



**COMPLEMENTARY AND
ALTERNATIVE MEDICINE**
and
MULTIPLE SCLEROSIS

Second Edition

Allen C. Bowling, M.D, Ph.D.



*Complementary and Alternative
Medicine and Multiple Sclerosis*

Second Edition

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Second Edition

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To my wife, Diana

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Contents

<i>Foreword by Alan J. Thompson</i>	ix
<i>Preface</i>	xi
<i>Organization of Chapters and Reading Sequence</i>	xiii
<i>Acknowledgments</i>	xv
Part 1 <i>Complementary and Alternative Medicine</i>	
Chapter 1: Complementary and Alternative Medicine (CAM)	3
Chapter 2: Placebos and Psychoneuroimmunology	16
Chapter 3: Important Precautions About Complementary and Alternative Medicine and MS	22
Part 2 <i>Types of Therapy</i>	
Chapter 4: Acupuncture and Traditional Chinese Medicine	29
Chapter 5: Allergies	40
Chapter 6: Aromatherapy	43
Chapter 7: Aspartame	47
Chapter 8: Ayurveda	50
Chapter 9: Bee Venom Therapy and Other Forms of Apitherapy	55
Chapter 10: Biofeedback	62
Chapter 11: Candida Treatment	66
Chapter 12: Chelation Therapy	68
Chapter 13: Chiropractic Medicine	70
Chapter 14: Colon Therapy, Detoxification, and Enemas	74
Chapter 15: Cooling Therapy	76
Chapter 16: Craniosacral Therapy	80
Chapter 17: Dental Amalgam Removal	83
Chapter 18: Diets and Fatty-Acid Supplements	87
Chapter 19: Enzyme Therapy	106
Chapter 20: Exercise	110

Chapter 21: Feldenkrais	115
Chapter 22: Guided Imagery	117
Chapter 23: Herbs	120
Chapter 24: Hippotherapy and Therapeutic Horseback Riding	146
Chapter 25: Homeopathy	150
Chapter 26: Hyperbaric Oxygen	156
Chapter 27: Hypnosis	159
Chapter 28: Low-Dose Naltrexone (LDN)	163
Chapter 29: Magnets and Electromagnetic Therapy	165
Chapter 30: Marijuana	170
Chapter 31: Massage	174
Chapter 32: Meditation	178
Chapter 33: Music Therapy	182
Chapter 34: Pets	185
Chapter 35: Pilates Method and the Physicalmind Method	188
Chapter 36: Prayer and Spirituality	190
Chapter 37: Prokarin	195
Chapter 38: Reflexology	198
Chapter 39: Tai Chi	201
Chapter 40: Therapeutic Touch	204
Chapter 41: Toxins	207
Chapter 42: Tragerwork	209
Chapter 43: Vitamins, Minerals, and Other Nonherbal Supplements	212
Chapter 44: Yoga	240

Part 3 *A Five-Step Approach: Integrating Conventional and Unconventional Medicine*

<i>Appendix: Summary of the Effects of Popular Dietary Supplements</i>	263
<i>References</i>	267
<i>Index</i>	277

Foreword

Few areas in medicine raise as much controversy and debate as the use of the wide range of interventions contained under the banner heading of complementary and alternative medicine (CAM). However, it is important from the outset to appreciate that many approaches are grouped under this heading and that they often differ fundamentally from one another. One thing all these approaches do have in common is that they raise great interest and enthusiasm among people with medical conditions, and they are used by many who believe they derive benefit from them.

Taking a more critical view, major differences exist in the quality and quantity of evidence supporting the use of approaches contained within CAM. Furthermore, although such evidence is considered essential by most medical practitioners and those who seek to guide them, it can be less of an issue to those with chronic disabling conditions with no cure and inadequate symptom management. This is precisely the case with multiple sclerosis (MS), a variable condition that may result in progressive disability and cause a plethora of interacting and distressing symptoms. Many of those with MS are prepared to consider any possible remedy, and they certainly want accurate and up-to-date information about all possible therapeutic approaches.

It is, therefore, not surprising that many people with MS have tried at least one (and often many more than one) of the approaches constituting CAM. They require accurate and accessible information, provided in an objective and clear style, to inform and guide their decision to take (or not to take) these treatments. This is precisely what Dr. Allen Bowling has achieved in this comprehensive book on CAM. In his clear and authoritative style, he presents what is currently known on a wide range of potential treatments. He cites evidence where it exists, and discusses treatment options clearly and objectively. His approach is firmly based on his clinical experience and extensive interactions with people with MS. As a result, the book has a clear patient focus. It is an essential resource for people with

MS and for all those who are involved in their care, and it will become an invaluable guide in their joint decision-making.

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Preface

This book was written to provide accurate and helpful information about complementary and alternative medicine (CAM) to people with multiple sclerosis (MS). The term CAM refers broadly to medical approaches, such as acupuncture or herbal medicine, that are not typical components of conventional medicine. Despite the fact that the majority of people with MS appear to use CAM, it may be difficult to find reliable information about the relevance and usefulness of these therapies in MS. Those who practice a therapy or who are selling products may not understand MS or may exaggerate claims in order to make sales. On the other hand, physicians and other health care professionals often have little or no information or experience in CAM and may not have the resources to provide accurate information to their patients. This book was written to fill the information gap in this area.

The first edition of this book was published in 2001. About four years later, I was told by Dr. Diana Schneider and others at Demos Medical Publishing that a second edition needed to be written and that it was “not a big deal” to write a second edition. After my experiences of the past several months, I would respectfully disagree with this statement. In a way, it is exciting that it was a huge task to write the second edition. This indicates that the area of CAM and MS is dynamic and growing, that new research is underway, and that ongoing interest persists in the subject. Certainly, my own experience indicates that people with MS continue to use and be interested in CAM and that MS health professionals are increasingly interested in and open to discussing the subject.

Providing CAM information has many potential benefits. People with MS may realize that unconventional treatment options may offer relief and hope for situations in which limited conventional medical therapies are available. Providing access to reliable CAM information also should allow people to avoid potentially dangerous interactions between CAM therapies and conventional medicine and to distinguish CAM therapies that are

possibly effective, low risk, and inexpensive from those that are ineffective, dangerous, or costly. Finally, it is hoped that the objective information in this book will remove some of the prejudices and misperceptions that are rampant in this area, stimulate serious thought and discussion about CAM and MS, and lead to further study of those therapies that are widely used or appear promising.

This book is divided into three main sections. The first section provides a general introduction to MS and CAM. The second section, which is the main portion of the book, presents detailed information on a large number of CAM modalities. This section is organized alphabetically, which should allow the reader to quickly find information on a particular CAM therapy. The final section includes a chapter that outlines a five-step strategy for integrating conventional and unconventional medicine. At the end of the book, a Glossary of Popular Supplements provides a quick source of MS-relevant information about commonly used supplements.

A large number of references were used to write this book. More than 80 books and more than 2,000 scientific and clinical journal articles were reviewed. The most relevant books and journal articles are listed under an Additional Resources section at the end of the chapters. These resources include technical as well as nontechnical material. In addition, when specific data are mentioned in the text, a numerical reference is given that may be found in a detailed reference section at the end of the book. Most of the books referenced should be available through public libraries, medical libraries, or bookstores. Summaries or abstracts of the journal articles may be found by using Medline searches, available through the website of the National Library of Medicine (www.nlm.nih.gov). The entire articles may be obtained from medical libraries.

Organization of Chapters and Reading Sequence

The second section of this book evaluates many different CAM therapies, which are arranged alphabetically so that they are easy to locate. This arrangement of chapters may be awkward if you intend to read through the entire book. A possibly useful organization and reading sequence is one based on the National Institutes of Health classification for CAM. If this sequence is followed, the structured reading sequence is as follows:

Biologically Based Therapies

- Diets—Diets and Fatty Acid Supplements

- Herbal Medicine

 - Herbs

 - Marijuana

 - Aromatherapy

- Orthomolecular Medicine

 - Vitamins, minerals, and other nonherbal supplements

- Pharmacologic, Biologic, and Instrumental Interventions

 - Allergies

 - Aspartame

 - Bee venom therapy

 - Candida treatment

 - Chelation therapy

 - Cooling therapy

 - Dental amalgam removal

 - Enzyme therapy

 - Hyperbaric oxygen

 - Low-dose naltrexone (LDN)

 - Prokarin

 - Toxins

Alternative Medical Systems

Acupuncture and Traditional Chinese Medicine
Ayurveda
Homeopathy
T'ai Chi

Lifestyle and Disease Prevention

Exercise

Mind–Body Medicine

Biofeedback
Guided Imagery
Hypnosis
Meditation
Music Therapy
Pets
Prayer and Spirituality
Yoga

Manipulative and Body-Based Systems

Massage and Body Work
 Chiropractic medicine
 Craniosacral therapy
 Feldenkrais
 Massage
 Pilates method
 Reflexology
 Tragerwork
Unconventional Physical Therapies
 Colon therapy
 Hippotherapy and therapeutic horseback riding

Energy Therapies

Magnets and Electromagnetic Therapy
Therapeutic Touch

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Many individuals and organizations made this book possible. First, I would like to thank my wife, Diana, for her patience and ongoing support. She offered valuable and provocative insight into the subject of CAM. She created time for me to write and provided free psychotherapy during the more challenging times! I thank our two daughters, Elizabeth and Sarah, for tolerating my time away from home, my time working at home, and for teaching me regularly that in daily life, as in medicine, there are many different perspectives on a given situation. I thank all of my family for tolerating late nights, early mornings, laundry baskets piled high with books and files, and counters and tabletops crowded with papers.

This book would not have been possible without the support of the Board of Directors, as well as Karen Wenzel, Executive Director, and other staff at the Rocky Mountain Multiple Sclerosis Center. Dr. Ronald S. Murray encouraged development of this project in the early stages. Thomas Stewart, J.D., PA.-C., M.S., played an important role by devoting time and energy to the research and by providing creative input. Patricia Kennedy, R.N., C.N.P., and Lee Shaughnessy read the initial manuscript carefully and made valuable suggestions. Research assistance was provided by Lee Shaughnessy, Dr. Ragaa Ibrahim, and Julie Lawton for the first edition and by Kathy Haruf for the second edition.

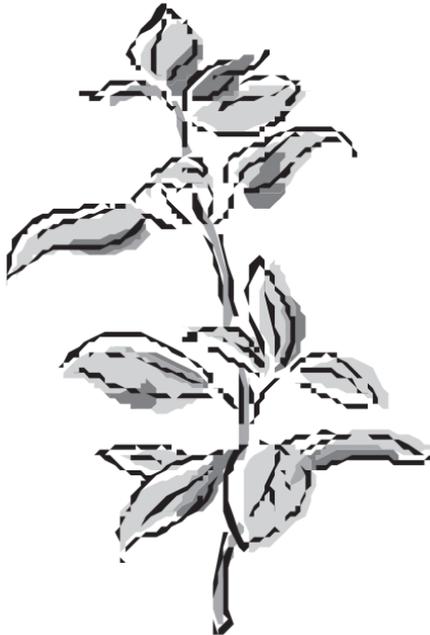
Many of my patients at the MS Center motivated me to write this book. Through my patients, I learned that many were quite devoted to CAM therapies. I realized that I knew little about some of these therapies that obviously were an important component of their health care. I respect my patients for their willingness to openly share their feelings and experiences related to CAM, and I thank them for providing first-hand information that was critical in the development of this book.

I thank the users of www.ms-cam.org, the CAM website of the Rocky Mountain Multiple Sclerosis Center. Users of this website have generously participated in our surveys, which allow us to research the types of CAM

that people with MS are using and determine whether these therapies are thought to be helpful or harmful. The results of many of these surveys are included in this book, have been published in lay and professional publications, and have been presented to lay and professional audiences.

A number of organizations and individuals provided valuable advice, information, and financial or moral support: Therese Beaudette, R.D.; my parents, Dr. Franklin Bowling and Ruth Bowling, R.D.; Scott Boynton, DiplAc, B.Ac.; Dr. Jay Schneiders; Joan Wolk and Edith Barry at Demos Medical Publishing; Doris Borchert at the Medical Library at Swedish Medical Center; HealthONE Foundation; Denver Botanic Gardens; Hudson Gardens. Lastly, I thank Dr. Diana M. Schneider at Demos Medical Publishing for her ongoing support, thoughtful input, and willingness to pursue this controversial subject.

Complementary and Alternative Medicine



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1

Complementary and Alternative Medicine (CAM)

Multiple sclerosis (MS) is a common disease of the nervous system. Most people with MS use some form of conventional medical treatment. In addition, many people with MS also use complementary and alternative medicine (CAM), which refers to unconventional medical practices that are not part of mainstream medicine. Despite the fact that CAM is used frequently and MS is a common neurologic disorder, it may be difficult to obtain accurate and unbiased information specific to the use of CAM for MS.

Before considering the relevance of unconventional medicine to MS, it is important to understand the approach of conventional medicine to this disease. Dramatic advances have occurred recently in the field of MS research. Through scientific studies, we now have an increased understanding of the disease process itself. Also, clinical studies using experimental medications have yielded new therapies that slow the disease process and control MS-related symptoms, such as stiffness or pain.

Who Develops MS?

MS is a common neurologic disease that affects 350,000 to 400,000 people in the United States. Women are diagnosed with the disease about twice as frequently as are men. Although MS may affect people in all age groups, it is typically diagnosed between the ages of 20 and 40 years. A striking relationship exists between the prevalence of MS and the geographic area in which an individual lived during childhood. In general, an individual has a higher risk of developing MS if he or she grew up in an area that is far from the equator and a lower risk if the childhood years were spent near the equator.

How Does MS Affect the Nervous System?

In contrast to many diseases that affect a single part of the human body, MS affects two different body systems: the immune system and the nervous system. The immune system is not a distinct organ like the brain or liver. Instead, it is composed of many different types of molecules and cells (known as white blood cells) that travel through the bloodstream. The immune cells use chemical messages to protect the body from attack by bacteria, viruses, and cancers. MS is believed to be an *autoimmune condition* in which the immune system is excessively active and actually attacks the nervous system.

The *central nervous system* (CNS) is the part of the nervous system involved in MS. The CNS includes the brain and spinal cord. The nerves in the CNS communicate with each other through long, wire-like processes that have a central fiber (*axon*) surrounded by an insulating material (*myelin*). In MS, the immune system cells produce inflammation that injures the myelin. In addition, damage occurs to the axon. This damage is known as *degeneration*, which is the process that occurs in aging-related neurologic diseases such as Alzheimer's and Parkinson's disease. The injury to the myelin and axons results in a slowing or blocking of nerve impulses that prevents the affected parts of the nervous system from functioning normally.

The cause of MS is not entirely clear. It is believed that two important factors are involved in developing the disease, one of which is environmental and the other genetic. The characteristic geographic distribution of MS indicates that an environmental factor is present. One hypothesis is that individuals are exposed to a particular virus during childhood. This viral infection may be more common in cooler climates that are more distant from the equator. Another theory relates the geographic distribution to vitamin D, which mildly suppresses the immune system and thus could be protective against MS. Because vitamin D becomes active with sunlight exposure, those who live farther from the equator (with less-direct sunlight exposure) may have lower levels of vitamin D levels and higher risks of developing MS.

The presence of a genetic factor is suggested by family studies that demonstrate a hereditary predisposition to MS. Some genetic diseases are "dominant" and are clearly passed down through generations. MS usually is not passed on in such a well-defined pattern. Rather, there may exist an inherited predisposition to the disease that must be present in addition to an environmental agent to cause disease. Ongoing, intensive research efforts are aimed at identifying specific genes that increase the risk of developing MS or affect the severity of the disease.

What Symptoms Do People with MS Experience?

The symptoms of MS depend on which areas of the brain and spinal cord develop MS *lesions*. For example, if the nerve that is involved in vision (the optic nerve) develops a lesion, blurring of vision occurs. This is referred to as *optic neuritis*. If a lesion develops in the part of the brain that produces movement on the left side of the body, left-sided weakness develops. In addition to visual blurring and weakness, other common MS symptoms include fatigue, depression, urinary difficulties, walking unsteadiness, stiffness in the arms or legs, tingling, and numbness.

The time course over which MS lesions develop and the number and location of lesions is different for each individual. Consequently, the time frame in which symptoms occur and the specific types of symptoms experienced are unique for each person. Also, as a result of the large variability of lesions between individuals, MS varies greatly in severity. Some people may have rare, mild attacks over their lifetime and may not experience any permanent symptoms, whereas others may develop severe, permanent symptoms over a relatively short period.

MS symptoms may occur episodically or may progress continuously. Episodes of symptoms are known as *relapses*, *attacks*, or *exacerbations*. Usually, some improvement in symptoms occurs after an attack. This improvement is referred to as a *remission*. In contrast to these relapsing-remitting symptoms, some people have symptoms that develop slowly and then progressively worsen over time with no clear remissions. These symptoms are referred to as *progressive*.

Specific combinations of relapsing-remitting and progressive symptoms are the basis for classifying MS. People who experience attacks and then improve have *relapsing-remitting MS*. This is the most common type of MS at the time of diagnosis. Some people who initially have relapsing-remitting disease may subsequently develop progressive symptoms. This is known as *secondary-progressive MS*. People who have exclusively progressive symptoms from the onset of the disease, which is relatively rare, have *primary-progressive MS*, whereas those with *progressive-relapsing MS* have progressive symptoms from the onset (as occurs with *primary-progressive MS*), but also experience intermittent relapses.

Conventional Medical Therapy for MS

Dramatic advances have been made recently in the treatment of MS. In the past, no particularly effective therapies were available to change the course of disease.

Since 1993, six medications for MS have been approved by the U.S. Food and Drug Administration (FDA). Four of these are commonly used as initial MS therapies: interferon beta-1b (Betaseron), interferon beta-1a once-weekly (Avonex), interferon beta-1a three-times-weekly (Rebif), and glatiramer acetate (Copaxone). Mitoxantrone (Novantrone) is a chemotherapy medication that is typically used for people who do not respond to the other four medications. Another MS medication known as natalizumab (Tysabri) was approved by the FDA in 2006. These drugs decrease the number and severity of relapses, slow the progression of the disease, and decrease the development of new brain lesions.

Because of the positive effects of the FDA-approved medications, all people with MS should be strongly considered for treatment with one of these drugs. A 1998 statement by the National Multiple Sclerosis Society emphasized the importance of treatment. The statement recommended that treatment with these medications should be started soon after an MS diagnosis is made and should be considered in all people with MS, regardless of age, rate of relapses, and level of disability.

In addition to these medications, several other medications are used to treat MS. Steroids are used for exacerbations. These may be taken orally (prednisone, dexamethasone) or intravenously (methylprednisolone or Solu-Medrol). Some chemotherapy medications other than mitoxantrone, including methotrexate, azathioprine (Imuran), and cyclophosphamide (Cytoxan), occasionally are used in an attempt to slow disease progression.

Given the wide range of symptoms caused by MS, multiple treatment approaches are possible. Therapies for symptoms include medication-based and nonmedication approaches, such as physical therapy, occupational therapy, speech therapy, and psychotherapy. Common MS symptoms that are treated using these therapies include fatigue, depression, weakness, incoordination, walking difficulties, stiffness, bowel and bladder disorders, and sexual difficulties.

(For more information on conventional approaches to MS, see the other, more extensive texts in this area in the “Additional Readings” section at the end of this chapter.)

Complementary and Alternative Medicine

CAM is a controversial area. In fact, even the term and its definition are not entirely agreed on. In addition to complementary and alternative medicine, other frequently used terms are *unconventional medicine* and *integrative medicine*. The term complementary medicine refers to therapies

that are used *in addition* to conventional medicine, while the term alternative medicine is used to describe treatments that are used *instead* of conventional medicine.

CAM has many different definitions. These definitions frequently state what CAM “is not” as opposed to what it “is.” For example, in the United States, CAM is sometimes defined as medical therapy that is not widely taught at American medical schools or is not generally available in American hospitals. This definition recently has become less clear because unconventional medicine is now part of the curricula of many medical schools and is available in some medical communities. Also, as clinical trials are done to evaluate the effectiveness of CAM therapies, some forms of CAM may eventually become components of conventional medicine.

CAM includes a vast number of therapies. Multiple schemes have been proposed for categorizing these diverse and often unrelated therapies. A cumbersome yet useful CAM classification scheme has been developed by the National Institutes of Health (NIH). This scheme and some representative examples of therapies are:

- Biologically based therapies—Dietary supplements, diets, bee venom therapy, hyperbaric oxygen
- Mind–body therapies—Guided imagery, hypnosis, meditation
- Alternative medical systems—Traditional Chinese medicine, Ayurveda, homeopathy
- Manipulative and body-based therapies—Chiropractic, reflexology, massage
- Energy therapies—Therapeutic touch, magnets

Several studies have documented that CAM is used frequently in the United States. One well-known large study was conducted in 1997 and was reported in the medical literature in 1998 by Dr. David Eisenberg (1). In this study of more than 2,000 people, approximately 42 percent used some form of CAM. It was estimated that 629 million visits were made to practitioners of alternative medicine; this was greater than the number of visits to all primary care physicians in that year. Nearly 20 percent of people were taking some type of herb or vitamin along with a prescription medication. Most people used CAM without the supervision of a CAM practitioner, and most people did not discuss their use of CAM with their physicians. As a result, nearly half of the people were using CAM without the advice of a physician or a CAM practitioner. This demonstrates the need for increased communication in this area between patients and health care providers.

This 1997 study was a follow-up to a previous study conducted in 1990 (2). From 1990 to 1997, CAM use increased by 25 percent, and the yearly visits to CAM practitioners increased by 47 percent. Interestingly, no change was noted in the percentage of people who did not discuss CAM use with their physicians: Approximately 60 percent did not discuss CAM use with their physicians in both studies.

Several U.S. studies indicate that the use of CAM continues to be relatively high and will be high in the future. A large analysis of CAM use in the U.S. was conducted in 2002 (3). In this survey, 50 percent of the general population had, at one time or another, used some form of CAM (excluding two widely used therapies, prayer and exercise). Another U.S. study found that CAM use is not a short-lived fad (4). In this report, CAM use by the age of 33 was evaluated relative to birth date. For those born before 1945, about 30 percent of respondents used CAM. The percentage of CAM users rose to about 50 percent for those born between 1945 and 1964, and was even higher, about 70 percent, for those born between 1965 and 1979. This study also found that nearly one-half of people who tried a specific form of CAM continued to use that CAM therapy more than 20 years later. Overall, this study indicates that CAM is not a short-lived phenomenon because some CAM therapies are used long-term and CAM use in general is higher among younger people.

Several studies of the general population have identified certain characteristics of CAM users. CAM use tends to be higher in women and in those who have conditions that lack definitive cures, have unpredictable courses, and are associated with discomfort, pain, and side effects from prescription medications. Because these are characteristics of MS and people with MS, these findings suggest that CAM use may be more prevalent in people with MS than in the general population.

CAM Use in MS

Several studies have evaluated CAM use in MS. One of the earliest studies was conducted in Massachusetts and California in the 1990s (5). Approximately 60 percent of people had used CAM, and, on average, people used two to three different types of CAM. We conducted a similar survey, in 1997, at the Rocky Mountain Multiple Sclerosis Center and found that approximately two-thirds of those who responded to the survey used CAM.

Several subsequent studies have investigated CAM use in people with MS. If one evaluates the results of various U.S. studies of CAM use among people with MS, and if one uses a definition of CAM that includes therapies

that have ever been used and excludes two widely used therapies (prayer and exercise), 50 to 88 percent of people with MS have used CAM (5–9). As noted previously, a 2002 study of the general population in the U.S., using a similar definition of CAM, found that 50 percent of people use CAM. It is difficult to compare studies with such different methodologies. However, rough comparisons of these various studies indicate that the use of CAM in people with MS appears to be similar to or somewhat higher than that in the general population.

A different type of study, reported in 1999, examined visits to CAM practitioners by people with MS (10). This study did not evaluate overall CAM use and, of note, most people who use CAM do not visit a practitioner. CAM practitioner use in this study, which was about one-third, was higher than the rate of about 10 percent reported for CAM practitioner use in several studies of the general population done during the 1990s.

The use of CAM among people with MS does not appear to be an American phenomenon. Studies of other countries indicate similar results for the percentage of people with MS who use CAM: 82.5 percent in Australia, 70 percent in Canada, 27 to 55 percent in Denmark, and 41 percent in Spain (11–14).

In surveys of people with MS and of the general population, a consistent finding is that CAM usually is used in conjunction with conventional medical therapy. In other words, CAM usually is used in a complementary way. Approximately 90 percent of people who use CAM also use conventional medicine. This leaves a relatively small fraction of people who use CAM in a truly alternative manner.

It is sometimes erroneously believed that only two preference groups for medical therapy exist: one group that uses only conventional therapy and another group that uses only CAM therapy. In fact, a third “mixed” group combines conventional medicine and CAM. Of importance, the studies of CAM use in people with MS demonstrate not only that this “mixed” group exists but also that it actually appears to represent the majority of people with MS.

With a large number of people with MS pursuing CAM therapies, it is essential for people to be knowledgeable about the therapies they choose and for physicians, other health care providers, and CAM practitioners to be aware that multiple conventional and CAM therapies are in use and that interactions among them are possible.

People with MS use a wide range of CAM therapies. Those that appear to be especially popular include massage, dietary supplements, diets, chiropractic medicine, acupuncture, meditation and guided imagery, and yoga.

The reasons why people with MS pursue CAM are as varied as the different CAM modalities used. “Curing MS” is not a frequently cited reason for using CAM. Common reasons include decreasing the severity of MS-associated symptoms, increasing control, improving health, and using a method that accounts for the interrelation of mind, body, and spirit. Some people are drawn to CAM because of the lack of effectiveness of conventional medications and anecdotal reports of benefits or recommendations from friends, relatives, or physicians (5,8,12). One study of CAM use in people with MS and other chronic diseases concluded that CAM was an important component for self-care and was not generally embraced as a rejection of conventional medicine or an unrealistic search for a cure (15).

Some characteristics have been reported more frequently in those with MS who use CAM. These include being female, having a lower level of health, and being more highly educated. One recent study also found that people who used CAM were less likely to use one of the FDA-approved MS medications and were more likely to have a lower level of physical well-being (9).

Information About CAM and MS

For CAM in general, the information available to the general public is vast but of variable quality. For CAM that is relevant to MS, the amount of information is limited and the quality also is variable. To attempt to understand the type of information that is available on CAM and MS, we conducted an informal survey of the popular literature on CAM at the Rocky Mountain Multiple Sclerosis Center. At two local bookstores, we found 50 CAM books written for a lay audience. Two-thirds of these books had sections on MS. In some books, MS was incorrectly defined as a form of muscular dystrophy. Other books made the erroneous—and potentially dangerous—statement that, because MS is an immune disorder, it is important to take supplements that stimulate the immune system. In fact, MS is an immune disorder, but it is characterized by an excessively active immune system; thus, immune-stimulating supplements actually may be harmful. On average, the CAM books recommended five or six therapies for MS. In 20 percent of them, 10 or more therapies were recommended. It was rare for books to discourage the use of any CAM treatment. Interestingly, none had the same recommended therapies. In general, therapies that are used more frequently by patients appear to be those that are recommended more often in books; the fact that this information contains inaccuracies is therefore troubling.

In addition to books, information about CAM can be obtained from vendors of products and CAM practitioners. Unfortunately, product vendors, such as people who sell supplements, often exaggerate claims about their products. Practitioners of CAM (as well as product vendors) sometimes have limited experience with MS and are not certain how their therapy relates to such a specific and complex disease process.

Physicians and other mainstream health care providers are another potential source of information about CAM. Unfortunately, this group generally is not trained or experienced in CAM use and, for a variety of reasons, often is reluctant to become involved in this area. Even for conventional health care providers who are interested in CAM, only a limited amount of objective and accessible MS-specific information is currently available in the medical literature.

People with MS are “Caught in the Middle”

Many people with MS pursue some form of CAM but may not readily be able to obtain objective and practical information. They may seek out CAM books, products, or practitioners, but find that MS is not specifically addressed or that claims of the effectiveness of the therapy are exaggerated. On the other hand, they may attempt to obtain CAM information from their physician or other health care provider and find that little or no information is available. In this way, pursuing CAM can be frustrating and confusing for people with MS.

A Website Focused on CAM and MS

This book was written to provide objective, MS-relevant CAM information to people with MS. Also, because the area of CAM is changing rapidly, we developed a website devoted to CAM and MS at the Rocky Mountain Multiple Sclerosis Center. This site, www.ms-cam.org, is updated regularly and has interactive features. This site has several missions:

- To create a worldwide community of people interested in CAM and MS
- To provide accurate and unbiased information
- To allow users to discuss their experiences with CAM through threaded discussions
- To conduct surveys to assess the effectiveness and safety of CAM therapies for people with MS

A Matter of Perspective

CAM is controversial for many different reasons. One important issue to keep in mind is that of *perspective*. Because of differences in perspective, mainstream health care providers and people with a disease may view the same set of facts differently.

Physicians view the use of basic science and rigorous clinical trial methods as a powerful tool to develop new disease understanding and new therapies. People with MS may believe that this process is powerful, but that it is also slow and may yield limited advances during their lifetimes.

The “gold standard” for developing new therapies is a randomized, controlled clinical trial. This clinical testing employs specific and rigorous methods, including the use of a placebo-treated group, “blinding” of patients and investigators (so that neither patients nor investigators know who has received placebo and who has received active medication), and randomly selecting those who will receive placebo or active medication. Physicians and other mainstream health care providers generally use therapies only after they have been found to be effective in these well-designed clinical trials. Through this process, a black-and-white distinction exists between those therapies that have been proven effective in clinical trials and those that have not.

Some of the interest in and controversy over CAM stems from the fact that there may not be such a black-and-white distinction, but rather shades of gray. For example, some therapies have not undergone rigorous large-scale clinical testing, but scientific studies in animals or small clinical studies in people have produced promising results. These types of therapies generally are not incorporated into mainstream medicine. However, people with a disease may have an interest in such promising therapies, especially if they are relatively safe and inexpensive.

Another difference in patient–physician perspective is apparent with proven mainstream therapies. Conventional medications that are 30 to 40 percent effective may represent a major advance for physicians and other health care providers but, for people with MS, these therapies may be seen as 60 to 70 percent away from a cure (which would be 100 percent effective).

In some areas of CAM, the same set of facts is viewed negatively by conventional medicine and positively by some people with MS. This emphasizes the importance of first establishing the facts about a therapy and then realizing that these facts may be interpreted differently by mainstream health care providers and people with MS. Under some circumstances, it is as if two different cultures exist: that of the health care provider and that of the person who has the disease. These two cultures may have strikingly different belief systems.

The difference in perspective becomes especially apparent when a physician develops a disease. In this situation, a dramatic shift may occur in an individual's attitudes about what constitutes an appropriate medical therapy. There have been several published examples of this shift in perspective.

Dr. Alexander Burnfield, an English psychiatrist who has MS, wrote a book entitled *Multiple Sclerosis: A Personal Exploration*. With reference to evening primrose oil, he states: "I started taking it before the research was published and, being only human, take it just in case I get worse if I stop. This is, I know, an unscientific and emotional response, and the logical-doctor part of me is quite shocked" (16).

Dr. Elizabeth Forsythe, also an English physician with MS, wrote *Multiple Sclerosis: Exploring Sickness and Health*. With reference to diet and MS, she states: "It is what you feel in your own body and mind that is the most important thing, and it is very easy for doctors and patients to forget that. I believe that a little of what you fancy does do you good!" (17).

In *Healing Lessons*, Dr. Sidney Winawer, chief of gastroenterology at Memorial-Sloan Kettering Hospital in New York City, gives a provocative account of his transformational experiences with CAM through his relationship with his wife, who pursues various unconventional and unproven cancer therapies. He writes: "I failed to see that Andrea's cancer, of all things, would wake us up. I knew least of all that my beliefs as a doctor were about to be turned upside down" (18). He also begins to view therapies from a different perspective: "I shared her conviction that uncertain hope was better than hopeless certainty" (19).

A Unified Perspective

Should we abandon these mainstream methods because basic science research has not fully elucidated the cause of MS and clinical trials have not developed a cure? NO. These methods of conventional medicine provide the greatest hope for understanding and curing MS. The difficulty is that MS is a complex disease, and an uncertain amount of future work is needed.

Should we acknowledge that areas of CAM exist that may be of interest to people with MS because conventional medicine does not have a cure for MS? YES. It is a disservice to people with MS who have an interest in CAM to not acknowledge that these therapies exist. Part of this acknowledgment should involve providing accurate information. By focusing more attention on CAM, we may actually develop a new understanding of the disease process and perhaps discover new therapies.

It is possible to simultaneously acknowledge, respect, and use conventional medical therapy and CAM therapy. This dual approach is a way to bring together the sometimes disparate views of mainstream health care providers and people with MS.

Additional Readings

Websites

www.ms-cam.org. CAM website of the Rocky Mountain Multiple Sclerosis Center

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