1

APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE

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EDITORS' INTRODUCTION

This highly influential IOM report, edited by Marilyn J. Field and Christine K. Cassel, called for fundamental change in health professionals' education, research priorities, and the structure of the health care system. It served as a blueprint for the investment of hundreds of millions of dollars in private sector philanthropy. Many of the report's key recommendations have been accomplished, but others, equally important to assuring access to quality care during advanced illness, remain unfinished or are works in progress.

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SUMMARY

Dying is at once a fact of life and a profound mystery. Death comes to all, yet each person experiences it in ways that are only partly accessible to the physician or family member, the philosopher or researcher. In principle, humane care for those approaching death is a social obligation as well as a personal offering from those directly involved. In reality, both society and individuals often fall short of what is reasonably—if not simply—achievable. As a result, people have come both to fear a technologically overtreated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress.

A humane care system is one that people can trust to serve them well as they die, even if their needs and beliefs call for a departure from typical practices. It honors and protects those who are dying, conveys by word and action that dignity resides in people—not physical attributes—and helps people to preserve their integrity while coping with unavoidable physical insults and losses. Such reliably excellent and respectful care at the end of life is an attainable goal, but realizing it will require many changes in attitudes, policies, and actions. System changes—not just changes in individual beliefs and actions—are necessary.

A number of developments suggest that the time is right for action at all levels to improve care at the end of life and to assure people that they will be neither abandoned nor maltreated as they approach death. This Institute of Medicine report is intended to support such action by strengthening popular and professional understanding of what constitutes good care at the end of life and by encouraging a wider societal commitment to caring well for people as they die. More specifically, it is intended to stimulate health professionals and managers, researchers, policy makers, funders of health care, and the public at large to develop more constructive perspectives on dying and death and to

improve the practices and policies under their control. To these ends, this report stresses several themes.

- Too many dying people suffer from pain and other distress that clinicians could prevent or relieve with existing knowledge and therapies.

- Significant organizational, economic, legal, and educational impediments to good care can be identified and, in varying degrees, remedied.

- Important gaps in scientific knowledge about the end of life need serious attention from biomedical, social science, and health services researchers.

- Strengthening accountability for the quality of care at the end of life will require better data and tools for evaluating the outcomes important to patients and families.

CONTEXT AND TRENDS

In the United States, death at home in the care of family has been widely superseded by a technological, professional, and institutional process of treatment for the dying. That process—its benefits notwithstanding—often isolates the final stage of life from the rest of living. Likewise, the mobility of Americans quite literally puts distance between many younger and older family members. Many adults, even in middle age, have not lived with or cared for someone who was dying.

Because Americans, on average, live much longer now than they did at the end of the nineteenth century, a much larger proportion of the population dies at an advanced age. More than 70 percent of those who die each year are age sixty-five or over, and those who die in old age tend to die of different causes than those who die young. For both younger and older people, the major causes of death and the typical experience of dying differ from one hundred years ago. The dying process today tends to be more extended, in part because medical treatments can manage pneumonia, infections, kidney failure, and other immediate causes of death that come in the wake of cancer and other "slow killers."

The field of palliative care is one response to the changing profile of death in the twentieth century. It focuses on the prevention and relief of suffering through the meticulous management of symptoms from the early through the final stages of an illness; it attends closely to the emotional, spiritual, and practical needs of patients and those close to them. Other community, professional, and governmental responses include the development of hospice programs, bereavement support groups, and policies and programs that encourage communication about people's goals and preferences as they approach death.

The twenty-first century will bring new realities as well as continuing problems and opportunities in care at the end of life. It will undoubtedly deliver improvements in what medical science can do to prevent and relieve distress for those approaching death, but demographic, economic, and other trends will strain systems that already find it difficult to deliver what clinical knowledge currently allows—and what compassion should grant.

The next century will see the final demographic consequences of the post–World War II baby boom. The oldest members of the baby boom generation will reach age

sixty-five in the year 2011, and the youngest members will do so nearly twenty years later. The elderly will constitute a larger proportion of the population than today, and the absolute numbers of dying patients will be substantially higher. Although health care and social service providers have a long lead time compared with the educators and communities who had to scramble to provide schooling for the baby boom generation, the difficulties that policy makers are already having with Social Security and Medicare do not bode well for the nation's ability to cope with the social, medical, economic, and other effects of an aging population.

Contrary to some popular thinking, however, the increase in overall personal health care spending is not explained by disproportionate growth in costs for end-of-life care. The small percentage of people who die each year do account for a significant proportion of health care expenditures, but the share of spending accounted for by this group does not appear to have changed much since the 1970s. Overall, increased health care spending is primarily accounted for by population growth, general inflation in the economy, and additional medical care inflation. One reason for the attention to the cost of care at the end of life is that such care is, in considerable measure, funded through Medicare, Medicaid, veterans, and other public programs.

Pressures to control public and private health care costs will continue and, indeed, will likely intensify with consequent restructuring of how health care is organized, delivered, and financed. More older people with advanced disease will be served by different kinds of managed care organizations. If effective quality monitoring and improvement methods are in place, the strengths and limitations of these varied arrangements will become clearer as their experience with end-of-life care grows. Possible problem areas include contracting, payment, and review mechanisms that limit access to clinicians and care teams experienced in palliative care; patient scheduling norms that limit time for careful patient-clinician communication; and marketing strategies that may discourage enrollment by seriously ill people.

CONCEPTS AND PRINCIPLES

Notions of "good" and "bad" deaths are threaded throughout discussions about dying and death. These concepts are not fixed in meaning but rather are shaped by people's experiences, spiritual beliefs, and culture and by changes in social mores, technology, and options for dying. Reflecting its members' personal and professional experiences and philosophical perspectives, the study committee that developed this report proposed that people should be able to expect and achieve a decent or good death—*one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards*. A bad death is characterized by needless suffering, disregard for patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended.

The committee that prepared this report was guided by a set of working principles that reflect a combination of value judgments and empirical assumptions. Only the first of the following principles applies exclusively to care at the end of life.

Care for those approaching death is an integral and important part of health care. Everyone dies, and those at this stage of life deserve attention that is as thorough,

active, and conscientious as that granted to those for whom cure or longer life is a realistic goal.

Care for those approaching death should involve and respect both patients and those close to them.
Particularly for patients with a grim prognosis, clinicians need to consider patients in the context of their families and close relationships and to be sensitive to their culture, values, resources, and other characteristics.

Good care at the end of life depends on strong interpersonal skills, clinical knowledge, and technical proficiency, and it is informed by scientific evidence, values, and personal and professional experience.
Clinical excellence is important because the frail condition of dying patients leaves little margin to rectify errors.

Changing individual behavior is difficult, but changing an organization or a culture is potentially a greater challenge—and often is a precondition for individual change.
Deficiencies in care often reflect flaws in how the health care system functions, which means that correcting problems will require change at the system level.

The health care community has special responsibility for educating itself and others about the identification, management, and discussion of the last phase of fatal medical problems.
Although health care professionals may not have a central presence in the lives of some people who are dying, many others draw heavily on physicians, nurses, social workers, and others for care—and caring. Thus, health care professionals are inescapably responsible for educating themselves and helping to educate the broader community about good care for dying patients and their families.

More and better research is needed to increase our understanding of the clinical, cultural, organizational, and other practices or perspectives that can improve care for those approaching death.
The committee began—and concluded—its deliberations with the view that the knowledge base for good end-of-life care has enormous gaps and is neglected in the design and funding of biomedical, clinical, psychosocial, and health services research.

CARING AT THE END OF LIFE: DIMENSIONS AND DEFICIENCIES

Care for most dying patients involves several basic elements: (1) understanding the physical, psychological, spiritual, and practical dimensions of caregiving; (2) identifying and communicating diagnosis and prognosis; (3) establishing goals and plans; and (4) fitting palliative and other care to these goals. In looking at current systems and practices, the committee found much that was good, including clinical, organizational, and ethical practices of palliative medicine that are implemented through hospices,

interdisciplinary care teams in varied settings, innovative educational programs, and nascent outcomes measurement and quality monitoring and improvement strategies.

Notwithstanding these positive features, the committee concluded that very serious problems remain. It identified four broad deficiencies in the current care of people with life-threatening and incurable illnesses.

First and most fundamentally, too many people suffer needlessly at the end of life, both from errors of omission (when caregivers fail to provide palliative and supportive care known to be effective) and from errors of commission (when caregivers do what is known to be ineffective or even harmful). Studies have repeatedly indicated that a significant proportion of dying patients and patients with advanced disease experience serious pain, despite the availability of effective pharmacological and other options for relieving most pain. Other symptoms are less well studied, but the information available to the committee suggested a similar pattern of inadequate care. In perverse counterpoint to the problem of undertreatment, the aggressive use of ineffectual and intrusive interventions may prolong and even dishonor the period of dying. Some of this care is knowingly accepted; some is provided counter to patients' wishes; much is probably provided and accepted with little knowledge or consideration of its probable benefits and burdens.

Second, legal, organizational, and economic obstacles conspire to obstruct reliably excellent care at the end of life. Outdated and scientifically flawed drug-prescribing laws, regulations, and interpretations by state medical boards continue to frustrate and intimidate physicians who wish to relieve their patients' pain. Addiction to opioids appropriately prescribed to relieve pain and other symptoms is virtually nonexistent, whereas underuse of these medications is a well-documented problem. Fragmented organizational structures often complicate coordination and continuity of care and impede the further development and application of palliative care strategies in patient care, professional education, and research. Medicare hospice benefits have made palliative services more available to a small segment of dying patients, but many more have illnesses that do not readily fit the traditional hospice model or government benefit requirements. Traditional financing mechanisms—including arrangements based on discounted fees—still provide incentives for the overuse of procedural services and the underprovision or poor coordination of the assessment, evaluation, management, and supportive services so important for people with serious chronic or progressive medical problems.

Third, the education and training of physicians and other health care professionals fail to provide them the attitudes, knowledge, and skills required to care well for the dying patient. Many deficiencies in practice stem from fundamental prior failures in professional education. Undergraduate, graduate, and continuing education do not sufficiently prepare health professionals to recognize the final phases of illnesses, understand and manage their own emotional reactions to death and dying, construct effective strategies for care, and communicate sensitively with patients and those close to them.

Fourth, current knowledge and understanding are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life. Biomedical and clinical research have focused almost exclusively on the development of knowledge

that contributes to the prevention, detection, or cure of disease and to the prolongation of life. Research on the end stages of diseases and the physiological bases of symptoms and symptom relief has had negligible support. Epidemiological and health services research has likewise not provided a strong base for understanding the degree to which people suffer symptoms (except, perhaps, cancer pain), experience death alone rather than in the company of those who care, comprehend diagnostic and prognostic information, and achieve a dying that is reasonably consistent with their preferences, palliative care principles, and community norms. Methods development is important to define and measure outcomes other than death (including patient and family perceptions) and to monitor and improve the quality of care for those approaching death.

More generally, this committee concluded that people in this country have not yet discovered how to talk realistically but comfortably about the end of life, nor have they learned how to value the period of dying as it is now experienced by most people. Except for the occasional newspaper feature or television documentary, the reality of dying as most often experienced in the United States has been largely shunned by the news, information, and entertainment media as distasteful or uninteresting. One result is an unhelpful combination of fear, misinformation, and oversimplification that contributes to a public perception of misery as inescapable, pain as unavoidable, and public spending as misdirected for people approaching death.

RECOMMENDATIONS AND FUTURE DIRECTIONS

Seven recommendations address different decision makers and different deficiencies in care at the end of life. Each applies generally to people approaching death, including those for whom death is imminent and those with serious, eventually fatal illnesses who may live for some time. Each is intended to contribute to the achievement of a compassionate care system that dying people and those close to them can rely on for respectful and effective care.

Recommendation 1: **People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care.**
Educating people about care at the end of life is a critical responsibility of physicians, hospitals, hospices, support groups, public programs, and media. Most patients and families need information not only about diagnosis and prognosis but also about what support and what outcomes they should reasonably be able to expect. They should, for example, not be allowed to believe that pain is inevitable or that supportive care is incompatible with continuing efforts to diagnose and treat. They should learn—before their last few days of life—that supportive services are available from hospices and elsewhere in the community and that those involved in their care will help arrange such services. Patient and family expectations and understanding will be aided by advance care planning that considers needs and goals, identifies appropriate surrogate decision makers, and avoids narrow preoccupation with written directives. To these ends, health

care organizations and other relevant parties should adopt policies regarding information, education, and assistance related to end-of-life decisions and services. For those who seek to build public understanding of dying as a part of life and to generate public demand for better supportive services, one model can be found in the perspectives, spirit, and strategies that have guided efforts to promote effective prenatal care and develop mother- and family-oriented arrangements for childbirth.

Recommendation 2: **Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms.**
Patients often depend on health care professionals to manage the varying physical and psychological symptoms that accompany advanced illness. To meet their obligations to their patients, practitioners must hold themselves responsible for using existing knowledge and available interventions to assess, prevent, and relieve physical and emotional distress. When they identify organizational and other impediments to good practice, practitioners have the responsibility as individuals and members of larger groups to advocate for system change.

Recommendation 3: **Because many problems in care stem from system problems, policy makers, consumer groups, and purchasers of health care should work with health care practitioners, organizations, and researchers to:**

a. **strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them;**

b. **develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life;**

c. **revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and**

d. **reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering.**

Although individuals must act to improve care at the end of life, systems of care must be changed to support such action. Better information systems and tools for measuring outcomes and evaluating care are critical to the creation of effective and accountable systems of care and to the effective functioning of both internal and external systems of quality monitoring and improvement. Policy makers and purchasers need to consider both the long-recognized deficiencies of traditional fee-for-service arrangements and the less thoroughly understood limitations of alternatives, including various kinds of capitated and per-case payment methods. Particularly in need of attention are payment mechanisms that fail to reward

excellent care and that create incentives for under- or overtreatment of those approaching death.

State medical societies, licensing boards, legislative committees, and other groups should cooperate to review drug prescribing laws, regulations, board practices, and physician attitudes and practices to identify problem areas and then devise revisions in unduly burdensome statutes and regulations. Such regulatory change is not enough. It must be accompanied by education to increase knowledge and correct misperceptions about the appropriate medical use of opioids and about the biological mechanisms of opioid dependence, addiction, and pain management.

The committee identified characteristics of community care systems that would more effectively and reliably serve dying patients and their families. "Whole community" approaches to end-of-life care would include a mix of programs, settings, personnel, procedures, and practices that extend beyond health care institutions and policies to involve entire communities. The goals would be to make effective palliative care available wherever and whenever the dying patient is cared for; help dying patients and their families to plan ahead and prepare for dying and death; and establish accountability for high-quality care at the end of life. Exhibit 1.1 shows key features of a whole-community system for end-of-life care. A system with these components would reflect the understanding that there is not just one way to care for dying patients and that some flexibility is needed to respond to patients who do not comfortably fit the routines and standards that serve most patients well. Clearly, such a system represents an aspiration. The model implies cooperative effort involving public and private agencies on multiple levels—community, state, and national.

Recommendation 4: **Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients.**
Dying is too important a part of life to be left to one or two required (but poorly attended) lectures, to be considered only in ethical and not clinical terms, or to be set aside on the grounds that medical educators are already swamped with competing demands for time and resources. Every health professional who deals directly with patients and families needs a basic grounding in competent and compassionate care for seriously ill and dying patients. For clinicians and others to be held truly accountable for their care of the dying, educators must be held accountable for what they teach and what they implicitly and explicitly honor as exemplary practice. Textbooks and other materials likewise need revision to reflect the reality that people die and that dying patients are not people for whom "nothing can be done." Exhibit 1.2 outlines the fundamental elements of professional preparation for skillful, compassionate, and respectful care at the end of life.

EXHIBIT 1.1.   A Whole-Community Model for Care at the End of Life

Programs and settings of care suited to the needs and circumstances of different kinds of dying patients

- Home hospice programs
- Other palliative care arrangements for patients that do not fit the home care model
  - Day programs in hospitals and nursing homes, similar to those developed by geriatricians
  - ''Step down'' arrangements, including nursing homes that permit a less intensive and less expensive level of inpatient care when appropriate
  - Specialized inpatient palliative care beds for those with severe symptoms that cannot be well managed elsewhere
  - Respite programs to relieve families of patients with a long dying trajectory (for example, those with Alzheimer's disease) that imposes major physical and emotional burdens on families

Personnel, protocols, and other mechanisms that support high-quality, efficient, timely, and coordinated care

- Practical and valid assessment instruments and practice guidelines for patient evaluation and management that can be applied at both the individual and organizational level
- Protocols for evaluating patients' need for referral or transfer to other individual or organizational caregivers
- Procedures for implementing patient transitions in ways that encourage continuity of care, respect patient and family preferences and comfort, and assure the transfer of necessary patient information
- Consulting and crisis teams that extend and intensify efforts to allow patients to remain home despite difficult medical problems or crises
- Ongoing professional education programs fitted to the varying needs of all clinicians who care for dying patients
- Performance monitoring and improvement programs intended to identify and correct problems and to improve the average quality of care

Public and private policies, practices, and attitudes that help organizations and individuals

- Provider payment, coverage, and oversight policies that, at a minimum, do not restrict access to appropriate, timely palliative care and, as a goal, promote it
- Support systems provided through workplaces, religious congregations, and other institutions to ease the emotional, financial, and practical burdens experienced by dying patients and their families
- Public education programs that aim to improve general awareness, to encourage advance care planning, and to provide specific information at the time of need about resources for physical, emotional, spiritual, and practical caring at the end of life

EXHIBIT 1.2. Professional Preparation for End-of-Life Care

Scientific and clinical knowledge and skills, including

Learning the biological mechanisms of dying from major illnesses and injuries

Understanding the pathophysiology of pain and other physical and emotional symptoms

Developing appropriate expertise and skill in the pharmacology of symptom management

Acquiring appropriate knowledge and skill in nonpharmacological symptom management

Learning the proper application and limits of life-prolonging interventions

Understanding tools for assessing patient symptoms, status, quality of life, and prognosis

Interpersonal skills and attitudes, including

Listening to patients, families, and other members of the health care team

Conveying difficult news

Understanding and managing patient and family responses to illness

Providing information and guidance on prognosis and options

Sharing decision making and resolving conflicts

Recognizing and understanding one's own feelings and anxieties about dying and death

Cultivating empathy

Developing sensitivity to religious, ethnic, and other differences

Ethical and professional principles, including

Doing good and avoiding harm

Determining and respecting patient and family preferences

Being alert to personal and organizational conflicts of interests

Understanding societal/population interests and resources

Weighing competing objectives or principles

Acting as a role model of clinical proficiency, integrity, and compassion

Organizational skills, including

Developing and sustaining effective professional teamwork

Understanding relevant rules and procedures set by health plans, hospitals, and others

Learning how to protect patients from harmful rules and procedures

Assessing and managing care options, settings, and transitions

Mobilizing supportive resources (for example, palliative care consultants, community-based assistance)

Making effective use of existing financial resources and cultivating new funding sources

Recommendation 5: **Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.**
The objective is to create a cadre of palliative care experts whose numbers and talents are sufficient to (a) provide expert consultation and role models for colleagues, students, and other members of the health care team; (b) supply leadership for scientifically based and practically useful undergraduate, graduate, and continuing medical education; and (c) organize and conduct biomedical, clinical, behavioral, and health services research. More generally, palliative care must be redefined to include prevention as well as relief of symptoms.

Recommendation 6: **The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.**
The research establishment includes the National Institutes of Health, other federal agencies (for example, the Agency for Health Care Policy and Research, the Health Care Financing Administration, the National Center for Health Statistics), academic centers, researchers in many disciplines, pharmaceutical companies, and foundations supporting health research. One step is to take advantage of clinical trials by collecting more information on the quality of life of those who die while enrolled in experimental or treatment groups. A further step is to support more research on the physiological mechanisms and treatment of symptoms common during the end of life, including neuropsychiatric problems. Pain research appears to supply a good model for this enterprise to follow. To encourage change in the attitudes and understandings of the research establishment, the committee urges the National Institutes of Health and other public agencies to take the lead in organizing workshops, consensus conferences, and other projects that focus on what is and is not known about end-stage disease and symptom management and that propose an agenda for improvement. Demonstration projects to test new methods of financing and organizing care should be a priority for the Health Care Financing Administration. For the Agency for Health Care Policy and Research, the committee encourages support for the dissemination and replication of proven health care interventions and programs through clinical practice guidelines and other means.

Recommendation 7: **A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death.**
Individual conversations between practitioners and patients are important but cannot by themselves provide a more supportive environment for the attitudes and actions that make it possible for most people to die free from avoidable distress and to find the peace or meaning that is significant to them. Although efforts to reduce the entertainment and news media's emphasis on violent or sensational death and unrealistic medical rescue have not been notably successful, a modicum of balance has recently been provided by thoughtful analyses, public forums, and other coverage of the clinical, emotional, and practical issues involved in end-of-life care. Regardless of how the current, highly publicized policy debate over physician-assisted

suicide is resolved, the goal of improving care for those approaching death and the barriers to achieving that goal should not be allowed to fade from public consciousness. Much of the responsibility for keeping the public discussion going will rest not with the media but with public officials, professional organizations, religious leaders, and community groups.

The committee agreed that it would not take a position on the legality or morality of physician-assisted suicide. It does, however, believe that the issue should not take precedence over those reforms to the health care system that would improve care for dying patients.

CONCLUSION

The analyses, conclusions, and recommendations presented here are offered with optimism that people, individually and together, can act to "approach" death constructively and reduce suffering at the end of life. This report identifies steps that can be taken to improve care at the end of life and to create a solid foundation for maintaining such improvements through difficult times. It also highlights the reasons for believing that professionals, policy makers, and the public are becoming more aware of what can and should be done and are ready to embrace change. These reasons range from the examples of well-known men and women facing death with grace to the more intense focus on deficiencies in care that has been stimulated by the debate over assisted suicide. In sum, the timing appears right to press for a vigorous societal commitment to improve care at the end of life. That commitment would motivate and sustain individual and collective efforts to create a humane care system that people can trust to serve them well as they die.