM therapies such as osteopathy and chiropractic continue to gain wide acceptance and it becomes increasingly difficult to decide where to place them. Moreover, practices which are considered 'alternative' by the majority of people in Western society, are thought of as conventional and mainstream by people in other societies. As Millet (1999) observes 'The problems of vocabulary and confusion turn out to be problems of history, sociology, and power.' As the field continues to develop, trying to achieve a clear definition of CAM is like struggling to hit a moving target.

The goal, however, must be to find a definition that expresses the essential nature of CAM. The definition must apply fully to all kinds of alternative therapies yet not delineate too broadly or too narrowly. Clarity and care are essential since how the description is framed will influence the choice of data for study. The challenge here is to find appropriate language for description in an area where there is still so much controversy around value conflict and political dominance.

A panel convened by the Office of Alternative Medicine in 1995 to define and describe CAM, struggled with the difficulties outlined here and came up with the following general definition:

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. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting well-being. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed (1997, p. 50).

Such a definition treats both conventional medicine and CAM on an equal footing and avoids negative connotations. It also takes into account the existence of multiple healing systems which have various degrees of dominance and influence in the United States, Canada, Britain and other western societies.

Regardless of how they are defined, it is important to recognize that conventional medicine and CAM tend to operate under very different paradigms of theory and practice. In fact, Kuhn (1970) would probably describe them as

'incommensurate', since they are based on different assumptions. Conventional medicine typically treats disease as a breakdown in the human body that can be repaired by direct biochemical or surgical intervention. The theoretical underpinning is frequently claimed to be rational and scientific. The model on which it is based conceives illness as arising from specific pathogenic agents, and views health as the absence of disease. The concept of CAM, on the other hand, covers a diverse set of healing practices, which do not normally fit under the scientific medical umbrella. Instead, these practices emphasize the uniqueness of each individual, integration of body, mind and spirit, the flow of energy as a source of healing, and disease as having dimensions beyond the purely biological (Berliner and Salmon, 1979). The life force is very commonly seen as a crucial element of the healing process and strong emphasis is placed on the environment, the subjective experience of patients, the healing power of nature, and health as a positive state of being (Goldstein, 1999).

One way to think about the definition of CAM is to see it as a social creation that depends on the perspective of the individual who is doing the defining. For most medical scholars, CAM is defined by its location 'outside accepted medical thought, scientific knowledge, or university teaching.' (Ernst, 1996b; p. 244). In other words, the definition is derived from its differences to the dominant mode of health care which is conventional medicine. But this residual form of definition does not do justice to the healing capacities of CAM. Social scientists like O'Connor (1995) define CAM based on its alternative belief system with its distinctive views of the body, of health, and of the causes of illness. A third way of defining CAM is as a complementary adjunct to medical care. The term complementary implies the possibility of cooperation with conventional medicine and recognizes the widespread research finding that users of CAM also consult physicians on a regular basis (Kelner and Wellman, 1997b). The term alternative highlights the fact that CAM stands on the edges of the established health care system and receives almost no support from the medical establishment or the government (Saks, 1992). This definition points to the political dominance of medicine and its role in controlling research funding, and limiting inclusion of CAM in the basic medical curriculum.

Quoting from Menger (1928, p. 76), Popper (1959, p. 55), reminds us: 'Definitions are dogmas; only the conclusions drawn from them can afford us any new insight.' Each definition is arbitrary; each has its own consequences and requires its own methodological decisions. For the purposes of this book, a composite definition of CAM has been chosen to provide an extensive opportunity to analyze the various forms of health care described here. CAM is conceived as an approach to health care that while different from conventional medicine, is sometimes complementary to it and at other times is

distinctly alternative. The book focuses mainly on patient contacts with CAM practitioners rather than the many informal alternative health care activities that people employ such as use of megavitamins, special diets, folk remedies, herbal supplements and meditation.

Up to now, we have referred to CAM as a homogenous phenomenon. This is misleading, however, since individual therapies vary according to philosophy, terminology, practice, the degree of public acceptance, and the extent of efficacy. There have been several attempts to classify and categorize the various CAM therapies. One of the best known has been developed by Fulder (1996) who proposes a typology of five categories: ethnic medical systems (acupuncture, Chinese medicine and Ayrurveda), manual therapies (chiropractic, reflexology and massage therapy), therapies for mind/body (hypnotherapy, psychic healing and radionics), nature- cure therapies (naturopathy and hygienic methods), and non-allopathic medicinal systems (homeopathy and herbalism).

Here we suggest a different form of classification that arranges CAM therapies according to the context in which they are delivered. The categories are: (1) clinical forms (chiropractic, homeopathy, acupuncture and naturopathy); (2) psychological/behavioural forms (yoga, dance therapy, and biofeedback); and (3) social/community forms (faith healing and folk medicine). Another useful way to classify CAM therapies is based on the extent of legitimacy and public acceptance: (1) top of the hierarchy (osteopathy, chiropractic and acupuncture); (2) middle range (naturopathy and homeopathy); (3) bottom of the hierarchy (rebirthing and Reiki). CAM therapies can be categorized in still other ways; for example, according to the extent of scientific evidence for their efficacy, or whether or not they involve touching patients. The important point here is that these classifications are not permanent; they will continue to shift according to clinical, cultural, political and economic developments. Scholars have to choose their typologies according to the particular questions they are addressing at a given point in time.

What is important is to recognize that CAM is a complex and constantly changing social phenomenon which defies any arbitrary definition or classification. As social scientists design CAM research, it is not necessary or even possible that there be one agreed upon definition.

DESIGNING RESEARCH ON CAM

When social scientists think about research methods, they need first to establish the research question being asked. It is the question rather than the paradigm which should drive the design, data collection and data analysis used in the study. It is worth remembering that we do not live in a single, objective reality; there are various ways of looking at the world. Research questions

emanate from a variety of social contexts and cannot be separated from the environment in which they are situated. This means that in order for research paradigms to be appropriate, they need to reflect the social and cultural setting of the question being investigated.

To date, most social science research on CAM has been based on models of health care which were developed to study peoples' use of medical care. These models make the assumption that people act in rational ways when they make health care decisions. They are also focused exclusively on individuals, thus neglecting the larger social context in which people negotiate their health care options. This approach has yielded reliable data concerning the extent to which people use CAM, their motivations for doing so and something about the nature of their encounters with CAM practitioners. New and different models are needed to open up this research area to other kinds of questions and the use of innovative investigative strategies. This is one of the major purposes of this book.

One such strategy is based on social networks (Wellman, 1988). Network analysis is a technique for mapping the people in an individual's network. It measures the frequency of contact, the closeness of the bonds, and the relationships of the people in each person's network. Network analysis enables social scientists to answer questions such as: who people turn to when they have a health problem, who gives them recommendations to CAM therapies and therapists, and who gives them constructive assistance with their health care. Another perspective, communication research, allows us to explore the diffusion of an innovation such as CAM. This makes it possible for social scientists to chart the rate and extent to which new ideas and practices are adopted by the society at large.

Building on these research strategies, the Network Episode Model which Pescosolido describes in chapter 10, presents a dynamic approach which views all illness behaviours as embedded in day to day life. It includes diverse kinds of health care rather than studying any particular one in isolation. While previous models have been solely based on rational choice of health care, this model also includes a social component. It focuses on the illness episode as a dynamic process, rather than on decision-making about health care at any one point in time. This more inclusive approach views the individual as operating within a multidimensional context of shifting treatment options and service delivery systems. While the Network Episode Model adds depth to current research parameters, it also highlights the need to rethink the concepts and research strategies now being used to examine the use of CAM.

The field of anthropology provides an additional way of conceptualizing health care and in particular, researching the use of CAM as illustrated in chapter 2 by O'Connor. The ethnographic approach to studying CAM relies