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Diane E. Meier • Stephen L. Isaacs • Robert G. Hughes

EDITORS



PALLIATIVE CARE

TRANSFORMING THE CARE
OF SERIOUS ILLNESS

PALLIATIVE CARE

Transforming the Care of Serious
Illness

EDITORS

**DIANE E. MEIER, M.D.
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**FOREWORD BY
RISA LAVIZZO-MOUREY**

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FOREWORD

In the late 1970s and early 1980s, when I was a physician in training, the field of palliative care did not exist. More often than not, a very sick or dying patient was viewed as a failure—a failure of technology and know-how to cure disease, or at least to extend life. Too often I observed one of two equally inadequate responses to this perceived failure: apply more technology, more intensively, or withdraw completely, physically and emotionally. Performing heroic measures—chemotherapy, surgery, artificial life support—even when there was no hope for cure or significantly prolonging life was the standard of care.

Between 1989 and 1994, the Robert Wood Johnson Foundation funded a large study called SUPPORT—the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment—to improve the care given to seriously ill hospitalized patients by having patients and their loved ones discuss their wishes for treatment (or lack of treatment) with specially trained nurses, who would relay that information to the physicians and nurses in charge of the patients' care. The evaluation of SUPPORT showed that despite the program's work to improve communication among patients, family members, and those entrusted with their care, all too often these patients were subjected to aggressive life-prolonging treatment and spent their last days and weeks in significant pain and discomfort.

The failure of SUPPORT led the Robert Wood Johnson Foundation to embark on a multiyear, multifaceted effort to improve the care given to people with serious illness—an effort that was undertaken in loose collaboration with the Open Society Institute's Project on Death in America.

Together, the two foundations were instrumental in nurturing the field of palliative care, which is the subject of this book, the fourth in a series that highlights and examines fields that the Robert Wood Johnson Foundation has nurtured over many years. *Transforming Palliative Care* is about the field itself, not the Foundation's role in developing it. Like its predecessor volumes in The Robert Wood Johnson Foundation Health Policy Series—*Generalist Medicine and the U.S. Health System* (2004), *School Health Services and Programs* (2006), and *Tobacco Control Policy* (2006), *Palliative Care: Transforming the Care of Serious Illness* begins with a comprehensive review of the field. We are honored that Diane E. Meier, who co-edited this volume with Stephen L. Isaacs and Robert G. Hughes, wrote the introductory chapter. Dr. Meier's leadership in and contribution to the field of palliative care were recognized by her selection as a recipient of a 2008 MacArthur Foundation "genius award." Dr. Meier's chapter is followed by reprints of twenty-five of the most important or influential articles in the field, written by its leading practitioners and analysts.

The combination of Dr. Meier's review chapter and the reprints of key articles from books and professional journals will give readers the wherewithal to understand

the evolution of palliative care and the movement for better care of the seriously ill. We hope that the wisdom contained in these pages will inform academics, students, and the American public, and that it will serve to guide policy makers in developing meaningful approaches that will lead to better bedside care for all Americans.

*Risa Lavizzo-Mourey, M.D., M.B.A.
President and CEO
The Robert Wood Johnson Foundation
Princeton, New Jersey
May 2009*

EDITORS' INTRODUCTION

This book is intended as an introduction and guide to palliative care and, more broadly, to the medical care of the seriously ill. Although concerns about the suffering and pain that seriously ill people and their families endure is not new—the hospice movement in the United States can be dated to the mid-1960s, and Elizabeth Kübler-Ross's seminal book, *On Death and Dying*, appeared in 1969—it was during the 1980s and 1990s that the American public began to pay serious attention. This attention has, if anything, increased during the 2000s.

Some of the heightened attention is related, no doubt, to demographics. More and more middle-aged children have been forced to watch helplessly as their parents undergo fragmented and often incomprehensible medical care from multiple specialists who communicate neither with each other nor with the patients and families they are serving. After years of roller-coaster hospitalizations, more than half of Americans still die among strangers, hooked up to a variety of machines in a hospital setting. The public's attention has been riveted by high-profile legal cases, such as that of Terry Schiavo, by the intense controversy surrounding Dr. Jack Kevorkian, and by the legalization of physician-assisted suicide in the states of Oregon and Washington.

Away from the public spotlight, physicians, nurses, social workers, ethicists, attorneys, and laypeople have been working to make sure that people with serious illnesses are able to receive the kind of care that they want and the kind of relief from pain that they need—palliative care, in short. Those practicing palliative care serve the most ancient of goals in the practice of medicine—the relief of human suffering. Palliative care provides comfort and relief of pain to seriously ill individuals in a variety of settings and at various stages of illness. Hospice, one form of palliative care, provides comfort and pain relief specifically for people who are clearly dying, whereas palliative care in general provides comfort and pain relief for anyone with a serious illness regardless of their prognosis, whether they are expected to be cured or to live for years with a chronic disease. Palliative care is offered at the same time as medical care aimed at cure or life prolongation and is appropriate for all patients in need of it, whether they will live for years or days.

Palliative care has entered the mainstream of medical practice. More than half of U.S. hospitals reported a palliative care program in 2006, and many more programs are in the planning stages. Even so, as with other so-called cognitive specialties, it faces an uphill battle, due in part to the federal government's and private insurers' unwillingness to pay sufficiently for the kinds of medical care and social services needed by seriously ill people (many of whom are elderly and frail and have multiple chronic conditions). As a consequence of such inequities in reimbursement, fewer than 2 percent of graduating U.S. medical students choose to practice in a primary care (cognitive) specialty, and most leave their training with hundreds of thousands of dollars in educational debt,

virtually forcing them to pursue training in procedural subspecialties that are much more generously reimbursed by payers. The growth of the palliative care field is limited by the difficulty of recruiting and retaining the necessary workforce under such adverse financial incentives.

Nonetheless, the aging of the population makes it unavoidable that health professionals will spend more of their time caring for older people, many of whom suffer from multiple chronic conditions, and the sickest of whom require palliative care. Moreover, because palliative care improves the quality of care and reduces costs for a key population of patients—those with serious and complex illness who, while accounting for under 10 percent of patients, drive more than two-thirds of health care spending—it ought to be a central part of the solution to America's health care crisis. For these reasons, palliative care—as part of health care reform—is almost certain to rise higher on the nation's health policy agenda.

The initial chapter, by Diane E. Meier, M.D., offers a comprehensive review of the field of palliative care, covering, among other topics, the history of care of seriously ill people; the religious, legal, and ethical issues; the evolution of views regarding relief from pain; the growth and current state of the field of palliative care; and the challenges confronting it.

In selecting twenty-five of the most influential or important articles to reprint—out of literally hundreds of superb pieces that the field has generated—the editors faced what proved to be a difficult, if not impossible, task. In making our selection, we looked for “classic” articles, such as Eric J. Cassell's “The Nature of Suffering and the Goals of Medicine”; pieces written by the giants who founded the field, such as Elisabeth Kübler-Ross; and pieces that captured the most critical issues in palliative care. In making the selections, we first asked many of the field's leading experts—listed in the acknowledgments—what they considered to be the most important, influential articles in the field. We owe each of them an enormous debt of gratitude for their thoughtful responses.

After receiving the guidance of these experts, we turned to the process of winnowing the reprint list down to twenty-five, which is all that space would allow. We are fully cognizant that a number of important articles were omitted, and that three different editors would have compiled a different list. Nonetheless, we believe that the articles we have chosen to reprint offer a reasonable selection of the most important, influential articles on palliative care.

Like Dr. Risa Lavizzo-Mourey, who wrote the foreword, we too hope that this book will inform the debate about health reform and efforts to improve the delivery of long-term care to seniors. The aging of the population, the increasing number of people suffering from chronic illness, the staggering cost of medical care, the great disparities in health care, and, simply, the human considerations in caring for seriously ill people make the issues addressed in this book of the highest priority.

Diane E. Meier, M.D.
Stephen L. Isaacs, J.D.
Robert G. Hughes, Ph.D.
Editors

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We asked some of the nation's leading experts in palliative care what they considered to be the most important issues in the field and what articles they felt had been the most significant or influential. Their collective judgment guided our thinking, and we are grateful to each of the individuals listed below for their time and thoughtfulness:

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xii Acknowledgments

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D.E.M.

S.L.I.

R.G.H.

**REVIEW
OF
THE PALLIATIVE CARE
FIELD**

THE DEVELOPMENT, STATUS, AND FUTURE OF PALLIATIVE CARE

DIANE E. MEIER, M.D.

4 Palliative Care: Transforming the Care of Serious Illness

The constants of the human condition are birth and death. No research, no new technology, no prayer, and no divine intervention has ever changed these defining characteristics of our species, and nothing we can foresee is likely to change them. But the nature of the experience—how we are born, how we die—has changed profoundly in the last several hundred years. For most of human history, death was a near random event, due to injury, infection, starvation, or childbirth. Humans were at least as likely to die during birth, infancy, childhood, or young adulthood as they were during middle age or old age. The meaning and the ritual attached to illness and death were predicated on this fact—death was common and unpredictable; it afflicted old and young and rich and poor alike; and it played a central role in the life of the community and the family.

Between 1900 and 2000, life expectancy in the United States rose from forty-seven to seventy-seven years—equivalent to the gain in longevity between the Stone Age, more than ten thousand years ago, and 1900. A gain of this magnitude in the relatively short evolutionary time frame of a century has had dramatic effects on the human experience of illness and dying and death. Where illness and death were once central and routine community experiences, with rituals designed to heal and to reintegrate the bereaved into new roles and new relationships, modern medicine and technological innovations have removed them from their place of gravity at the close of each life and have made them seem to be accidental and almost unseemly failures, associated with the belief that they could and should have been prevented.

Yet in the last two decades Americans have begun to recognize the limitations of technology and modern medicine in meeting the needs of the chronically and seriously ill, and also to fundamentally restructure the care that people require during the last years of their lives. These developments have spawned a new field of medicine called palliative care—from the Latin *palliare*, to clothe. Palliative care focuses on the relief of suffering for patients with serious and complex illness and tries to ensure the best possible quality of life for them and their family members. It is delivered at the same time as other appropriate curative and life-prolonging treatments and is not limited to the terminally ill. In this respect, it is not limited to hospice care, a component of palliative care focused on the care of the terminally ill who have opted to stop life-prolonging treatments.

Palliative care has grown rapidly in the United States in recent years and is now poised to become a universally available approach to meeting the needs of the country's sickest and most vulnerable patients. It is a central part of the solution to America's health care crisis, since it improves the quality of care and reduces costs for a key population—those with serious, complex illnesses who, while they number less than 10 percent of patients, account for more than two-thirds of health care spending.

This chapter examines the field of palliative care. It begins by exploring why the care of seriously ill patients has become such an important issue in the United States, and why the current health care system (or lack of a system) is unable to cope with it. It then looks at past efforts to provide care for dying people, the way that treatment of pain has evolved, and the growth of hospice care. This is followed by an analysis of legal,

social, and political concerns and of the research that has highlighted the problems and offered potential solutions, many of which have been tested and launched by private philanthropy. Finally, it reports on the state of palliative care in America and offers some thoughts on its future.

CARE OF THE SERIOUSLY ILL: WHY IS IT AN IMPORTANT ISSUE?

The unprecedented growth in the numbers and the needs of the chronically ill, especially the elderly; the availability and widespread use of costly medical technologies that may prolong life without restoring health or functional independence; exponential cost increases due both to larger numbers of persons turning to the health care system for help and to per-capita increases in health care spending attributable to technological advances and overuse; the crippling impact of employer-based health insurance on the American economy and the lack of government control over rising drug and device pricing; the failure to recognize and treat the pain and other distressing symptoms experienced by seriously ill people; and the consequent widespread dissatisfaction with and confusion about the medical care system—all form the context and justification for attention to medical care of the seriously ill and those approaching the end of life and the rapid recent growth of the field of palliative care.

America Is Aging, and More People Are Living with and Suffering from Years of Chronic Illness

From the standpoint of sheer numbers, the population of the United States is aging, and the odds of living a long life and dying during old age are far better than they were a hundred years ago. The average baby born in the United States today can expect to live to age seventy-eight, despite the fact that the United States is ranked forty-second in the world in life expectancy at birth, behind Jordan, Guam, and the Cayman islands.¹ If a man survives to age seventy-five, he can expect to live ten years longer, on average; a woman living to age seventy-five can expect to live twelve years longer. As a result of this dramatic increase in longevity, about 20 percent of the American population will be over age sixty-five by 2030, as compared to less than 5 percent in 1900—a demographic shift unprecedented in human history, and one for which our society is unprepared. While many people died of acute infectious illness a century ago and for millennia before then, today the leading causes of death are chronic degenerative diseases such as heart failure, emphysema, stroke, dementia, and cancer—diseases with which people may live for years, and sometimes for decades, before they die.

During the twentieth century, the location of care for the dying shifted away from the home and into hospitals and nursing homes—institutional settings where more than 70 percent of American citizens now die. The reasons for this shift are complex and include financial incentives built into the health care system that favor institutional death as well as the burden that long-term chronic care of functionally dependent loved ones places on families.

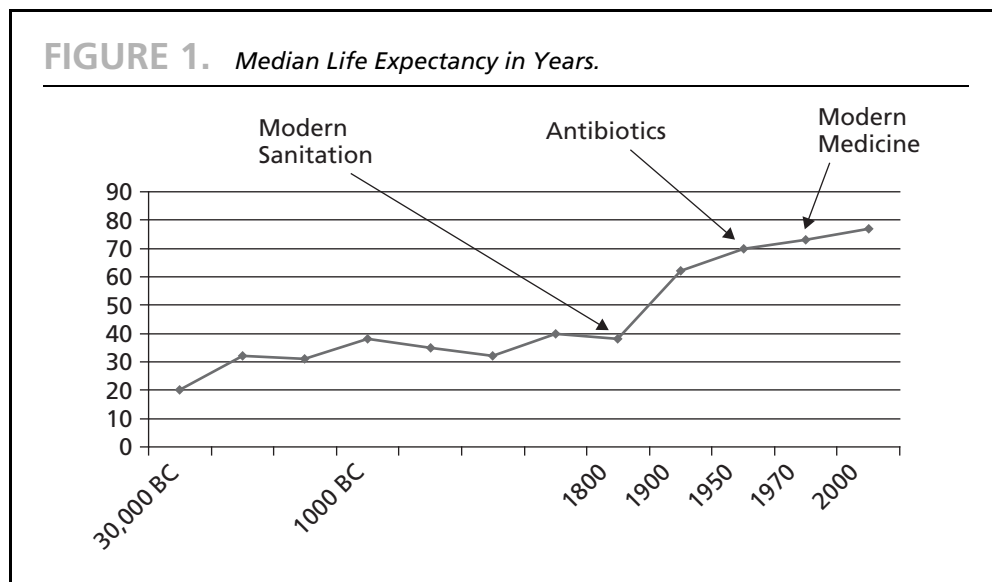
6 Palliative Care: Transforming the Care of Serious Illness

In addition, the successes of modern public health and medical care have created an expectation that all illness can be treated, if not cured, and that *ipso facto*, with enough research, death itself is preventable. Hence family members' worry that if they had just gotten another opinion, searched a little harder on the Internet, or pushed for an experimental treatment, they could have forestalled decline and death. This anxiety is part of the reason for overuse of health care services, and for costly and burdensome medical care near life's end.

The Impact of Public Health Measures and Modern Medicine on Longevity

In the mid-nineteenth century, scientists began to develop the germ theory of disease based on observations of epidemic infections from unclean drinking water. The subsequent separation of drinking water from sewage led to dramatically reduced infant, child, and maternal mortality and a gain in life expectancy at birth from under fifty years at the start of the twentieth century to nearly eighty years at present. A smaller portion of the last century's dramatic thirty-year gain in life span can be attributed to the discovery of antibiotics and the widespread use of vaccination during World War II. Most of the century's gain in life expectancy predates the recent rise in preventive and high-technology medicine, such as the control of blood pressure and smoking and the effective treatment of heart disease, stroke, and cancer (see Figure 1).

Fully 75 percent of the gain in life expectancy occurring during the twentieth century is due to decreased mortality for persons under the age of forty, resulting in a much higher likelihood of living to old age. This large gain is both the context for and a contributor to our present challenge—how to understand the meaning of serious



illness and death when it comes, and what our society owes us when we reach this stage in our lives.

Modern medical care and technology have also contributed to longevity in the United States. A recent study attributed roughly half of the 50 percent reduction in death from coronary heart disease during the last two decades in the United States to medical therapies and half to reductions in risk factors such as control of lipids, hypertension, and smoking.²

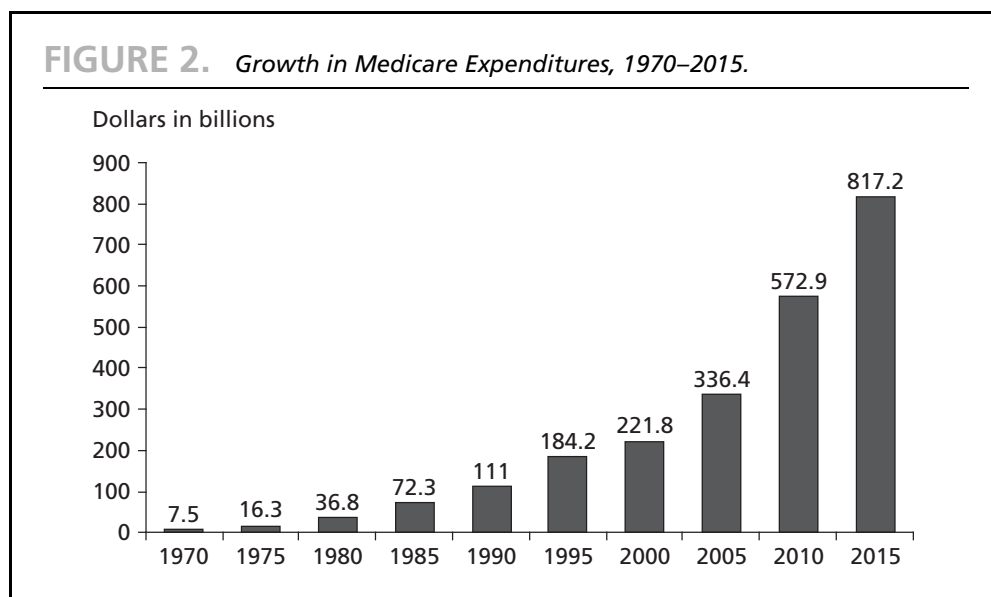
Consequences of an Aging Society The successes of public health and modern medical care have led to unprecedented growth in the number of older adults. The current generation of older people is healthier and less disabled than its predecessors, with additional gains in active life expectancy due to public health and biomedical research leading to new treatments for, and later onset of, chronic diseases.

But although the *proportion* of people with chronic disability is declining and more people are living longer and better, the sheer *number* of the elderly with chronic disability (seventy-seven million people will be over age sixty-five by 2040) means that an unprecedented number will experience prolonged functional dependency and frailty before they die. Some 57 percent of Americans age eighty and older report a severe disability.³ The probability of needing help from another person to get through the day because of functional dependency increases with age; more than 40 percent of persons over sixty-five report at least one functional limitation, and more than 70 percent of those over age eighty require personal assistance with one or more of their everyday activities.⁴ This functional impairment is due in great part to the rising prevalence of cognitive impairment after age sixty-five: more than 13 percent of the over-sixty-five population and 42 percent of those eighty-five or above have Alzheimer's disease, the most common cause of dementia (prevalence is even higher if vascular dementia is included), a number projected to rise by more than 50 percent by 2030 with the aging of the baby boom generation. Not surprisingly, and as an unintended consequence of modern medical successes, as death rates from heart disease, cancer, and stroke have declined in the last few years, Alzheimer's as a cause of death has skyrocketed, increasing by 33 percent between 2000 and 2004.

Caring for Seriously Ill People Is Very Costly

In 2007, health care spending in the United States reached \$2.3 trillion (16.9 percent of the nation's gross domestic production, or GDP), and it is expected to reach \$4.2 trillion by 2016 (20 percent of GDP).⁵ Medicare spending (government health insurance for those over sixty-five and the disabled) is growing exponentially in tandem with the numbers, needs, and cost of care of its beneficiaries (see Figure 2).

Although nearly forty-six million Americans are uninsured, the United States spends roughly twice as much per person as other industrialized nations (more than \$7,500 for every American, man, woman, and child), and those countries provide health insurance to all their citizens, and do so at under 11 percent of GDP (see Figure 3).



Note: Figures for 2010 and 2015 are projected.

Source: The Commonwealth Fund; Data from 2006 Medicare Trustees' Report.

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Despite our high expenditures, a 2008 Commonwealth Fund survey of chronically ill adults in Australia, Canada, France, the Netherlands, New Zealand, the United Kingdom, and the United States found that U.S. patients are more likely to forgo needed care because of costs (54 percent), run into problems with care coordination (34 percent), and experience a significant medical error (34 percent).⁶

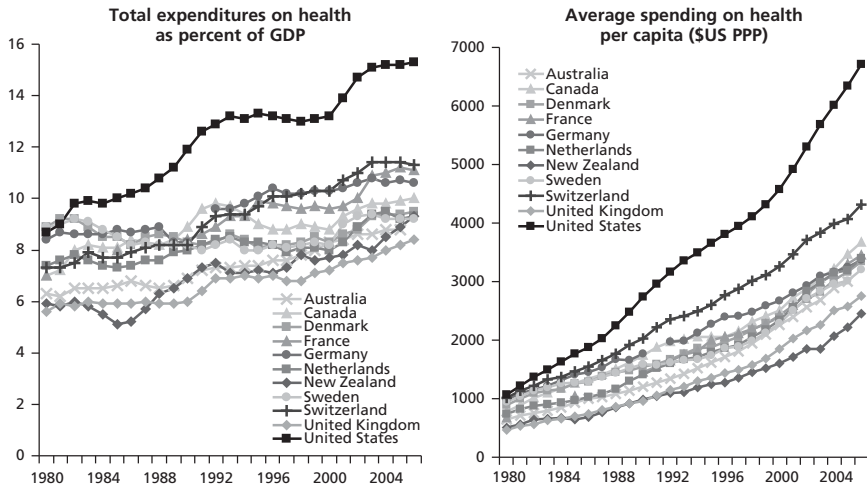
The primary factors driving these high costs are both intensity and pricing of service delivery—the United States uses more of the newest (and costliest) technologies and delivers various invasive procedures (such as magnetic resonance imaging and coronary bypass procedures) at a rate several times higher than other developed nations.

In addition, prices for medical care services in the United States are significantly higher than those in other countries (see Figure 4), and Americans spend five times as much per person (\$486) as the OECD (Organization for Economic Cooperation and Development) median (\$74) on health insurance and administrative costs.⁷

Individuals with five or more chronic illnesses are the largest consumers of health care and account for two-thirds of all Medicare spending. This patient population represents about 20 percent of all Medicare beneficiaries and is the group most likely to benefit from palliative care services (see Figure 5).

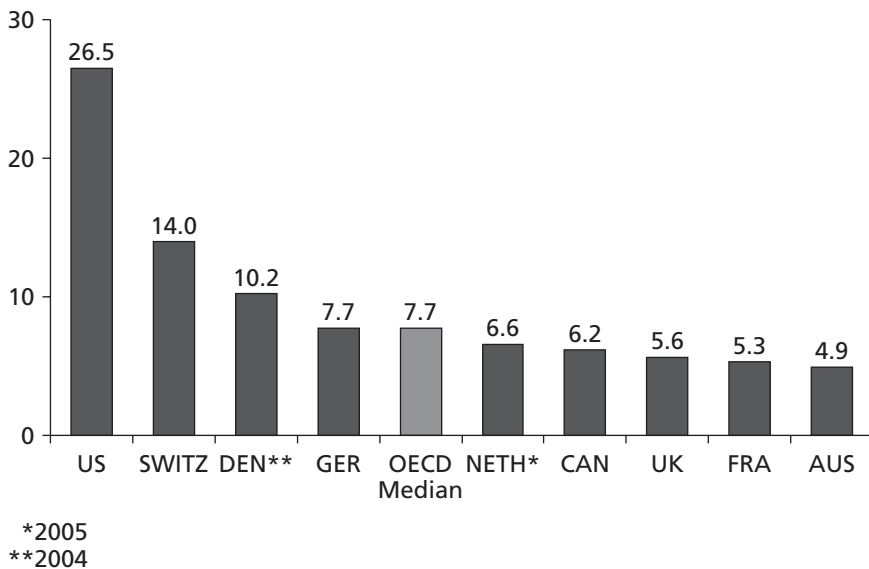
The costs associated with the number and expense of new life-prolonging technologies (such as kidney, heart, lung, and liver transplantation, implantable cardiac defibrillators, drug-eluting stents for coronary artery disease, ventricular assist devices, and new drugs to battle cancer) have risen dramatically. Medical ethicist Daniel Callahan

FIGURE 3. *International Comparison of Spending on Health, 1980–2006.*



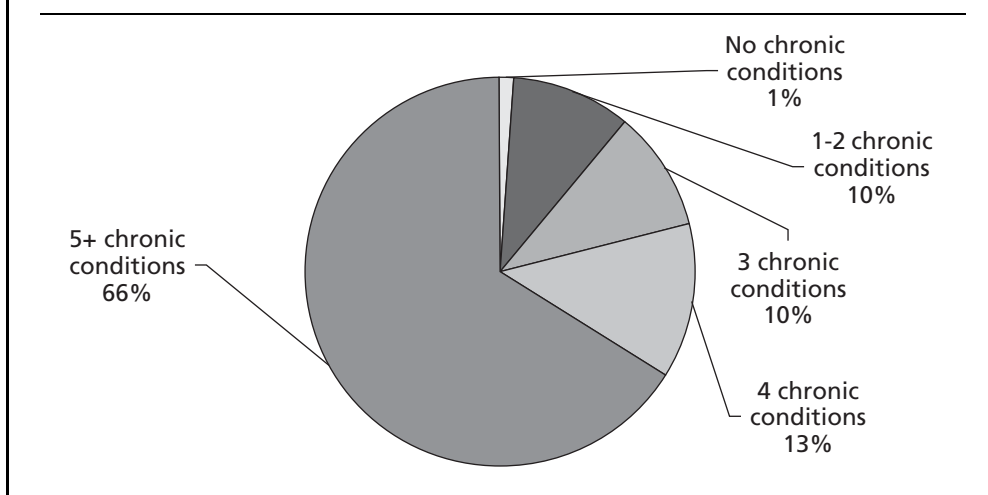
Source: The Commonwealth Fund; Data from OECD Health Data 2008 (June 2008). Reprinted with permission.

FIGURE 4. *Magnetic Resonance Imaging (MRI) Units per Million Population, 2006.*



Source: The Commonwealth Fund; Data from OECD Health Data 2008 (June 2008). Reprinted with permission.

FIGURE 5. *Two-Thirds of Medicare Spending Is for People with Five or More Chronic Conditions.*



Source: The Commonwealth Fund; from G. Anderson and J. Horvath, *Chronic Conditions: Making the Case for Ongoing Care* (Baltimore, MD: Partnership for Solutions, December 2002). Reprinted with permission.

argues that the unquestioning commitment to medical progress, regardless of cost and no matter how marginal the benefit, threatens to swamp other social priorities, such as education, safe roads, clean air, and universal access to health care.⁸ Despite the acknowledged critical nature of the problem, little or no social consensus exists on the distribution of our finite resources among social goods, or on the place of death as a necessary and appropriate part of a healthy life in a healthy society.

The fact is that these numbers pose a threat to American economic competitiveness in the world market, and the current world financial crisis may help create the social consensus necessary for a reexamination of the current model of health insurance in the United States and also of the built-in financial incentives favoring hospitalization, procedural care, and more specialist intervention in the system.

Dissatisfaction with Care of the Seriously Ill

Despite uniquely high per-capita expenditures, Americans with serious illness, their families, and their doctors and nurses are not satisfied with the care system. According to the 2006 *Health Confidence Survey*, dissatisfaction with the health care system, specifically how much it costs, has doubled since 1998, with 28 percent of respondents rating it fair and 31 percent rating it poor because of rapid growth in out-of-pocket expenses.⁹ Of Americans responding to a national representative survey conducted by

the Commonwealth Fund, 46 percent called for fundamental change and 30 percent for a complete rebuilding of the health care system; 42 percent reported experiencing inefficient, poorly coordinated, or unsafe care.¹⁰ Among family members of Medicare decedents, substantial percentages reported inadequately treated pain (24 percent), inadequate emotional support (50 percent), and poor communication from physicians (30 percent); interestingly, the hospice care given at home was ranked excellent by more than 70 percent, compared with fewer than 50 percent of those whose family members had died in a hospital or a nursing home.¹¹

EFFORTS TO COPE WITH DEATH AND PROVIDE CARE FOR THE DYING

*I don't want to achieve immortality through my work.
I want to achieve it by not dying.*

Woody Allen

A Brief History

In *The Hour of Our Death*, published in 1981, author Philippe Ariès described death and the history of Western attitudes toward it as both a communal and an individual act, associated with the ritual and ceremony of any major life milestone.¹² These rituals have been transformed in the last hundred years by the simultaneous decline of religious faith in many Western nations and the advent of the scientific revolution. The key components of this rite of passage are the individual's role in the acceptance of his coming death; the opportunity to say goodbye; and the period of mourning and bereavement. Ariès divides his study into four overlapping historical periods: "The Tame Death," "The Death of the Self," "The Death of the Other," and "The Invisible Death."

The Tame Death roughly corresponds with pre-Christian through the early Middle Ages. Death was central, routine, and unpredictable and was tamed through social rituals and codes of behavior. From earliest recorded history, death was a central and common part of the life and rites of the community—"*rites in the bedroom or those of the oldest liturgy express the conviction that the life of a man is not an individual destiny but a link in an unbroken chain, the biological continuation of a family or a line that begins with Adam and includes the whole human race. The community was weakened by the loss of one of its members . . . it had to recover its strength and unity by means of ceremonies . . . death was not a personal drama but an ordeal for the community, which was responsible for maintaining the continuity of the race.*"

The Death of the Self begins in the Middle Ages, when mendicant Christian orders worked to convert a quasi-pagan population, with a corresponding rise in individuals' fears about their own death and an afterlife of punishment for sin. A change in attitude developed with the rise in the sense of individual fate as opposed to collective

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destiny—an individual destiny in an afterlife that could be secured by good behavior, prayer, simony (purchase of divine favor), and control of what happens after death through the use of wills and testaments.

The Death of the Other corresponds to the subsequent (post-Middle Ages) rise in the centrality of the family and a few intimate relationships, and the associated Romantic Movement (the deathbed scene, *ars moriendi* [the art of dying], weeping, drama). After the Middle Ages, the rise of intimate family relationships replaced the community as the primary seat of loyalty and personal survival. The rise of the family, with the associated realization that there is good and bad in each person, reduced both the conceivability and the acceptability of punishment for sin through hell and eternal damnation and encouraged a vision of permanent reunion with loved ones after death.

Arguing that death has been banished as an unacceptable and unendurable truth in our own century, Ariès describes the Invisible Death, our current phase, as a period where death is unconsciously or theoretically believed to be avoidable with enough investment in research—an expectation strengthened by the successes of public health and modern medicine in allowing, for the first time in human history, most people in Western societies to live to old age. If the presumption is that science can defeat death, each death that does occur requires explanation, is something that could theoretically have been prevented, and hence must reflect a failure—a failure of the family to find the right doctor; of the patient to take proper care of himself or herself; of the doctors to know the latest protocols; of the hospital to prevent the unpreventable; of society to invest adequately in research. Despite the fact that over 80 percent of Americans report a religious affiliation, someone or something under human control must be to blame if death is preventable.

If death is avoidable and therefore a failure, it is unsuitable for everyday life—stigmatized, hidden, and avoided in polite conversation. Since each of us still dies, each person (and the family) may come to experience his or her own dying and death as a mistake, something that could have been prevented, a personal failing, or someone else's fault—in a word, wrong.

Combining the stigma of death with the widely held belief that modern medicine and hospitals can perform miracles in the battle against death, the hospital and the nursing home have become the dominant sites for gravely ill, dying people (more than 70 percent of deaths in the United States occur in an institution). The health care institution offers families a break from the work of caring for a seriously ill person, a place to hide from prying eyes, and a respite from the shame and failure implicit in the dying process. The hospital is believed to have the professionals and the technology necessary to defeat disease and keep death at bay. The modern ritual of death involves several prolonged stays in a hospital—often in an intensive-care unit. This ritual allows the family to say to their friends and neighbors, “We did everything possible, we got the best care possible;” to keep the concrete and physically distressing aspects of the illness at a controlled and safe distance; and to avoid

being labeled as a friend of death because of the acceptance of death. The physician becomes the agent of his society—battling death is the *raison d'être* of modern medicine.

Tolstoy was among the first to write about the stigma of death in his great novella *The Death of Ivan Ilych*. Ilych, a middle-class government functionary, is dying of cancer, but no one tells him the truth. His doctors and family all talk around the illness with euphemism, and the patient, desperate for genuine human relationship, experienced even greater suffering due to their denial of death's reality.

What tormented Ivan Ilych was the lie, this lie that for some reason they all accepted, that he was only sick and not dying, and that if he would only remain calm and take care of himself, everything would be fine; whereas he knew very well that no matter what was done the result would be only worse suffering and death. He suffered because no one was willing to admit what everyone, including himself, could see clearly. He suffered because they lied and forced him to take part in this deception. This lie that was being told on the eve of his death, that degraded the formidable and solemn act of his death. . . had become horribly painful to Ivan Ilych.

Leo Tolstoy, "The Death of Ivan Ilych"¹³

Hiding from the indecency of death extends to the mourning process. By the mid-twentieth century, the traditional community mourning rituals and codes of behavior that not only reintegrated the bereaved back into the world of the living but that also helped the group recover from the threat of death and loss in their midst—wearing black, avoiding social events—had all but disappeared in the United States and other developed nations. The loss of these codes and rituals of bereavement in the last two centuries has left us with little protection from the terror of nature and death. Hence the modern tendency to repress references to death and to suppress evidence of mourning. As Geoffrey Gorer wrote in *Death, Grief, and Mourning in Contemporary Britain*:

At present death and mourning are treated with much the same prudery as the sexual impulses were a century ago. . . Today it would seem to be believed, quite sincerely, that sensible rational men and women can keep their mourning under complete control by strength of will and character, so that it need be given no public expression, and, if indulged at all, in private, as furtively as if it were an analogue of masturbation.¹⁴

Not only have the dying person and the grieving survivor been effectively banished from mainstream society but the reality of death itself has become taboo. It is treated as a contagious disease, something to avoid and to protect one's children from. Reaction against the stigma and the isolation of the dying that accompanied the view of death as somehow optional or preventable is the foundation of the hospice and, subsequently, palliative care movements in the United States.

Growth in the Use of Opioids for Treatment of Pain

Pain is a more terrible lord of mankind than even death himself.
Albert Schweitzer, 1922¹⁵

It has no future but itself.
Emily Dickinson, 1896¹⁶

Pope John Paul II has issued an apostolic letter on suffering in which he says physical, mental and moral pain pose a mystery that can lead to spiritual growth and salvation.

Kenneth A. Briggs, *The New York Times*, 1984

Through much of the nineteenth century, pain was viewed as God’s punishment for sin and a means of spiritual purification through suffering; it was felt to have healing power in and of itself. Invoking the biblical injunction “In sorrow, thou shalt bring forth children” (Genesis 3:16) as justification, some believed that the pain of childbirth was necessary to transform women into appropriately self-sacrificing mothers. Morphine was first isolated from crude opium in 1803, though opium and its derivatives had been used for millennia. Queen Victoria began using general anesthesia during childbirth in 1853. By the late 1880s, surgical anesthesia was widespread, and an increased demand for surgery transformed hospitals from charitable asylums for the poor and the dying into purveyors of cures and the relief of suffering from disease.

The neurological underpinnings of pain were first studied in the late 1800s, and by the mid-twentieth century pain was understood as the body’s warning to avoid injury. “The evolutionary purpose of pain was no longer to heal, to punish, or to ennoble, but to provide a mechanical warning of actual or potential damage to cells and tissues in a specific body area,” according to the noted pain researcher Raymond Houde.¹⁷ The twentieth century also saw the earliest efforts to measure and assess pain in humans, and to attempt quantitative study of the effectiveness of analgesics. Henry Knowles Beecher, at Harvard, wrote about the inextricable role of emotion in the experience of pain in 1959, and he, Raymond Houde, at Memorial Sloan-Kettering Cancer Center, and Cicely Saunders, at St. Christopher’s Hospice in London, conducted the fundamental studies of opioid analgesia that led to modern opioid pharmacotherapy. Modern opioid pharmacology includes listening to the patient as the best source of information about pain intensity and impact. “I found that I got the same answer from just asking the patient as I did by going through a long series of testing,” Houde said. It also includes keeping pain under steady control with scheduled dosing (rather than waiting for a pain crisis before offering analgesia) and having “rescue doses” available to relieve unpredictable or breakthrough pain.¹⁸

Perhaps few persons who are not physicians can realize the influence which long-continued and unendurable pain may have on both body and mind. . . Under such torments the temper changes, the most amiable grow irritable, the bravest soldier becomes a coward.

S. Weir Mitchell, M.D., 1872¹⁹

Understanding that chronic pain is actually harmful to the organism, as opposed to merely an unpleasant side effect of disease, was recognized as early as the 1870s and was well established by the middle of the twentieth century. John C. Liebeskind, a noted pain researcher at UCLA, provided evidence that pain actually leads to measurable immunosuppression and associated increased risk of death from cancer and other diseases. In 1943, W. K. Livingston wrote in *Pain Mechanisms*, “Pain is a sensory experience that is subjective and individual; it frequently exceeds its protective function and becomes destructive. . . If such disturbances are permitted to continue, profound and perhaps unalterable organic changes may result in the affected part. . . A vicious circle is thus created.”²⁰

Chronic pain is a symptom of many conditions and affects 76.2 million Americans, more than diabetes, heart disease, and cancer combined. Pain is a significant national health problem and is the leading cause of disability, suffering, and impaired quality of life.²¹ It is the most common reason individuals seek medical care, accounting for up to 80 percent of doctor visits.²² More than 25 percent of people in the United States report having had a chronic pain condition at some point in their life,²³ and the associated disability is a major liability for workers, employers, and society. More than 70 percent of cancer survivors have significant pain, and fewer than 50 percent of these report receiving adequate treatment.²⁴

In hospitalized and seriously ill patients, pain has been associated with increased length of stay, longer recovery time, and poorer patient outcomes, all of which have implications for health care quality and cost.²⁵ A study of the experience of 9,105 seriously ill patients at five major American teaching hospitals reported moderate to severe pain in half of conscious patients during the last three days of life.²⁶

Both patients and physicians agree about the extent of the problem of untreated pain. In a 1993 survey, 88 percent of physicians treating cancer patients reported that their own training in pain management was fair to poor; and 86 percent admitted that their patients were undermedicated for pain.²⁷ Racial minorities, the poor, patients with HIV-AIDS, women, and the elderly are all less likely than white males to receive appropriate pain treatment.²⁸

Translation of the growing body of evidence that pain is bad for your health, and that relief of pain improves clinical outcomes, into routine clinical practice falls short. The multidisciplinary pain clinic has emerged as the standard of practice, utilizing a range of approaches including pharmacology, physical therapy, behavioral therapies, acupuncture, hypnosis, and family education. Many Americans cannot, however, get insurance coverage for modern comprehensive multidisciplinary pain programs, and this has reduced access to and availability of these services in many communities.²⁹

DEBORAH'S STORY

Deborah, as I'll call her, is a thirty-seven-year-old mother of three young children, a practicing psychotherapist, and a breast cancer survivor. Despite state-of-the-art treatment from the best oncologists in New York City, her cancer spread to her bones, causing progressive and severe pain. Her oncologists focused on administration of chemotherapy and suggested ibuprofen and Tylenol, neither of which helped. Her pain got so bad that she was unable to take care of her kids and had to stop going to work. She spent most of her time curled on her side in bed, since the pain was much worse if she moved. She has been to the emergency room twice for the pain, but the doctors there were willing to give her only six tablets of Tylenol with codeine. When these were gone, she left messages for her oncologist, but three days later she had not received a call back. In desperation, she called her obstetrician, who referred her to a palliative care doctor. Her sister and her husband got her to the appointment and she was begun on oral morphine liquid in the office, with dose adjustments until the pain was reduced from 10 out of a possible 10 to 5 out of a possible 10 (with 0 being no pain and 10 being the worst imaginable pain). She went home with instructions for around-the-clock and rescue doses of the analgesic. Within three days, her pain was down to 2 out of a possible 10, and she was able to return to her family and work responsibilities and continue her pursuit of effective treatments for her breast cancer. Deborah wonders how she got through her illness without this kind of help, and she thinks that every patient with cancer should have not only an oncologist but also a palliative care doctor to manage all aspects of their illness.

The Hospice Movement

Origins and Growth The term “hospice”—from the Latin *hospitium*, the same linguistic root as “hospitality”—denotes a place to host, receive, and entertain guests or strangers. The term can be traced to medieval times, when it referred to a place of shelter and rest for weary or ill travelers. The original hospices, from the fourth to eleventh centuries, were houses of rest and shelter for pilgrims and crusaders traveling to and from the Holy Land; these hospices were usually kept by religious orders.

The earliest hospitals and hospices were one entity, again based in the church. St. Bartholomew's Hospital, in London, was founded in 1123 and became a secular hospital in 1546 “for the ayde and comferte of the poore, sykke, blynde, aged, and impotent persones beyng not hable to helpe themselffs nor havyinh any place certeyn whereyn they may be lodged, cherysshed, or refreshed, tyll they be cured and holpen of theyre diseases and syknesse,” wrote a surgeon, in a letter to Henry the Eighth.³⁰ During the eighteenth and nineteenth centuries, religious orders established hospices to care for the dying in France, Ireland, and London. One of these—St. Joseph's Hospice