

MINDFULNESS-BASED ELDER CARE

LUCIA McBEE, LCSW, MPH, is a geriatric social worker who has worked with elders and their caregivers for 27 years. For the past 13 years she has integrated mindfulness and other complementary therapies into her practice with frail elders in the nursing home and those who are homebound; elders with cognitive and physical challenges; patients at the end of life; and their formal and informal caregivers. Her work has been published in peer-reviewed journals and presented at national and international conferences.

Mindfulness-Based Elder Care

*A CAM model
for frail elders and their caregivers*

Lucia McBee, LCSW, MPH

 **SPRINGER PUBLISHING COMPANY**
NEW YORK

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Springer Publishing Company, LLC
11 West 42nd Street
New York, NY 10036
www.springerpub.com

Acquisitions Editor: Sheri W. Sussman

Production Editor: Rosanne Lugtu

Cover design: Joanne E. Honigman

Composition: Apex Publishing, LLC

07 08 09 10/ 5 4 3 2 1

Library of Congress Cataloging-in-Publication Data

McBee, Lucia.

Mindfulness-based elder care : a CAM model for frail elders and their caregivers / Lucia McBee.

p.; cm.

Includes bibliographical references and index.

ISBN 978-0-8261-1511-9 (alk. paper)

1. Frail elderly—Diseases—Alternative treatment. 2. Frail elderly—Nursing home care. 3. Alternative medicine. 4. Meditation. 5. Caregivers. 6. Mind and body. I. Title.

[DNLM: 1. Frail Elderly. 2. Health Services for the Aged. 3. Caregivers.

4. Communication. 5. Mind-Body Relations (Metaphysics) 6. Professional-Patient Relations. WT 31 M4778m 2008]

RC953.8.A48M23 2008

362.16—dc22

2007045872

Printed in the United States of America by The Edwards Brothers, Inc.

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For my mother
Mary Louise Haskell
Who continues to teach me about aging with creativity,
awareness and courage.

For my father
Weston Bradford Haskell, Jr.
Who taught me about dying with wit, wisdom and grace.

For my children
Cary Paul and Louisa McBee
Who light up my life.

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Foreword

Each one of us is growing older moment-by-moment; how might we live this season of our life more fully? As a society, will we make the commitment to escorting with dignity, high regard, and honesty those among us growing old? To do so, something will have to change. Most probably, as a starting point, our collective denial of old age will have to go—no matter our age or socioeconomic status, what generation we inhabit, or what ideas, opinions, and dogged fantasies we entertain about ourselves, our lives, our health, and our longevity.

Unearthing and slowly dissolving this denial is never easy. It is said that when the historical Buddha, sheltered and extremely protected as a young prince, finally came face to face with sickness, old age, and death, he was struck so hard by his recognition of the human condition's underbelly that any remaining semblance of safeguard from the world's suffering was irrevocably shattered. In its place a radical acceptance—a seeing of things just as they are—dawned, and his long journey toward the release from his and our undue suffering began. Twenty-five-hundred years later, we remain beneficiaries of this stunning recognition and the restorative, healing forces set loose by such clear seeing, unwavering attention, and compassion. While colored in various shades by the diverse palettes of culture, context, and time, the liberating affirmation of the inborn genius and luminosity of human beings is ubiquitous and universal. It is the hallmark of all visionary activity, as true of the Buddha as of Martin Luther King, Jr.; of Jesus as of Gandhi; of Nelson Mandela as of Ahn Sang Su Chi; of you as of me.

Now, with kindred recognition and lucidity, Lucia McBee sets before us the lived reality faced by too many of our elder folk: isolation, alienation, frailty, and the looming shadow of dementia. No matter what our occupation or age, we are all heading in this direction. How shall we approach this reckoning?

Who will provide us with a path, a way of working with ourselves, in the good company of others, when our time arrives? As caregivers—and most of us are in one capacity or another—how shall we work with people already wading deep into this stream? What if as a society we collectively begin asking ourselves questions like these: What abilities do elders actually possess? What stereotypical views do we persist in holding onto about old people? How do these preconceptions shape our willingness to work with them? Is it possible to honor and invigorate the innate resources of people who are living into their ninth or tenth decade? And if to this final question we answer “yes” or “I don’t know,” we will likely wonder if anyone has cleared a path through this forest before us and if they have left blaze marks on the trees for us to follow.

Lucia McBee has left such marks. You are holding them in your hands, but you will have to enter the forest with her to read the signs and know. There is no other way. This is Lucia’s path. As her longtime colleague and friend, I have watched and respectfully admired her unfolding work. Fifteen years into this effort, she is brave, humble, and wise enough to now share some portion of her passionate, clear-eyed journey with us. She began her journey by wondering and asking herself questions; it is palpably clear that her asking is ongoing. It is alive and vital, essential and innovative. Her presence and aliveness make the contents of this book attractive and compelling, startling and unsettling. Gently yet persistently, she asks nothing less of us than our willingness to look unwaveringly at growing old and at our work and relationships with those walking this path ahead of us. Lucia has explored this terrain; in her beautifully crafted account we have the great good fortune to be offered her experience, growing understanding, and yet unanswered questions.

While you now know that Lucia’s primary work has been with elders, what is absolutely unique about this book is that she has fused and infused her life and work with the practice of mindfulness and mindfulness meditation and the principles, practices, and attitudinal foundations of mindfulness-based stress reduction. Forged and tempered in the crucible of nursing homes and other elder care facilities, it is evident that Lucia has been *transformed*. Now, she shares with us her gold—the conception, trial-and-error implementation, and initial scientific investigation of a new, educationally oriented treatment approach that she has named mindfulness-based elder care.

This book is her *transmission* to us—a direct line into our hearts and minds, bodies and souls—made possible because she has kept her heart’s ear to the rail and reveals to us the sounds of this intimate listening and the actions that have risen out of such heartfelt and thoughtful lingering. She has labored in

love, holding close to her heart our Old Ones. Returning the gesture, they have broken open Lucia's heart, thereby releasing her enlivening genius. We are all better for this. I have been shaken and stirred by Lucia's unbending intention, enduring commitment, and pioneering vision. I trust that you will be, too.

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Preface

After I started writing this book I decided to go into a very large bookstore in mid-Manhattan to view other books on the subject of aging. I asked the salesperson to direct me, and she brought me to the section entitled “Disease.” She then pointed out the small selection on Aging—in between Acne and Alzheimer’s. These few books were titled *Overcoming Aging* or *Anti-aging*. I was taken aback, having just passed through an immense section devoted to pregnancy, childbirth, and raising children. In time, this same depth and variety of information on aging will be available. I look forward to returning to this bookstore and finding that aging resources are no longer in the Disease section. This book will be a part of this literature. I write it for elders, those who care for elders, those who care about elders, and those who will be elders.

Our culture is in widespread denial of aging. This denial has personal and social consequences as the over-65 population explodes and baby boomers turn 60. We are living longer, but with more chronic disease and disability. Our health care system, excellent with crises, is not designed to care for people with chronic, long-term illness. Nursing homes are the second most regulated industry in this country (nuclear power plants are first), and yet, most consumers find them inadequate at best.

Health care professionals in all settings and contexts have begun to question the way care is provided. Professionals and consumers are integrating Complementary and Alternative Medicine (CAM) with more conventional health care. Nursing home pioneers are advocating drastic changes in traditional models—a “Culture Change.” CAM and Culture Change programs and innovations cannot be viewed as supplements; the core foundation needs to be reconsidered. Multiple initiatives are called for; Mindfulness-Based Elder Care is one.

Mindfulness-Based Elder Care (MBEC) conveys the benefits of meditation, gentle yoga, and mindfulness—accessibly—to frail elders and their caregivers. Elders often cope with trauma, loss, disability, pain, and life-threatening illness. Professional and family caregivers also suffer. Focusing on abilities, not disabilities, mindfulness practices provide paths to the inner strengths and resources we all possess.

In 1994, I began holding mindfulness courses and groups for nursing home residents and caregivers in a large, urban, multiethnic, multifaith nursing home. These programs were inspired by and modeled on Mindfulness-Based Stress Reduction (MBSR), developed by Jon Kabat-Zinn in 1979, at the University of Massachusetts Medical Center. Mindfulness is a way of being, focusing attention on our life with naked awareness and compassion. In MBEC, I have adapted Kabat-Zinn's model to elders, their families, and professional caregivers.

Some of my readers may have experience with mindfulness, yoga, and meditation; to others, these practices may be new and, even, foreign. I have written the book for readers with all levels of experience. In it, I share what I have found to be useful in my personal experience with elders and their caregivers. The book also contains frequent opportunities and suggestions for personal experience.

When I started working in a nursing home 16 years ago, I began to wonder if there wasn't more that could be done for residents suffering from physical pain and emotional distress. One of my first clients was Mr. S. He was in the nursing home because of osteoarthritis, which caused him severe pain and an inability to care for himself. When we met, he grimaced if he had to move his hand from the arm of his wheelchair to his lap. He told me how much it hurt. Sometimes, I asked the nurse for more pain medication for him. The nurse would say, "He just had his pain medication; he is not due for more for two hours." I sensed a frustration on her part and that of the doctor when I asked what more could be done for Mr. S's pain. I also felt frustrated and saddened. This discontent, in part, motivated my journey, which I share with you in this book.

Acknowledgments

If books were able to have a godmother, this book's godmother would be Victoria Weill-Hagai. Victoria followed this work from its inception. She consistently encouraged me to write, nurtured my writing voice, edited the material in a way that made it clear and direct, and supported me in ways too numerous to iterate. She saw the diamond in the rough and helped me polish it. Thank you, Victoria.

Sue Young offered skillful feedback, encouragement, and wisdom from the perspective of a mindfulness practitioner and teacher. In the practice of writing this book, Sue has been my instructor, compassionately observing a judging tone, a goal-oriented reference, or an unmindful drift.

This book describes the challenges of aging and of working with elders. I sincerely hope that I have also conveyed the joy of working with elders and their caregivers. Everything I needed to learn, I learned in nursing homes. While the failings of institutional nursing homes are well known to the general public, I have witnessed remarkable kindness, everyday heroism, resilience, and resourcefulness embodied in the people who work and live there. Thank you, my teachers.

I also wish to thank my prereaders and those who have contributed to this book, and to the development of Mindfulness-Based Elder Care. Dr. Jenny Walker provided advice and insight on the sections relating to medical care. Amy Lombardo enhanced the writings on yoga and wellness in the nursing home with her thoughtful additions. Beth Roth developed and generously passed on the anger continuum, forgiveness meditation, midway review, and leadership in bringing mindfulness to underserved populations. Luis Sierra shared his skillful practices working with elders with dementia, and contributed to the handouts. Meg Haskell offered insights on the reality of working in nursing homes and feedback on this book. Diana Kamila provided initial direction on the use of humor, and she always makes me laugh. Elana Rosenbaum, a pioneer in her life and work, contributed inspiration and ideas on applying mindfulness practice creatively. Joyce Hitchcock shared her story on the use of music to connect. Dr. Gary Epstein-Lubow commented on and analyzed results of the Caregiver Mindfulness Group. Joan Griffiths-Vega shared observations and anecdotes on caregiver MBSR groups. Sarah Bober,

Sarah Segal-McCaslin, and Liz Arnone, among other social work students extraordinaire, kindly shared their remembrances of creative interventions they employed. Thanks to all, and also to Sheri W. Sussman and Alana Stein, my insightful editor and her attentive assistant.

My Sangha, if you see and hear yourself in this book—you are! Each one of you has educated and inspired me with your consistent openness to growth and possibility, laughter and joyfulness, intimacy and integrity.

The practices of mindfulness, as developed and taught by Jon Kabat-Zinn, have provided instruction and guidance for my work and my life. The Center for Mindfulness in Medicine, Healthcare and Society, now under the astute custody of Saki Santorelli, continues to be a beacon of light, expanding our vision of how we live and how we heal. And thank you, Saki, for your consistent personal encouragement.

I, and so many others, are indebted to the pioneers who care for elders and the disabled—those who do not accept the status quo, envisioning and advocating new ways of caring: the Pioneer Network, Eden Alternative, Paraprofessional Healthcare Institute, the Zen Hospice, the Spiritual Eldering Institute, and l'Arche.

During my journey I have not been alone or first. Rev. Fanny Erickson, whose leadership in establishing a Wellness Center at the Riverside Church served as a model for the incorporation of body, spirit, and mind in healing practices. Dr. Polly Wheat, who invited me to expand my teaching practice to a younger population and demonstrated the true integration of health care and mindfulness at the Barnard College Health Center. Dr. James S. Gordon, founder of the Center for Mind-Body Medicine, who wisely advised me “to start with the caregivers.”

At the Jewish Home and Hospital in Manhattan, I was privileged to work with many fine professionals, and their input into the development of this body of work has been invaluable. My initial social work mentor, Dr. Pat Kolb, also inspired and encouraged me to write. My first co-leader of mindfulness groups was Dr. Eric N. Buchalter. Dr. Melinda S. Lantz supported, initiated, and contributed to CAM interventions and was co-primary investigator on two grants described in this book. Lisa Westreich and Antonios Likourezos co-led and researched results of mindfulness groups, respectively. At the Jewish Home, Audrey Weiner and Deirdre Downes promoted innovation in care for both residents and caregivers. And I am most grateful to Frances Brennan, my supervisor for many years, who said “yes” to my idea of running meditation groups for nursing home residents.

Wise and capable teachers have nurtured my path. I attended retreats at Vipassana Meditation Center under the teaching of S. N. Goenka and his assistants. While they created a solid foundation for my personal meditation

practice, the methods described in this book are not intended to replicate these teachings. My yoga practice is informed by the Anusara and Iyengar methods taught by Rudrani Farbman and Rama Nina Patella, and more recently, by Amy Lombardo. I am also grateful to Russill Paul for teaching me the yoga of sound and movement. From afar, I have benefited from the writings and teachings of Ram Dass, Jack Kornfield, Sharon Saltzman, Joseph Goldstein, Bo Lozoff, and Stephen Levine.

I have been fortunate to have Sarah Haskell, Weston Haskell, and Amy Kramer as siblings and co-caregivers who consistently demonstrate a collaborative and loyal family network. Family and friends, whose names are spoken here and unspoken, your support and encouragement has meant more to me than you could know.

May the fruits of my practice benefit all beings.

SECTION I

Foundations

CHAPTER 1

A Box for Father: Health Care and Nursing Homes

A FABLE

A man lives on a small farm with his wife, son, and father. His father was once a productive farmer, but now is frail and cannot work. In addition, he requires some care, disrupting the farmer's wife from her other duties. So, the farmer decides to build a box, put his father in it, and throw it over a cliff. He builds the box and puts it on a wheelbarrow. He asks his father to get in, and wheels him to the edge of the cliff. When they arrive, his father gets out of the box. His son asks, "Why are you getting out of the box, old man?" The father replies, "I will not waste this box on me, I can go over the cliff myself, and you can save the box. Your son will need it for you someday." On hearing this, the farmer changed his heart and brought the old man down the mountain. He took care of him kindly the rest of his life.

How we treat our elders matters. Aging is a part of life. And if you don't like the certainty that your body will wear out—consider the alternative. Unique to current generations is the longevity that medical advances and improved conditions have provided. People are living longer even in developing countries. These changes present us with distinct opportunities and problems. Caring for elders has its own history and can be viewed in the context of health care provision as a whole.

WHAT IS HEALTH CARE?

What does *health care* mean, and how should it be provided? The definition is not static; it changes as we change our philosophy of how we care for or

identify those in need. Traditions of healing have been documented as an integral part of all civilizations. Ancient Chinese, Indian, and Grecian cultures viewed both the mind and the body as playing roles in illness and healing. Religion, creativity, and medicine were not considered separate until after the Industrial Revolution. In 18th- and 19th-century Western cultures, illness was treated at home by family, neighbors, local doctors, or midwives. With the discovery of antibiotics in the early 20th century, concepts of illness and treatment shifted. As medical knowledge and technology grew, health care provision moved from home to hospital. Many began to view illness as solely a physical problem, and treatment as unrelated to the mind or the spirit. Medical experts cured acute illnesses. Specialties emerged. Nursing homes offered “nursing” care for chronic or incurable illness, and for frail elders who, generally, were without family support. Healing not endorsed by Western medicine was considered risky or, at best, ineffective.

This model has been the trend in Western health care until recently. Culture and norms are not static; they are always in transition. Usually, we envision the way things are as the way they should be. It is hard to imagine things being different. Fortunately, when we realize that some alteration must happen and that the old way of functioning is limited, the need to change surpasses the challenges inherent in the change process.

SCENARIO

You are visiting your 75-year-old healthy parents. Your father suddenly looks pale, clutches his chest, and falls. You call 911. The medics arrive, begin emergency treatment, and transfer your father to a nearby hospital. An emergency room doctor meets you there. She tells you that your father probably had a heart attack and may have also broken his hip when he fell. She assures you that everything possible will be done. You are very grateful for the hospital and the medical professionals. This is contemporary, conventional medicine at its best. Your father survives the heart attack, but, unfortunately, he does not return to his previous level of functioning. He needs help with his basic needs: bathing, eating, toileting, and rehabilitation. Your mother cannot take care of him, and he is transferred to a long-term care facility. The nursing home looks like a hospital. Your father is brought to a shared room. He is transferred to his new bed and told to wait there until the doctor can check him out. The move increases your father's agitation, and he tries to get out of bed. The staff continue to tell him to stay in bed, and he begins to yell. Your family, already distraught by the placement, sees their worst fears come true. If your father continues to behave this way, you are told, he may have to be given medications to calm him down, or to be restrained temporarily. It is contemporary conventional medicine at its weakest.

Acute care provided by conventional medicine is lifesaving and can provide important relief to patients and their families. Care for patients with ongoing chronic conditions, however, has been inappropriately modeled on acute care and often increases the suffering and distress of patients and their families. Recently, new models of providing relief for chronic conditions have evolved. These models are presented under the category of complementary and alternative medicine (CAM), and (for nursing homes) Culture Change. Both acute and chronic care models are important in meeting today's health care needs. It is helpful to see these models not as exclusive, but as partners to be utilized appropriately.

THINK ABOUT THIS

What have you found helpful, or not, in health care services you have experienced; what have you found helpful, or not, in services as a caregiver? What would you like for yourself? What would you like for your dear ones? How is it different from or the same as your experiences? What would you change?

Health care is more than an abstract theory, it is a service that has or will impact all of us. We all interact with the health care system—in clinics, doctor's offices, hospitals, and nursing homes. We also interact with health care professionals who care for us and those we love.

TRENDS IN AGING AND HEALTH CARE

The population is aging worldwide, and living longer with more chronic illnesses and conditions. Increasing birth rates, lower infant mortality, and declining death rates have led to estimates that the aging population will continue to grow. In 2001, the world's population of people 65 and older was growing by almost 800,000 a month, and those over 80 years old were identified as the fastest-growing segment (Kinsella & Velkoff, 2001). While elders are living longer, they are also more prone to chronic problems, both physical and cognitive. In the United States, 80% of the over-65 population is living with at least one chronic condition and 50% have two (Centers for Disease Control and Prevention, 2003). Internationally, studies document that dementia affects 1 in 20 people over the age of 65 and 1 in 5 over the age of 80. Currently, an estimated 24 million people are diagnosed with dementia; by 2040 the number will have risen to 81 million (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). These statistics suggest significant changes will need to be considered in the way health and health care are viewed and implemented. Kinsella and Velkoff (2001) suggest that "health expectancy" will become as

important a measure as life expectancy is today. In Western countries, the baby boomers, a cohort known for its impact on culture in the 1960s, are now turning 60. It is anticipated that this group will expect, perhaps demand, changes in the ways health care is provided. The convergence of these trends has led many health care leaders to consider alternative, complementary healing: a more holistic approach.

Nursing Homes

With improved medical care, elders began living longer in the United States, but many lived past their ability to work and be self-supporting. Initially, elders who could no longer sustain themselves and had no family went to the almshouses. There, they lived with orphans, mentally and physically ill adults, the homeless, and others unable to care for themselves. Religious organizations established facilities to care for the “worthy” elders, those of their own faith (Haber, 2006). Eventually, nursing homes expanded, offering care that followed a model of hospital acute care. This model of nursing home care has been regulated and standardized, in large part due to attempts to minimize cost and avoid abuse. More recently, advocates for change have proposed alternatives to the standardized, medical model of care.

WHAT ARE THE ALTERNATIVES?

Complementary and Alternative Medicine (CAM)

The belief in the connectedness of the mind, body, and spirit is common to Eastern, ancient, and traditional cultures. Western medicine, and the philosophy behind it, is unique in its approach and treatment of these elements as separate and unrelated. Recently, however, this trend has shifted.

All healing systems, practices, and products that are not considered to be part of current conventional medicine fall into the category of Complementary and Alternative Medicine. CAM can be used *with* (complementary) or *in the place of* (alternative) conventional medical treatment. There is an extensive range of treatments under this rubric. A 2005 survey by the Institute of Medicine listed 100 CAM therapies, practices, and systems. Despite initial adverse reactions from some medical professionals and institutions, the inclusion of CAM in Western settings is increasing. Patients, residents, and their families are “voting with their feet” and choosing CAM treatments in addition to acute-care interventions (AGS Panel on Chronic Pain, 1998; Eisenberg et al., 1993; Ness, Cirillo, Weir, Nisly, & Wallace, 2005). In 2002, the National Center for Complementary and Alternative Medicine (NCCAM) found that 62% of U.S.

health care consumers already use some form of CAM, most often vitamins or prayer.

Older adults are even more likely to use CAM. One study found that 88% of those over 65 years old questioned in a large survey used CAM (Ness et al., 2005). Another noted that being age 40–64 was associated with highest rates of CAM use (Tindle, Davis, Phillips, & Eisenberg, 2005). Professionals in hospitals, clinics, and nursing homes recognize this desire and have increasingly added CAM services. They are generally low risk and low cost. In addition, CAM modalities appeal to diverse populations, reflecting international cultural traditions.

CAM models and interventions have fallen into the following categories as defined by the National Institutes of Health's Complementary and Alternative Medicine Program:

- Alternative medical systems
- Mind/body interventions
- Biologically based therapies
- Manipulative and body-based methods
- Energy therapies

Alternative medical systems fundamentally differ from the “diagnose and treat” model of Western medicine. Ancient alternative systems include Indian Ayurvedic medicine, traditional Chinese medicine, and homeopathy. *Mind/body interventions* incorporate meditation, prayer, and cognitive and creative therapies. *Biologically based therapies* use herbs, vitamins, and food. *Manipulative therapies* comprise massage and chiropractic medicine. *Energy therapies* include Reiki, chi gong, and magnetic fields.

ASK YOURSELF

In choosing a health care provider or institution, would you want one that only offered one modality—conventional treatments—or would you want to be offered a range of options that include a spa, massage, tai chi, and aromatherapy? Do you already use vitamins and prayer; do you exercise, meditate, or use other practices that are considered “alternative”?

Culture Change

Within nursing homes, the model of care is also shifting. Traditionally, nursing homes replicated the hospital model of care where medical treatment is primary, administrative structure is hierarchical, care is specialized, and the

environment is institutional. Newer models including Culture Change, the Pioneer Network, and the Eden Alternative offer a very different paradigm. For the purpose of this book, these movements will be called *Culture Change*. These models emphasize choice, a more homelike and less medical environment. Care is holistic and integrated. Quality of life as well as quantity is addressed in care planning. Residents and their families, and direct care providers are included. As with other new models of care, however, it is crucial that they not be viewed as an additional program, but as an essentially different way of operating. These inclusive, revolutionary models require deep systemic changes and often meet profound resistance. As with other CAM modalities, however, to many, Culture Change just makes sense.

The values outlined by the Pioneer Network (n.d.) nicely summarize Culture Change:

Pioneer Values

- Know each person.
- Each person can and does make a difference.
- Relationship is the fundamental building block of a transformed culture.
- Respond to spirit, as well as to mind and body.
- Risk-taking is a normal part of life.
- Put person before task.
- All elders are entitled to self-determination wherever they live.
- Community is the antidote to institutionalization.
- Do unto others as you would have them do unto you—yes, the Golden Rule.
- Promote the growth and development of all.
- Shape and use the potential of the environment in all its aspects: physical, organizational, psycho/social/spiritual.
- Practice self-examination, searching for new creativity and opportunities for doing better.
- Recognize that Culture Change and transformation are not destinations but a journey, always a work in progress.

What do these principles mean in practice? They mean that a medical model is not the *only* guide in the care of elders who are nursing home residents. Relationships are essential to quality of life. Understanding what makes the resident most comfortable is key to planning care rather than solely addressing medical concerns. These principles also mean that caring communities are always changing as they reflect the needs of those who live and work

there. Risk-taking and flexibility are encouraged. Elders are viewed as whole people, with abilities as well as disabilities. These approaches, ultimately, necessitate a commitment to changing the entire system of care.

ELEMENTS OF CARE PROVISION

The reason that CAM, integrative medicine, and Culture Change cannot be viewed as adjunct programs is apparent when one considers their underlying philosophy and how it differs from the underlying philosophy of conventional Western medicine. Following are some of the ways in which each of these models views health care provision.

Conventional

Cure
Quantity of life
Expert decision making
Specialized
Pathology-based
Institution-centered

CAM

Palliative care
Quality of life
Patient decision making
Holistic
Strength-based
Resident-centered

While nonconventional models are not identical, they tend to share common principles. A holistic view is inclusive, and considers healing needs unique to each individual's presenting problem, history, other medical conditions, environment, preferences, and lifestyle. Conventional medicine may have a more narrow focus. All treatment modalities are best used in context. As portrayed in the first scenario, there are times when Western acute care is excellent and appropriate. With chronic conditions, it is increasingly important to consider complementary and, at times, even radical alternatives.

Cure—Palliative Care

Most practitioners no longer perceive their goals as solely curing the bodies of their patients. The majority of health care problems are chronic, possibly life-long, and disabling. Patients at the end of life and their families now have the right to choose to end medical treatment, opting for comfort or palliative care. Hospitals and other health care settings are expanding their understanding of treatment options, viewing end-of-life care as more than "doing nothing." When curing is no longer the goal, healing expertise can focus on symptom management. Conventional health care providers may be frustrated by chronic

conditions that must be managed instead of resolved. Success is not so apparent in chronic care, and providers and patients may feel like failures when compared with their acute care colleagues. CAM and Culture Change models offer another interpretation: quality of life is as important as quantity of life.

Quantity of Life—Quality of Life

Acute health care provision has significantly increased the average length of life in developed countries, but at times, with increased disability. More and more, medical professionals view improving quality of life as an equally important goal. But how do we define quality of life? Quantity of life is measurable, while quality of life is individual and changeable. Treatment decisions regarding quality of life are judgment calls. The patient and his or her family must be considered and involved.

THINK ABOUT THIS

What is quality of life for you? What amount of disability and pain would be tolerable for you? What would be intolerable? Many of us believe we would not want to be kept alive by a machine, but would we be willing to be on a machine temporarily if we would get a little better?

These decisions are not easy, and yet they impact daily on the lives of our elders in the nursing home. Many of these elders are in conditions that most people would say are intolerable. Are we measuring quality of life by our own standards? Is it possible there are other standards?

Expert Decision Making—Patient Decision Making

Each patient carries his own doctor inside him. They [patients] come to us not knowing that truth. We [doctors] are at our best when we give the doctor who resides within each patient a chance to go to work.

—Albert Schweitzer, MD

Who is the expert in health care? The conventional medical model often locates decision making with the medical experts. When we do not feel well, we may rely on medical specialists to tell us what is “wrong.” Yet, there are times when we know, from familiarity with our own body or from a place of internal wisdom we all possess, what is going on with our body and why. Pain

assessment is a good example. Pain is associated with both acute and chronic conditions, but acute pain is temporary; chronic pain can be permanent. Pain relief and maximizing functioning are the foci of chronic care. Chronic illness is more likely to affect elders, who also may have multiple conditions. Previously care receivers were told by medical professionals whether they should be in pain, depending on their conditions, and if so, how much! Newer models of care understand that the resident/patient is the expert in his or her pain and pain relief. End-of-life pain relief even offers patients a pump to dispense their own pain medications at the time and dosage they prefer.

Another aspect of these differing approaches is their view of relationships and professional distance. In the past, health care professionals were encouraged to distance themselves from those for whom they provided care. Think of the professional, often in a white coat or uniform, standing over the bed of the patient who is semidressed and vulnerable. A collaborative approach considers both the practitioner and the patient as people exploring a problem or issue. The patient's family, also, may have information and points of view. All aspects are considered. This relationship is equal and respectful and is an important aspect of the care and healing process. Both CAM, Culture Change, and progressive Western practitioners consider the care receivers and their support system as the experts in their care. There is a team approach to the healing process including professionals, patients, and families.

Specialized—Holistic

Are we a bundle of diagnoses or a whole person? If we have a specific problem, we want to consult a specialist. In Western medicine, the specialist will treat that specific ailment. Holistic medicine views the body, mind, and spirit as interconnected and treats the whole system. Specialized medicine generally treats the presenting problem and may miss the underlying or concurrent pathologies. CAM and Culture Change both focus on the whole person. Relationships, spiritual issues, and lifestyle are all considered part of healing.

Pathology-Based—Strength-Based

Western medicine focuses on illness and pathology. Traditional nursing homes also tend to focus primarily on the medical needs of residents. Persons may be referred to by their medical diagnosis, disability, or illness. Patients may lose sight of their strengths and abilities. Holistic medicine focuses on the whole person, what ails that person, and what his or her remaining strengths are.

In addition, holistic medicine tends to be preventative, whereas conventional medicine is often reactive and crisis-oriented. Conventional nursing homes may restrict resident choices as a safety measure. Culture Change nursing homes consider the ability to make choices an important factor. Choices that endanger the resident or others are not ignored, but residents are more able to live as they wish. Choice trumps caution.

TRUE STORY

Simon was an 80-year-old nursing home resident who had some medical problems and mild confusion. He loved to take walks and would leave the nursing home daily to walk to a nearby store. One day, one of the nursing home employees saw Simon crossing the street when the caution light was flashing. A meeting with Simon's family was called to discuss restricting his walks outside. Simon's family said they would rather that he continue to have his freedom, with the risks, than to be restricted.

Questions: How would you feel if you were Simon's family? Would you want to protect him at all costs? How would you feel if you were Simon?

Meeting Institutional Needs—Meeting Resident Needs

Hospitals and nursing homes are institutions that thrive on consistency and routine. In short-stay hospitals this condition is uncomfortable but necessary to some extent. A long-term care facility, however, is the *home* of the residents. Elders, who have lived alone or with a partner for years, with their own unique lifestyles and routines, are often robbed of these basics. The institution itself may decide much of the life of the resident, such as, when, where, and what to eat, when to bathe and to sleep. Newer models of care place the resident, and those closest to the resident (typically the family or direct care provider), at the center of these decisions. They play a role, with the consultation of the health care professionals, in their daily-life activities and health care.

WHAT WE VALUE

Currently, hospitals and nursing homes value curing illness in an environment of medical hierarchy, efficiency, consistency, uniformity, compliance with medical regimes, and tasks. These models are appropriate for acute, critical, medical care. There are other models of care that make sense for chronic

CONSIDER THIS

Take a moment to consider your daily routine. When do you get up; what do you like to do? You may like to shower, or not, make tea or coffee or breakfast, exercise, or watch the news. What makes you comfortable; what gets you off to a good start, and what doesn't? Does it bother you if you have to wait for your coffee? Do you want to talk to anyone before you eat breakfast and read the paper?

Now, imagine you are in a nursing home that has its own routine with which you—and all your fellow residents—are expected to comply. You are awakened at 5:00 a.m., dressed and toileted, and then, placed in a long, noisy corridor where you have to wait for your 7:00 a.m. breakfast. Maybe, it is cold and drafty. The chair might be uncomfortable. If you complain, you might be told just to be patient. If you get upset, you might be scolded, put in your room, referred to the psychiatrist for medication.

Thinking about your morning routine again: how different would you feel if you could follow a routine in the nursing home that was more similar to your lifelong practices? For some, it may mean staying up late and playing cards, eating a midnight snack, and sleeping in till 11:00 a.m., waking up and having a light breakfast followed by a shower. For others it could mean getting up at 6:00 a.m., cleaning up and folding clothes, eating a hearty breakfast, and going to “work” again. Imagine your life now. When do you get up; what do you like to do first thing in the morning; what is the rest of your day like; what do you like to do before bed? How would it be to be in an institution where it was all changed and out of your control? Would you be angry, depressed, noncompliant, even combative?

conditions. Because they make sense, people will use them. CAM and Culture Change represent two new models in a larger movement aimed at transforming health care. In order to be effective, both modalities must be viewed as a paradigm shift, not as additional programs to supplement an inadequate system. Nowhere is this change more urgent than in the care of our elders.

REFERENCES

- AGS Panel on Chronic Pain in Older Adults. (1998). The management of chronic pain in older persons. *Journal of the American Geriatric Society*, 46(5), 635–651.
- Centers for Disease Control and Prevention. (2003). Public health and aging: Trends in aging—United States and worldwide. *Morbidity and Mortality Weekly Report*, 52(6), 101–106.

- Eisenberg, D. M., Kessler, R., Foster, C., Norlock, F. E., Calkins, D. R., & Delbanco, T. (1993). Unconventional medicine in the United States: Prevalence, costs and patterns of use. *New England Journal of Medicine*, 324(4), 246–256. <http://www.un.org/esa/socdev/ageing/ageing/agewpop.htm>
- Haber, C. (2006). Nursing homes: History. In *Encyclopedia of Aging* (pp. 1005–1008). Macmillan Reference. Retrieved May 13, 2007, from http://www.amazon.com/NURSING_HOMES-HISTORY-Macmillan-Reference-Encyclopedia/dp/B000M4QKFI
- Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 census. *Archives of Neurology*, 60(8), 1119–1122.
- Institute of Medicine of the National Academies. (2005). *Complementary and Alternative Medicine in the United States*. Washington, DC: National Academies Press.
- Kinsella, K., & Velkoff, V. A. (2001). *An Aging World: 2001*. (U.S. Census Bureau, Series P95/01-1). Washington, DC: U.S. Government Printing Office.
- National Institutes of Health's Complementary and Alternative Medicine. (n.d.). <http://nccam.nih.gov/health/whatiscom>.
- National Institutes of Health's Complementary and Alternative Medicine. (2002). http://nccam.nih.gov/news/camsurvey_fs1.htm <http://nccam.nih.gov/timetotalk/>
- Ness, J., Cirillo, D. J., Weir, D. R., Nisly, N. L., & Wallace, R. B. (2005). Use of complementary medicine in older Americans: Results from the retirement study. *The Gerontologist*, 45(4), 516–524.
- Pioneer Network. (n.d.). *Pioneer Values*. Retrieved May 14, 2007, from www.pioneer-network.org
- Tindle, H. A., Davis, R. B., Phillips, R. S., & Eisenberg, D. M. (2005). Trends in use of Complementary and Alternative Medicine by U.S. adults: 1997–2002. *Alternative Therapies in Health and Medicine*, 11(1), 42–49.