INTRODUCTION

New Dimensions of Dying

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THE DEATH of an individual is about as significant to the survival of the community as the death of a cell is to the future of a complex biological organism. It happens all the time; the individual is dead but life continues in kind. The notion is well captured in the monarchic cliché: "The king is dead, long live the king."

At the same time, the human mystique requires that we treat the death of every individual as a universal tragedy, a loss to all as well as to him. "Any man's death diminishes me," John Donne said. Such a view appears to be not only a logical extension of a democratic philosophy of individual freedom and responsibility, but also an apparent consequence of the intellectual and emotional uniqueness of human experience. To the extent that we fail to appreciate the singular value of human life, so the humanist argument goes, we reduce our humanness by that much. The case can be restated, of course, in terms of love, love of self and love of others.

The Dilemma of Mortality

We have reiterated the old dilemma of individual versus social good, nothing more. The supreme irony in human life is that, whereas we can reason that the renewability of life—the facts of birth, of the young replacing the old, of metabolism, of the constructive and destructive processes of energy exchange—practically dictates the inevitability of death for any given unit, we find it emotionally difficult
to admit the mortality of life in the individual case. Herein we may perceive a rationalization for a traditional belief in immortality. To release ourselves from the dilemma of personal death versus social survival, we have only to convince ourselves that no one really dies.

It is the intention of the editors and authors of *The Dying Patient* to address themselves to new dimensions of this ancient dilemma, not with any immediate hope of resolving it, but with the definite desire to describe what seems to be, in certain aspects, a new phenomenon involving a shift of attitudes and expectations about life and death—particularly about the quality of life in the period preceding death—as seen from the standpoint of the individual and society. The new dimensions involve the impact of science, technology, economics, and communications. We hope not only to illuminate what is happening but also to identify some of the problems and issues, and to define the outstanding questions that may be answered through social research.

To provide the reader with a frame of reference—one might even call it a plot line—we must indulge in a few historical generalities at this point. Some, of course, may regard our generalizations about attitudes and trends as suspect, since any effort to generalize engenders staggering problems of variation and complexity in people, their character, and custom, as well as in place and time. We are well aware that institutions for dealing with the dying person and, after death, his body, are not uniform among societies; indeed, they vary widely within the American, or Western-style, community.

Some persons, for example, die in complete isolation from medical attention; some are attended, but inadequately; others have the benefit of what has aptly been called “medicated survival,” involving the employment of virtually every technique and therapeutic intervention known to practitioners in highly sophisticated medical complexes. In addition, the cause of death, the duration of illness, the individual’s age, his social, economic, or ethnic background, his good or bad fortune in where he lives and in whose hands his fate is placed, and indeed the community’s respect or lack of respect for him, all may determine whether his life is to be prolonged and for how long.

Such variables have been at work throughout history, yet we do feel justified in speculating that a change in outlook has occurred in
the last hundred years. That long ago, when annual death rates, particularly among children, were at least twice as high as they are now, even more fortunately situated families were compelled to live amid the dying and sometimes to care for them personally. For many, death was a household event, not only involving the loss of the elderly but also of young children and young parents. A comparative few reached maturity without witnessing the passing of a loved one or friend, often of several such persons.

**Confrontation and Evasion of Death**

In those times, as we now may reconstruct the life style, there was no turning away, no escaping from association with the Grim Visitor. At any rate, such rejection was not socially respectable. The survivor was obliged to stand by or lend a hand during the terminal illness of a family member or neighbor, and to feel the presence of death in the house. The only possible way of softening the emotional impact, of circumventing tragic reality, it seemed, was to define death as a beginning, not an end. Every well-established family had its deathbed scenes and, often enough, the off-stage drama of the absent kin racing against time, not in any hope of forestalling death but just to be present and be able to say farewell, and so to join with the clan in common alarm and then grief. In the social circumstances we describe, an individual's death was treated as a Great Event as well as a loss. A person about to meet his Maker deserved attention.

All this investment of interest and feeling in the *rite de passage* has not disappeared, as anyone can see from the impressive hearse-and-ten-Cadillac funerals as they roll by, headlights on. Yet, as we look around us and examine the facts, death has not continued to be a central feature in the lives of many people. Even in our well-organized, well-exploited anxiety about heart disease, cancer, and stroke, our concern is not in a mastery of the event but in simply avoiding death from these major causes. For instance, it does not seem that we are much inclined to obey Freud's injunction, "To endure life, prepare for death." Rather, many of us appear to gaze upon death with a frozen stare, as if it were not there, or as if we were looking through a pane of glass at something of which we were not a part.
As some of the authors in this book suggest, death in the twentieth century has replaced sex as the socially taboo topic. In this view, it has become the fashion in youth-idolizing America to focus attention on living, on a longer life, on a better life, on "living it up." People turn their backs on death as much as possible, symbolically taking out and renewing all the life insurance they can get. They cannot help but note that others die, a reason perhaps for turning the music up, but on the whole there now seems to be a tendency in American society to regard death as a technical error, to write off the dying as if they were a business loss.

A reawakened interest in death and dying appears to be developing, however, as if we now have found time (or reason?) to examine a subject that we had felt justified in putting aside during a period of rapid scientific progress and social change. The decision to write and publish this book is but one evidence of this interest. More can be found in the annotated bibliography at the end.

A New Social Phenomenon?

How can we be sure that we are describing a social phenomenon, an actual trend in modern society? We cannot, in the present state of knowledge. The lines of information, of fact and interpretation, weave in and out, do not quite cover the holes in the fabric, and sometimes are frightfully snarled. What, to shift the metaphor, can a goldfish tell us about life in a goldfish bowl?

But there are some things we know on evidence.

American death rates for more than fifty years followed a sweeping downward curve, a trend that continued until 1954. During a half-century normal life expectancy increased from 40 to 70 years. By far the greatest gain, as already suggested, was among children. Nowadays, children do not frequently die; they get sick and suffer injuries, but they usually recover. More than nine out of ten born alive will still be alive at age 40. Finally, whereas half the population used to die before the age of 40, half now live beyond the age of 70.

These days, statistics show that the opportunity to die or to witness death among one's peers has greatly diminished, and does not
become statistically overwhelming until old age. Except for the news media—they never cease to remind us—dying remains only a small cloud on the horizon during the young and middle years for people as a whole.

We have another piece of evidence that is not quite as solid but is impressive and permits us to presume a good deal. We know that “in the old days” sick persons did not go to the hospital as much as they do today. Indeed, from the information handed down, it appears that it was mainly the poor who died in institutions, if they lived to reach one. Physicians delivered medical care, such as it was and as much as there was, mainly in the home.

Current information, on the other hand, indicates that the majority of deaths now occur in hospitals, nursing homes, or similar institutions, and that this number is growing. Unmistakably, the more common scene of “natural death” has shifted, and is continuing to shift, from the home to the institution, just as the more common age of death has shifted from the younger to the older age groups.

“Well and good,” the scientist or technologist might say, “this is progress.” The effects of this shift, the special concern of the social sciences, are more difficult to measure. Certain corollaries of the trend are hard to dispute, however. Apparently it has become the fashion among American families to delegate the care of their dying relatives to someone else, who functions as a third-party agent or stand-in.

We can easily discern who this someone else is, collectively. It is often a community hospital, small or large, that must organize itself bureaucratically in order to handle hundreds and thousands of patients as they come and go; this operation must be carried out rather commonly in the face of certain shortages of staff and financial resources, meaning priorities of need and attention have to be established. It may be a chronic disease hospital or a mental hospital. Or the place of assignment for dying may be a nursing home; increasingly this is so. This institution, while quite unlike any home the patient has known, may meet every sensible test of considerate care, professionally administered; or it may be a grossly inadequate facility, perhaps with a primarily proprietary and profit-taking motive.
Low Quality in Care of the Dying

Apparently the terminal patient is progressively losing the privilege of dying in old, familiar surroundings, with his family around him, with himself as a center of interest and therefore, in an important human sense, in control of his environment, master of his fate. Still, we may ask, since the American home is no longer competent to this responsibility, and because of the advancement of scientific and technical competence and the need for special equipment, is it not better to find a good hospital or a good extended-care facility and put the sick person in competent hands, trained and experienced in such matters?

Theoretically this alternative appears reasoned and sound. Yet the specific point made by some of our authors on the basis of close scrutiny of health professionals and their institutions is that, outside of any fortunate native endowments of personality that they may have, the professionals are quite unprepared to cope with the needs of the dying patient. For example, few physicians and nurses receive any training qualifying them to deal with the approach of death; indeed, their training emphasizes healing and prolongation of life almost to the exclusion of how to provide care once death is inevitable.

Wholly consistent with their own technical objectives and the death-avoidance attitudes of the society they serve, health professionals commonly avoid discussions of impending death with the patient or his relatives; when their efforts to forestall the dying process fail, or when any effort is useless, they customarily lose interest and withdraw from the scene. In effect, death offends their profession!

The patient is left to face the end alone in many instances, depending on circumstance, as still another species of alienated individual in a society increasingly scolded for its gaps in the communication of the meaningful and relevant, its gaps in social transactions, its gaps in interpersonal relationships. We have heard so much about the depersonalization, or dehumanization, of medical care as it has become technology-based and more specialized, that the extension of the phenomenon to the dying patient should come as no surprise, even though it may shock the humanist.

There are some ironic features of incidental interest, one concern-
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ing the hospital and the other the physician. The traditional hospital was a place where the sick poor, deserving of charity, were sent to die. It evolved in our time into the modern hospital where people of any class went to recover, hopefully. The hospital is again being identified as the place where people, now of any class, go to die (as well as to recover). What effect, if any, this new view may have on the future of hospitals is uncertain. Because of their marked tendencies toward overutilization and high expense and the concurrent failure to meet the need for primary care in the community, however, there is presently some agitation among health care leaders to keep patients out of hospitals. There are signs that many technically and scientifically well-trained physicians themselves are not content to let the human, the comforting, the reassuring side of the doctor-patient relationship go by default; some of them, along with some community health leaders, are trying to keep alive and revitalize the spirit that the old family doctor was supposed to have and that, in its absence, we are supposed to miss.

There is, as we suggested, some evidence of a new willingness to face the individual and social issues of death and dying. It is not possible to measure the increase in interest quantitatively, but it is fair to say that we are in a period where the prolongation and termination of life is receiving unusual attention from a good many people—medical educators, scientists, practitioners, social scientists, legal scholars, students of ethics, the mass media, policy makers, and the informed public.

Some of the interest naturally stems from the fact that dying is a matter on everybody's agenda. The fact presses harder when we pass middle age and find ourselves in a no-win foot race against time. The question then turns, in some minds, to whether it is the idea of decline and discomfort—the period of dying—or the end result of death that we fear and hate the more. Whatever, the normal human ego is such that it finds it difficult to visualize a world in which it does not exist.

Part of the interest also arises from the unsolved and unresolved moral and human issues that confront both individuals charged with deciding the course of care for seriously and terminally ill patients and those engaged in the development of social policies on health at a local and national level.
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The casualties of the Vietnam War have provided a special area of preoccupation, not so much because they include American boys, because American boys “have given their lives for their country” many times before. Rather, popular concern with their deaths arises from the fact that minorities, including youth, have had the courage to confront national policy makers and say that these youths are not giving their lives in defense of their country but essentially in defense of a mistaken policy. In this instance, the protest against death, visited upon bombed civilians as well as our soldiers, has had major political manifestations.

Of course, part of the recent interest in death and dying reflects simply the fact that the behavior of the community and its health professionals, and the organizational and operational mechanisms they have developed to deal with the terminally ill, are the legitimate concerns of the social sciences. Attitudes toward the dying reflect many of the problems of social deviance and disorganization that pervade our society.

Much of the interest, and certainly a leading journalistic topic, arose from the further development of radical surgical procedures, especially in the transplantation of the human heart. Other forms of organ transplantation, such as the older and more successful kidney transplant, have lacked the dramatic appeal of replacement of a heart, preceded, of course, by death of the donor. (A Belgian patient broke all records by surviving the more delicate transplantation of a lung for ten months.)

Crucial Issues and Need for Decisions

These surgical innovations and heroic acts, the subject of Chapter 6, have presented the practitioner in his relationship with the individual patient and the health care system vis-à-vis the community, as well as government itself, with the need for a number of critical decisions leading to the reformulation and refinement of legal norms and social policies. When is someone “dead,” so his organs may be removed for transplants? Should a “technically dead” man be flown halfway across the country so his organs can be delivered in living condition to waiting patients who need them? Should, or does, the clinical judgment of the transplant surgeon lie outside the law, or is it
superior to administrative regulation? What length of time constitutes a “useful” or “worthwhile” prolongation of life in a person receiving a transplanted organ? How does one justify the large expenditure of public funds to save a single life in the face of the unmet needs of unhealthy thousands? Who should be selected and who should be rejected for costly periodic treatment with the limited number of life-saving artificial kidneys? These are only a few of the questions now being discussed not only within the medical profession, which carries the primary responsibility, but also by the press, by lawyers, by legislators, and by economists.

Part of current concern about the quality of medical care available to people of all classes might be interpreted as a backlash in the perennial promise by some health leaders of mass life-saving as justification for Federal support of biomedical research. Beyond question, the application of research results related to the major causes of death have prolonged many individual lives but, overall, the mortality trends in heart disease and cancer have been upward, and the gains made have not been reflected in increased average life expectancy. Knowledge of these diseases is still not sufficiently advanced to bring them under general control, and what is known suggests that the only hope for substantial reductions of incidence, disability, and mortality lie not in medical care but in changes in such individual responsibilities as one’s habits of eating, exercising, and smoking.

Also essential to our understanding is a subject that has received relatively little attention; it has been conveniently labeled “the mythology of American medicine” ; René Dubos called it The Mirage of Health. Vocal elements of the American public and medical profession, it has been observed, share the conviction that the historic decline in death rates was primarily the result of medical science; this is in part true, but illusion enters in when, as commonly happens, this is interpreted as meaning “medical care” or “the private practice of medicine.” Epidemiologists for the most part do not see health progress in this way. The role of medical care, they conclude, has been secondary to improvement of living conditions, including sufficient food, housing, sanitation, and the elements that go into a safe, clean, home environment, including the educational opportunities and purchasing power that make it possible. The greatest gains have been
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made, and are still being made, in the prevention of infectious diseases through sanitation, control of insect vectors, and immunization. Except for the antibiotics in the control of pneumonia and other bacterial infections, plus certain types of emergency surgery that are truly life-saving, there is nothing in therapeutics to compare with public health approaches to disease prevention.

The Unfulfilled Promises of Public Health Policy

Ironically, typical private practitioners, while perhaps too busy openly to disavow the heroic role bestowed upon them, do not see themselves—when their opinion is invited—as primarily engaged in saving lives. Rather, they are engaged in taking care of the sick within the limits of their time and competence, part of their responsibility being to relieve anxiety in the needlessly alarmed and other concerns being to reduce discomfort, distress, and disability. With the exception of a few specialties like brain, heart, cancer, or traumatic surgery, death is an adversary rarely encountered in medical practice.

It is certainly true that public campaigns against infectious diseases—smallpox, tuberculosis, typhoid fever, venereal disease, diphtheria, malaria, and so on—have been sold to the public on the basis that they would prevent sickness and death. It is also true, but generally overlooked, that the application of the same kind of appeal in the chronic degenerative diseases, mainly diseases of late life, has led to distortion and misrepresentation. Neither the target populations, the nature of the disease, nor the methods of attack generally have been comparable. As a consequence of misguided strategy and the limitations of science, as well as deficiencies of manpower and system, those who have made government health policy have left the public with a collection of unfulfilled promises (e.g., to save us from “dread diseases”).

It is for the complex of reasons set forth that some sectors of medicine, both clinical and preventive, both private and public, have become concerned with the nontechnical, the human, and social aspects of medical care, including, of course, the economic reality that little or no adequate medical care is available to those who cannot afford it.

It is difficult to establish how widely such concerns are felt throughout the medical profession, whether in clinical medicine of the private-
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practice or academic group type. There is ample recent basis for assuming that organized medicine in its leadership expresses less public than it does political and professional interest.

In addition to the resistance within medicine to the equitable provision of services, health care leaders have charged that an insufficient concern has been shown in improving the quality of care available. The medical educator and medical scientist come as much under criticism as the average practitioner in this regard.

The target area of constructive criticism reveals itself most sharply in problems in the care of the mortally ill: Physicians emerge from their long years of specialized training without a systematic consideration of how to relate to the dying or their relatives; badly run, poorly staffed, and inadequately planned medical facilities result in increased discomfort and even technically incompetent care for dying patients. The lack of a realistic program for developing personnel and facilities to care for the terminally ill has resulted in a lack of continuity of care and a disorganized system of facilities characterized at its worst by some nursing homes that are hardly more than dying bins.

The Unsettled Question of Terminating Life

Concern with the social consequences of life and death reflect, and are reflected in, shifts that have occurred in more general social values. Concern with medical care and particularly with prolongation of life is associated with a long-term trend toward increased humanitarianism in Western society; suffering is no longer regarded as having special value in character-building or spiritual purification. The quality of dying, like the quality of life, is being scrutinized. A related, but perhaps more recent, trend is an increased belief in the feasibility and propriety of human intervention at both the beginning and end of life. A majority of the population no longer accepts either birth or death fatalistically; contraception and abortion are more acceptable; the community's evaluation of suicide and "mercy killings" may be somewhat more liberal. All of this seems to be associated with a decline of belief in an afterlife.

Such value changes have had their effect on the conduct of the physician and on social policy regarding the producing, prolonging,
and terminating of life. There is considerable evidence that doctors do terminate lives in certain situations. Some have been criticized for failing to do so. The long-time argument against euthanasia seems to be essentially twofold. First, there is the question whether people could enjoy the therapeutic benefit of faith in their physician if they knew his commitment to keeping them alive was not an absolute one. Opposed to this view would be patients in pain who beg the doctor to end their lives. A second argument against legalizing euthanasia is the difficulty of regulating decisions to terminate a patient’s life. This position implicitly assumes that such decisions do not occur. Since they are occurring, is not some sort of public regulation desirable?

**Dying as a Field of Inquiry**

Finally, the social sciences have changed; the field of medicine has become an important research area for sociologists, psychologists, and anthropologists. Most recently, social scientists have reawakened to the important interface between social and biological behavior. Moreover, the appropriateness of being critical of existing patterns of organization, of social inequities, and of the existing norms and values of community life has increased. It is just as fair to question what happens to dying patients and to examine the conduct of those responsible for their care as it is to inquire into other disturbances of social life and social order, such as crime and violence.

Although a reasonably strong case can be made for an increased interest in the dying and in the social consequences of their medical care—one of the strongest reasons is that those involved professionally have not shown much interest—there is but limited systematic social research on the prolongation and termination of life, minimal agreement on the resolution of the moral and social dilemmas that dying provokes, less than full consideration of the legal and economic ramifications of the current state of affairs, and a lack of systematic programs of research and scholarship to remedy the limitations in knowledge and its dissemination.

An attempt to unravel the reasons for past attitudes toward death and medical conduct would be instructive, but a more constructive
alternative, in our opinion, is to make known existing works and hopefully to codify and integrate them. The desired consequence of such an effort is not only to stimulate additional professional and public interest but to promote increased research and scholarly inquiry as well. Hence, this book. We feel this work should be interesting not only to physicians and nurses—whatever the problems of the dying patient, they have to deal with them every time a patient becomes terminally ill—but also to political leaders and social critics concerned with what is and what ought to be, including the wise allocation of economic and manpower resources.

It had been our intention to include in this introduction brief remarks on each of the fourteen chapters as our authors—physicians, sociologists, lawyers, economists—have tackled them. We have decided, however, to refrain from such a pedestrian exercise. Rather, we have attempted in spirit, if not in a complete summary, to capture the content of the book, and in so doing we have leaned heavily on the contributions of each author.

The breadth, depth, and variety of viewpoints the contributors have brought to the subject of the dying patient is clear from the book's contents page. It begins with three chapters describing the social context of dying—when, where, and why people die, what they think about death, and the cultural background of their attitudes.

The book moves into the heart of the matter in seven chapters on how doctors, nurses, and their institutions cope with terminal illness—the prognosis of death, the physician's behavior toward the dying patient, the impact of mortality on the health professions and their institutions, patterns of dying, how terminally ill patients themselves react, and the dismal "social death" role played by many patients dying in a public hospital.

The book closes with four chapters examining the social, ethical, legal, and economic questions arising from the prolongation and termination of life—dying as an emerging social problem, control of medical conduct, legal and policy issues in the allocation of death, and the economic and social costs of death. Finally, a concluding chapter deals with the research questions arising from dying and its dilemmas.
The editors would like to call the reader's attention to the fact that, although this is a book of primary interest to health professionals and social scientists, we have gone to some length to free it of terminological and semantic sins against literary nature. Doubtless, some readers variously will point out that we (1) have not wholly succeeded, and (2) have been too simplistic. Nevertheless, it is our hope that the work will be of interest to many general readers. In a period of social activism, we believe it will be.